Volker Amelung · Viktoria Stein ·
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Handbook Integrated Care

Second Edition

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Preface

Only two years after publishing the first edition of this handbook, we started working on a second edition. Three reasons were responsible for why we thought that a second edition should be published quite soon after the first one: first, even though the first edition had already more than 600 pages, we felt that some important topics were missing and therefore gaps need to be closed. Secondly, the research field changed quite dramatically and an intensive new discussion about ecosystems, population health management and their development evolved. The final reason came up unexpectedly during the preparations for this edition. COVID-19 made it very clear that strategic thinking about health system design and population health management is not a nice to have, but one of the most fundamental questions we are facing today.

The gaps we tried to close in this second edition are new chapters on people-centredness, complexity theories and evaluation methods, additional management tools and many more experiences from different countries and localities.

While there are still many different definitions and frameworks for integrated care available, a common understanding on the key building blocks of integrated care has emerged nonetheless. As we hear so often, it is not the "what is integrated care", which eludes us, it is the "how" of implementation.

There are mainly three different ways to look at integrated care: integrated care as a theoretical framework of how to organize our health systems, such as Ed Wagner's chronic care model or WHO's global strategy on integrated people-centred health services. These concepts are generic and focus on the way how we should think about healthcare provision. They are more like a compass, explaining the right way to think and defining the key elements, without giving specific instruction of how to execute it. These frameworks are referenced throughout this book as guiding lights in theory and practice.

Secondly, integrated care could be understood as a health system design tool to answer to (context-specific) challenges. Some of the most advanced examples, such as Scotland, the Basque country, Singapore or Canterbury, are described in more detail in Part B of this book. The focus here is on a whole-of-system design, which is very slowly moving towards a health in all policies understanding. This is mainly a (health) policy and political decision, defining the strategy and way forward for countries or regions.

Lastly, integrated care could be understood as a business model, for example hospitals or insurance companies investing in extending their value chain or expanding their scale and scope. In this case, integrated care is used as a strategy from different players to differentiate themselves in a competitive market, be it among primary care practices, hospital networks or private service providers. If it is seen primarily as a business model, with income generation as its primary aim, then this bares many obvious problems. There are hybrid forms, however, which argue that better and more integrated care ultimately brings better financial outcomes as well. Many ACOs and Health Maintenance Organizations (HMOs) in the USA are examples of this approach. The key lesson here is that it is futile to deny that there are huge financial interests playing out in the background, and financial disincentives to coordination and integration abound in every system.

All three approaches are highly valuable for the discussion about integrated care, but it is crucially important to make the intentions transparent. Ideally, integrated care could be both, a health system design and a convincing strategy for market participants, too. In relation to this, one of the most fascinating emerging topics is around evolving healthcare ecosystems. Again, there are two, diametrically opposed views on what healthcare ecosystems are in the first place. Based on systems theory, complex adaptive systems and similar theories, ecosystems can be understood as idealistic entities of numerous interdependent agents sharing values and goals. On the other hand, ecosystems such as Amazon, which are sophisticated, transnational and data-driven technical platforms, might become an alternative to healthcare systems, offering both—financing and provision of services. We might not like it, but other business giants like Google, IBM or Philips are all competing for a slice of the lucrative healthcare market. This development needs to be observed very carefully, as they offer both—more patient orientation, but also loosing the control of health system planning.

This second edition was finalized during the COVID-19 shutdown in most of our countries. Even if we are still far away today to judge on the right strategies and correct policies, the pandemic made blatantly obvious that public health and health services research is fundamental for a well-prepared and responsive health and care system. COVID-19 further underlines the need for more evidence-informed policy-making and interdisciplinary decision-making. We need to understand health and the management of crises as a continuous, emergent issue, with many unknowns, which require flexible and innovative approaches. In order to be able to learn from the crisis and better prepare for future outbreaks, we need to ask the right questions, invest in sound research and not sacrifice research principles due to the urgency and pressure of the crisis. This is much in line with what is required in any integrated care approach as well. COVID-19 has accentuated the stark reality that, despite the efforts of the past 20 years, there remains a continued failure to embrace integrated care systems. It has also demonstrated how quickly systems, organizations and individuals can change, if they must. As an international community of research and practice in integrated care, we must make sure not to waste this opportunity and help make the change stick.

This extensive second edition of the handbook would not have been possible without the help of many colleagues and staff members. A special thanks goes to Anna-Sophia Bilgeri, who dedicated many hours, emails and unabating positive energy to the tedium of following up with authors, keeping the editors on their toes and integrating the different pieces of this book. We are also grateful to Dr. Johannes Glaeser and Judith Kripp of Springer Verlag for their patience and continual support in the realization of this project. Ultimately, this book could not have been done without the contributions of the many authors and their willingness to share their expertise and experience with the reader.

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Part I

Foundations of Integrated Care

What is Integrated Care?

1

Nicholas Goodwin, Viktoria Stein, and Volker Amelung

1.1 Introduction

Integrated care is a concept that is now widely used and accepted in different health and care systems across the world. Yet the concept is not new since concerns about fragmentations in the way care is designed and delivered have a long historical lineage. The origins of the term date back to the ancient Greeks who recognised the need to treat people's mental health alongside their physical symptoms. In more recent times, integrated care as a terminology became commonplace in the 1970s in the fields of child and adolescent health as well as long-term care for the elderly.

By the late 1970s, one of the strongest drives towards more integrated and coordinated care provision emerged from the birth of the primary healthcare (PHC) movement following the World Health Organisation's Alma-Ata Declaration on Primary Health Care in 1978 (WHO 1978). Strengthening primary health care has subsequently been the cornerstone for action in health sector reforms worldwide with good evidence to demonstrate its impact in terms of health system strengthening and promoting universal health coverage (WHO 2008).

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A key element to the PHC movement has been to improve what Barbara Starfield termed the 'four C's' of primary care: accessible contact; service coordination; comprehensiveness; and continuity of care (Starfield 2002). So, in the most fundamental of ways, a key role of the PHC movement has been to promote the delivery of more integrated care to people living in local communities. This PHC movement has been sustained to the present day where initiatives, such as multi-speciality community providers in England and the patient-centred medical home model that originated in the USA, underpin their rationale through such evidence.

In parallel to the PHC movement has been the global response to the growth of age-related chronic illnesses and comorbidities. The development of the Chronic Care Model (CCM) and its variants (Wagner et al. 1999) has been of specific importance in tackling this growth. The CCM has become accepted in many countries as the comprehensive framework for the organisation of health care to improve outcomes for people with chronic conditions. The model focuses on six key and inter-related components including: support for self-management; decision support to professionals; care coordination and case management; clinical information systems; and community resources to promote healthy living; and health system leadership (Wagner et al. 1999).

The development of the CCM came in recognition that most health systems were failing to meet the needs of people with chronic illnesses since they remained largely built on acute, episodic models of care rather than care that focuses on more longitudinal, preventive, community-based and integrated approaches. The CCM has thus been a catalyst to help reorient systems of care to become more integrated in the management of chronic illness that has strengthened PHC and promoted self-management and patient empowerment.

More recent variations of the CCM model have focused on including the broader determinants of health with coordinated interventions that cut across the primary, secondary and tertiary levels of care and that extend beyond the boundaries of the healthcare system to cover issues such as public health (i.e. population health promotion, prevention, screening and early detection), rehabilitation and palliative care (Barr et al. 2003; WHO 2002). Indeed, approaches to develop population-based 'managed care' organisations have emerged not only as a policy imperative in many countries (e.g. such as through the development of Integrated Service Organisations in the Basque Country) but also as a business strategy [e.g. such as Kaiser Permanente in the USA and Gesundes Kinzigtal in Germany—see the Case Studies (Part 6)].

PHC, CCM and approaches to 'managed care' have been significant steps towards integrated care. Yet, many existing programmes continue to use a vertical and disease-oriented approach to care when the evidence suggests that better outcomes occur through adopting an integrated approach between health care and other sectors that is more preventative and community-based. Disease-based approaches tend to foster duplication and the inefficient use of resources and produce gaps in the care of patients with multi-morbidity. The structural solutions in the way care has been organised to promote chronic care require reappraisal if the ultimate

Table 1.1 Aspects of care that distinguish conventional health care from integrated care (adapted from WHO 2008, p. 43)

Conventional ambulatory medical care in clinics or outpatient departments	Disease management programmes	Integrated care
Focus on illness and cure	Focus on priority diseases	Focus on holistic care to improve people's health and wellbeing
Relationship limited to the moment of consultation	Relationship limited to programme implementation	Continuous care to individuals, families and communities across the life course
Episodic curative care	Programme-defined disease control interventions	Coordinated and people-centred care integrated around needs and aspirations
Responsibility limited to effective and safe advice to the patient at the moment of consultation	Pro-active management of a patient's risk factors to meet targets	Shared responsibility and accountability for population health, tackling the determinants of ill-health through systems thinking and inter-sectoral partnerships
Users are consumers of the care they purchase	Population groups are targets of specific disease control interventions	People and communities are empowered to become co-producers of care at the individual, organisational and policy levels

objective is to promote more people-centred integrated care. Table 1.1 attempts to provide an understanding of how the characteristics of integrated care should be distinguished from that of conventional care and approaches to disease management.

Most recently, there has been a surge in interest in how integrated care needs to be 'people-centred' and embrace patients and service users as partners in care and to ensure services are well coordinated around their needs (e.g. see Blomfield and Cayton 2009; Ferrer 2015; The Health Foundation 2011, 2012). More broadly still, the notion of integrated care has gone beyond the borders of the health and social care systems to think more strategically about how to embrace the social determinants of ill-health through bringing together the wider range of community assets to promote public health, prevent ill-health and secure wellbeing to populations.

This complex and emergent story of the focus and rationale for integrated care perhaps explains why there remains a lack of a common definition for integrated care which is universally accepted. Integrated care is, and remains, a polymorphous concept that has been applied from several disciplinary and professional perspectives and which is associated with diverse objectives. This diversity therefore represents a challenge to policy-makers, managers, professionals and researchers alike in developing 'common ground' in their understanding to the meaning and logic of integrated care.

This opening chapter, therefore, seeks to respond to the commonly asked question '*what is integrated care?*' To do so, the chapter briefly examines the rationale that lies behind integrated care before seeking to make sense of various attempts that have been made to define it. The chapter then seeks to outline the core aspects of integrated care and reviews how a range of models and frameworks have been (and are being) created to understand the building blocks and dynamics of integrated care systems. The chapter concludes with some forward thinking on integrated care as an evolving science.

1.2 The Rationale for Integrated Care

Notwithstanding the long history to the origins of the term, integrated care as an ongoing policy concern has come as a response to the significant shift in global demographics that has seen age-related and long-term chronic conditions replace communicable disease as the most significant challenge facing all health and care systems. This shift means that the economic burden of chronic illness now represents as much as 80% of expenditure on health (Nolte and McKee 2008). This growth is significantly associated with ageing populations. For example, it has been estimated that by 2050, more than 6% of all people in the European Union (still including the UK) will be aged over 85, which translates into more than 31 million people in absolute numbers. The number of centenarians will increase five times from 2018 to 2050, to more than half a million (Eurostat 2019). More than one-fifth of those aged 85 and over will be living with five or more comorbidities (concurrent physical and mental health needs) (European Commission and Economic Policy Committee 2009). Similar increases are projected for most countries around the world, irrespective of income levels. 2018 was the first year that people aged 65 and older had outnumbered children under the age of 5 globally (UN 2020).

Coupled with ageing populations is a dramatic increase in the use of long-term care by older people. For example, a comparative analysis on long-term care services in Europe projected dramatic increases in the use and costs of long-term care (more than 300% in the case of Germany) between 2000 and 2050 (Comas-Herrera and Wittenberg 2003). More recently, long-term care spending in the EU was the only healthcare service registering a continuous increase from 2004 to 2016, that is, throughout the financial crisis, with an average between 2 and 4% over this time period (OECD and European Union 2019). Therefore, community-based and home-based alternatives to institutionalisation in residential homes through the deployment of multi-disciplinary professional teams have become a commonplace response (e.g. Leichsenring et al. 2013; de Bruin et al. 2020).

These projections in the future demands on health and long-term care systems are observed to be so acute that even the World Health Organisation has passed a resolution across its 194 member states to adopt a *Framework on Integrated People-Centred Health Services* (WHO 2016). In their interim report, it was argued that unless a people-centred and integrated health services approach is adopted, health care will become increasingly fragmented, inefficient and unsustainable (WHO 2015, p. 7). In other words, integrated care represents a fundamental paradigm shift in the way health and care services must be funded, managed and delivered.

The case for making such a change towards integrated care is a compelling one. Since the future of our health and care systems is increasingly shaped by ageing populations, urbanisation and the globalisation of unhealthy lifestyles, it is clear that current approaches to care that focus on curative, specialist-led and hospital-based services need to be revised. People living with non-communicable diseases (NCDs), mental health problems, and long-term and multiple comorbidities need to make strenuous efforts to access the care they need and too often find themselves disempowered, disengaged and unable to manage their health needs. By missing the opportunity to promote health and prevent complications care has become more complex and more expensive.

The hypothesis underpinning integrated care, therefore, is that it represents an approach to promote quality improvement among people and populations where care is currently fragmented and poorly coordinated. Indeed, it has increasingly been recognised that integrated care should be seen as a means to promoting the '*Triple Aim'* goals in care system reform (Berwick et al. 2008): greater cost efficiency; improved care experiences; and improved health outcomes. Bodenheimer and Sinsky (2014) expanded this to the 'Quadruple Aim' adding the experience of the workforce as a crucial fourth objective to a high-quality health system. It is for this reason, in times of scarce resources and growing demands, that so much hope and weight have been placed on the integrated care movement as a mechanism for system transformation. Integrated care represents an approach to strengthen and/or introduce a set of fundamental design features for health systems that can generate significant benefits to the health and health care of citizens, whether rich or poor.

As this Handbook will reveal, the positive impact of integrated care can be seen to accrue at the level of the individual patient as well as to communities and care systems. Yet, in many areas such as health economics, such impact remains contested, and there are also significant issues in understanding how best to deploy integrated care initiatives in practice. Nonetheless, given the projections on the future demand for health and care services, we are past the 'tipping point' where action needs to be taken to transform care systems. The move to more people-centred and integrated care is a core strategy in that task.

1.3 Defining Integrated Care

Integrated care is a concept that is widely used, but recent literature reviews have uncovered more than 175 overlapping definitions and concepts linked with the term (Armitage et al. 2009). This large number of definitional possibilities demonstrates that they tend to be either generic or disaggregated in nature to reflect the complexity and multidimensionality of the concept. Over many years, a plethora of terms have been used including: ‘managed care’, ‘coordinated care’, ‘collaborative care’, disease management’, ‘case management’, ‘transmural care’, ‘continuity of care’, ‘seamless care’, ‘service-user-centred care’ and many others.

This ‘confusion of languages’ stems from different meanings and objectives that various stakeholders within care systems attribute to the term. This might relate to differing professional points of view (e.g. clinical vs. managerial; professional vs. patient) or from the disciplinary perspective of the observer (e.g. public administration, public health, social science or psychology) (Nolte and McKee 2008). Work by Shaw et al. (2011) provides a graphic representation of some of these different viewpoints (see Fig. 1.1). It should be recognised from this that different

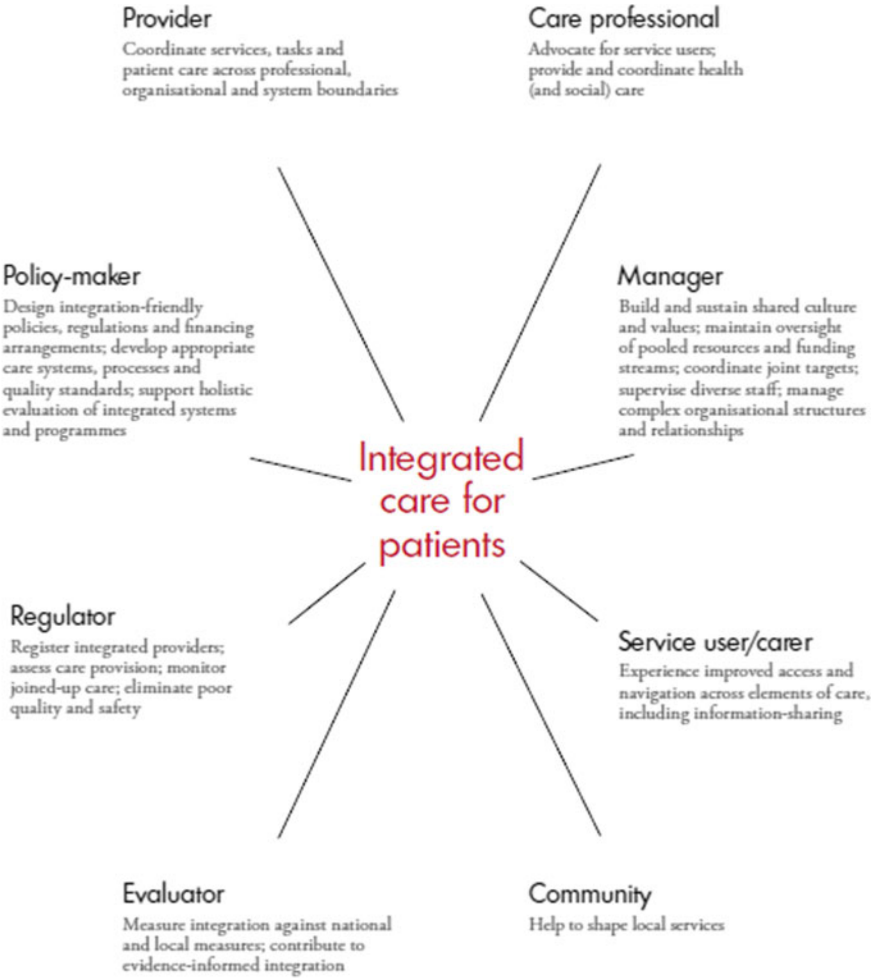

Fig. 1.1 Perspectives shaping integrated care (Shaw et al. 2011, p. 13)

interpretations and meaning of integrated care are *all* potentially legitimate. This suggests that integrated care as a concept cannot be narrowly defined in its meaning, but must be seen as an umbrella term—perhaps linked to a set of broader ideas and principles—that captures this wide-ranging set of viewpoints.

In considering the variability in the way integrated care has been defined, let us consider the five definitions presented in Box 1.1. The first of these definitions, from the World Health Organisation, imbues integrated care with the qualities of care coordination as a continuous support process over time. It is focused on the delivery of public health or clinical interventions and is largely bounded within the confines of health care (WHO 2015). The second definition, used, for example, to underpin integrated care strategies in the Basque country, is again different since it primarily discusses the importance of the structural re-organisation required to enable care organisations to work together collaboratively (Contandriopoulos et al. 2003). The third definition represents a more whole-system definition where healthcare services are integrated with other care services (Leutz 1999) in contrast to the more limited fourth definition that focuses on chronic care only (Nolte and Pitchforth 2014). The final definition is lengthier but seeks to describe the complexity and inter-sectoral nature of integrated care as a process. It also has the added advantage of distinguishing between integration (the process by which professionals and organisations come together) and integrated care (which is the outcome as experienced by service users). This is an important distinction since it implies that integrated care should only be judged successful if it contributes to better care experiences and outcomes for people (Goodwin and Smith 2012).

Box 1.1 Four Commonly Used Denitions of Integrated Care

1. A health system-based definition

   “The management and delivery of health services such that people receive a continuum of health promotion, disease prevention, diagnosis, treatment, disease-management, rehabilitation and palliative care services, through the different levels and sites of care within the health system, and according to their needs throughout the life course” (WHO 2015).
2. A health care manager's defintion
   “The process that involves creating and maintaining, over time, a common structure between independent stakeholders (and organisations) for the purpose of coordinating their interdependence in order to enable them to work together on a collective project” (Contandriopoulos et al. 2003)
3. A whole of systems’ definition
   “The search to connect the healthcare system (acute, primary medical and skilled) with other human service systems (e.g., long-term care, education and vocational and housing services) to improve outcomes (clinical, satisfaction and efficiency)” (Leutz 1999).

4. A definition from the chronic care perspective
   “Initiatives seeking to improve outcomes for those with (complex) chronic health problems and needs by overcoming issues of fragmentation through linkage or coordination of services of different providers along the continuum of care” (Nolte and Pitchforth 2014).
5. A process-based definition
   “Integration is a coherent set of methods and models on the funding, administrative, organisational, service delivery and clinical levels designed to create connectivity, alignment and collaboration within and between the cure and care sectors. The goal of these methods and models is to enhance quality of care and quality of life, consumer satisfaction and system efficiency for people by cutting across multiple services, providers and settings. Where the result of such multi-pronged efforts to promote integration lead to benefits for people the outcome can be called ‘integrated care’” (adapted from Kodner and Spreeuwenberg 2002).
6. A person-centred definition
   “I can plan my care with people who work together to understand me and my carer(s), allow me control, and bring together services to achieve the outcomes important to me” (National Voices 2011).

However, the criticisms behind these well-used definitions are that they treat integrated care as a set of systemic or organisational processes as opposed to the essential quality of ‘caring’ for people. Hence, the final definition seeks to define integrated care from the person’s perspective such that the terms might have meaning to the end user (National Voices 2011). This definition was developed by National Voices in the UK to create for NHS England a defining narrative for the national strategy to promote integrated care and support. By consulting with people across its 130 health and social care charities, National Voices asked what matters most to patients and service users and produced a series of ‘I statements’ on how care and services should be integrated around their needs with a core focus on care planning, care transitions, communication, information and shared decision-making towards specific goals and outcomes.

What is implicit to all of the definitions presented in Box 1.1 is the notion that integrated care should be centred on the needs of services users, their families and the communities to which they belong (Shaw et al. 2011). Indeed, there is evidence to suggest that the more successful integrated care programmes require the common language of *people-centeredness* to create a unifying narrative across stakeholders with potentially very different professional, organisational and political objectives (Ham and Walsh 2013).

As Goodwin and Alonso (2014) point out, there is good reasoning behind developing such a ‘people-led’ definition to integrated care. For example, in reflecting on the real-life context of a patient with advanced dementia and his principal carer (his spouse), it has been demonstrated how a highly diverse,

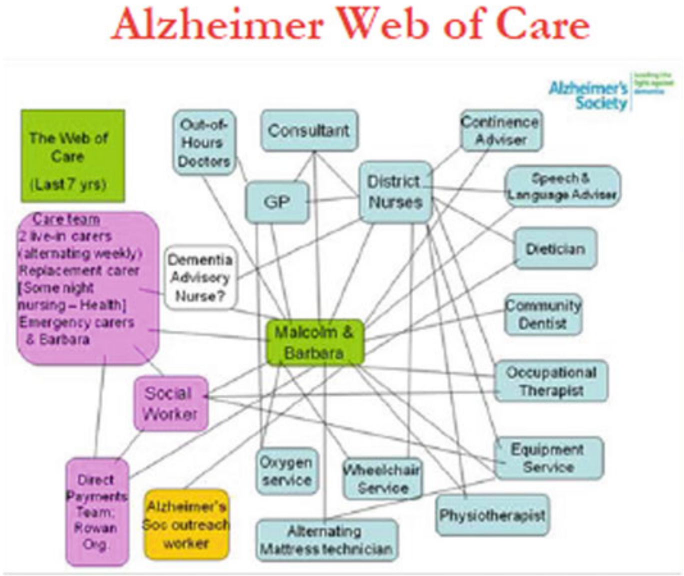

Fig. 1.2 Tackling complexity: the Alzheimer web of care (National Voices 2011)

complex and largely unconnected 'web of care' can result from fragmented health and care systems (National Voices 2011) (Fig. 1.2). These fragmentations are manifest in a range of key problems including:

- *a lack of ownership* from the range of care providers to support 'holistic' care needs;
- *a lack of involvement of the patient/carer in* supporting them to make effective choices about their care and treatment options or enabling them to live better with their conditions;
- *poor communication between professionals and providers*, exacerbated by the inability to share and transfer data, silo-based working, and embedded cultural behaviours;
- *simultaneous duplication of care* (e.g. repeated tests) *and gaps in care* (e.g. as appointments are missed or medications mismanaged);
- *a poor and disabling experience for the service users*;
- *reduced ability for people to live and manage their needs* effectively; and ultimately;
- *poor system outcomes,* for example, in terms of the inability to prevent unnecessary hospitalisations (Goodwin and Alonso 2014).

A key aspect of integrated care, then, is the ability to effectively coordinate care around people's needs. What is important to understand is that effective care coordination can be achieved without the need for formal integration of structures or organisations. Within single providers, integrated care can often be weak unless internal communication or silo-based working has been addressed. As Curry and Ham (2010) demonstrate in their review of the literature, it is the coordination of care at a clinical and service level that matters the most.

While a user-centred definition appears to be the most logical and useful approach to take to define integrated care, it is not for this Handbook to provide the overarching definition of integrated care that should be adopted by all. If the evidence for adoption tells us one thing, it is that there is a requirement for all local stakeholders to come together and agree on their own definition and meaning for integrated care as a means to guide their collective actions. However, in many ways, our overall understanding of the definition of integrated care should be made very simple. Integration (from the Latin *integer*, meaning whole or entire) generally means combining parts so that they work together or form a whole. Care, which can have many meanings, does in this context refer to providing attentive assistance or treatment to people in need. Hence, *integrated care* results when the former (integration) is required to optimise the latter (care) and so is particularly important where fragmentations in care delivery have led to a negative impact on care experiences and outcomes.

The advantage to such a simple definition is that it might help overcome the tendency to focus on structural or organisationally-based solutions, or those that focus purely on integration as a means to create cost efficiencies (which as we will see later in this Handbook might often lead to negative results). Rather, by providing the definition of integrated care with a purpose, so integrated care is given a compelling logic as to its objectives and, therefore, leads to a recognition for how success through integrated care might be judged (Lewis et al. 2010).

In conclusion, integrated care is an approach for individuals or populations where gaps in care, or poor care coordination, leads to an adverse impact on care experiences and care outcomes. Integrated care may be best suited to frail older people, to those living with long-term chronic and mental health illnesses, and to those with medically complex needs or requiring urgent care. However, integrated care should *not* be solely regarded as a response to managing medical problems, and the principles extend to the wider definition of promoting health and wellbeing.

1.4 The Core Dimensions of Integrated Care

One of the key problems to understanding integrated care is its complexity. To support this, there have been a number of different taxonomies developed in order to manage our understanding. Typically, these have examined (after Nolte and McKee 2008; Goodwin and Alonso 2014):

- the *process* of integration (i.e. the mechanisms—both technical and behavioural—required to integrate the work of people and organisations);
- the *degree* or *intensity* of integration (i.e. whether the process involves the ‘full integration’ of health and social care organisations into a new organisational

model or whether the approach supports the creation of non-binding linkages or ties that support better coordination between them);

- the *breadth* of integration (i.e. whether it is fully oriented to: a whole population group; a specific client group—say older people or children; or a specific illness, such as diabetes);
- the *types* of integration (i.e. organisational, professional, cultural, technological);
- the *time span* for integration (i.e. whether it is a 'life-course' approach to people over time, or whether focused on specific episodes of care); and
- the *level* at which integration occurs (i.e. macro-, meso- and micro- and even nano- at the point of care with the individual).

Moreover, integrated care appears to have taken a number of key forms, including (after Goodwin and Smith 2012; IJIC no date):

- *Horizontal integration.* Integrated care between health services, social services and other care providers that is usually based on the development of multi-disciplinary teams and/or care networks that support a specific client group (e.g. for older people with complex needs);
- *Vertical integration.* Integrated care across primary, community, hospital and tertiary care services manifest in protocol-driven (best practice) care pathways for people with specific diseases (such as COPD and diabetes) and/or care transitions between hospitals to intermediate and community-based care providers;
- *Sectoral integration.* Integrated care within one sector, for example, combining horizontal and vertical programmes of integrated care within mental health services through multi-professional teams and networks of primary, community and secondary care providers;
- *People-centred integration:* Integrated care between providers and patients and other service users to engage and empower people through health education, shared decision-making, supported self-management, and community engagement; and
- *Whole-system integration:* Integrated care that embraces public health to support both a population-based and person-centred approach to care. This is integrated care at its most ambitious since it focuses on the multiple needs of whole populations, not just to care groups or diseases.

One of the most important issues when adopting integrated care as a service design principle is the extent to which funders and/or care delivery organisations should opt to formally create new structural entities or otherwise seek to coordinate their activities in a less formal network. As discussed above, what really appears to matter is not the organisational solution but the service-level and clinical-level integration that occurs with and around service users. Yet there is evidence to suggest that the more severe the need of the patient, the more appropriate it might be to develop 'fully integrated' organisations to manage their complex needs (see Fig. 1.3).

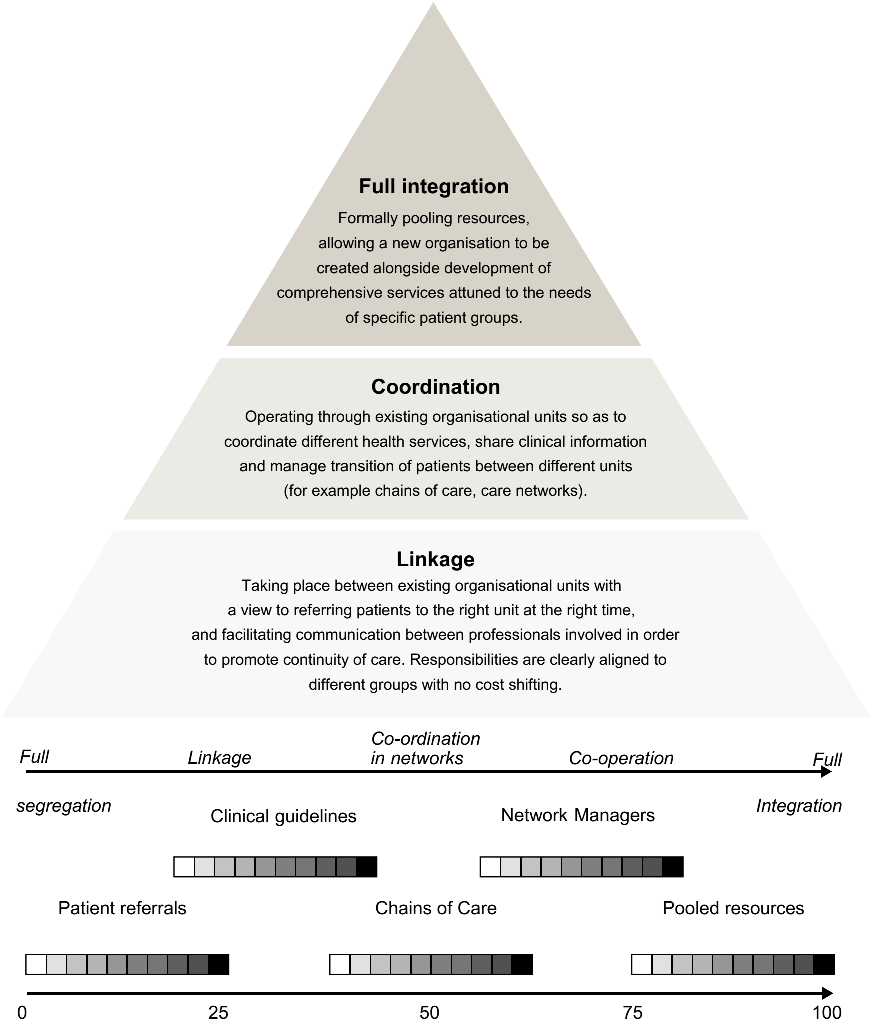

Fig. 1.3 Intensity of integration (Leutz 1999 cited in Shaw et al. 2011, p. 15 and adapted from Ahgren and Axelson 2005)

Hence, there appears to be a continuum of forms of integrated care from a ‘linkage’ approach (sometimes referred to as ‘virtual’ integration) that might seek to ensure effective information sharing and focus on effective referral practices; to a ‘coordination’ model that might develop more formal connections such as care pathway agreements to enable effective care transitions between service providers; to a ‘fully integrated’ service where new organisational forms, perhaps using pooled budgets, become dedicated to the management of care to defined patient groups or populations (Ahgren and Axelson 2005).

Table 1.2 Matching client needs with approaches to integrated care (Leutz 1999)

Client needs	Linkage	Coordination	Full integration
Severity	Mild to moderate	Moderate to severe	Moderate to severe
Stability	Stable	Stable	Unstable
Duration	Short to long-term	Short to long-term	Long-term to terminal
Urgency	Routine/non-urgent	Mostly routine	Frequently urgent
Scope of need	Narrow to moderate	Moderate to broad	Broad
Self-direction	Self-directed	Moderate self-directed	Weak self-directed

Moreover, the intensity of the organisational solution to integrated care has been argued to reflect the severity of the needs of the patient or service user. As Table 1.2 demonstrates, full integration is argued to work best when aimed at people with severe, complex and long-term needs. Hence, for a person with lower levels of need, an appropriate response to care integration might focus more on a 'linkage' model. This might encourage systems that seek to identify people in local communities with emergent needs (e.g. are at risk of becoming frail and/or having one or more chronic conditions) and support the appropriate follow-up and information sharing. Conversely, for people with high needs, integrated care might require the development of intensive multi-disciplinary care teams, common management structures enabled through pooled funding and shared information systems (Leutz 1999).

The ability to match resources to the needs of population groups, for example, as a means to promote care management to high-risk individuals, has become one of the most well-established approaches to integrated care strategies. Pioneered by Kaiser Permanente in the USA, stratifying populations to their risk profiles (see Fig. 1.4) can enable targeted, community-based and pro-active approaches to care that seeks to prevent unnecessary institutionalisation (Singh and Ham 2006).

However, there is a countervailing argument that suggests that fully integrated systems for people with highly complex needs might not necessarily be an appropriate solution and does not necessarily lead to the better management of their needs (6 P et al. 2006). This is because it can be very difficult to predict the variable demands of the high-risk patient on a day-to-day basis and, as a result, the creation of care management organisations might not have the human and financial resources available to respond effectively (Ross et al. 2012). Recent research on care coordination to people with complex needs suggests that a 'core team' is required to support day-to-day needs, but a responsive provider network is also needed to support people when unmanageable complexities in care arise (Goodwin et al. 2013, 2014). One of the most recent developments in the discussion of integrated care is evolving ecosystems. There are several ways of defining ecosystems. One is the understanding based on complex adaptive systems and existing integrated care networks (see Chap. 35 in this book and Dessers and Mohr 2019). Another is along the lines of Amazon, which developed from an online book seller to a whole-sale retailer and a one-stop shop (Davidson et al. 2015; Jacobides et al. 2018).

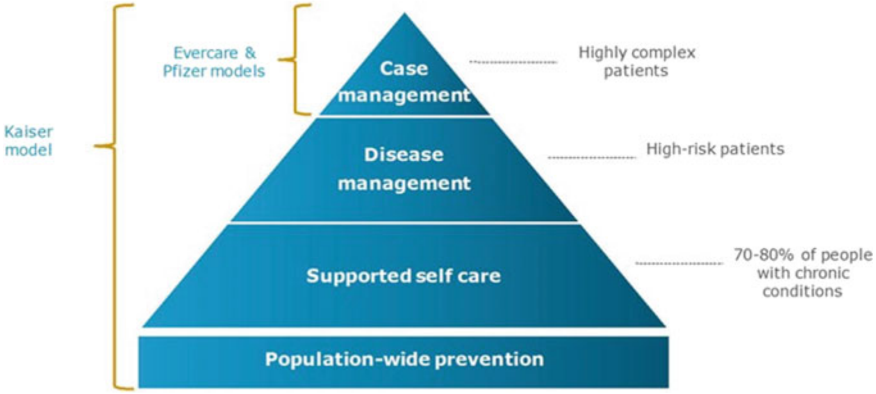

Fig. 1.4 'Kaiser Triangle': deploying different strategies for integrated care according to the risk profiles of populations (adapted from Singh and Ham 2006)

1.5 The Building Blocks of Integrated Care

Many frameworks have been developed to understand the key elements, or building blocks, that comprise a successful integrated care programme. One of the most influential frameworks, as described above, has been the CCM that set out the design of integrated chronic care initiatives to improve quality and outcomes. The CCM was developed from a Cochrane systematic review of factors in recognition of the failures of health systems in meeting the needs of people with chronic illnesses since they remain largely built on acute, episodic models of care rather than care that focuses on more longitudinal, preventative, community-based and integrated approaches. The CCM aimed to provide a comprehensive framework for the organisation of health care in order to improve outcomes for people with chronic conditions (see Box 1.2).

Box 1.2 The Six Interrelated Components of the Chronic Care Model

1. self-management support,
    a. patient education
    b. patient activation/psychosocial support
    c. self-management assessment
    d. self-management resources and tools
    e. collaborative decision-making with patients
    f. guidelines/education

2. decision support,
    a. decision-support tools and guidelines
    b. provider education
    c. expert consultation support
3. delivery system redesign,
    a. care management roles
    b. team practice
    c. care coo-ordination and care coordinators
    d. pro-active follow-up
    e. planned visits
4. clinical information systems,
    a. patient registries
    b. information use for care management
    c. feedback on performance data
5. community resources
    a. for patients
    b. for community
6. health system (support)
    a. leadership
    b. provider engagement
    c. system to spread innovation and improvements

Further revised since to include: cultural competency; patient safety; care coordination; community policies; and case management.

Source: Wagner et al. (1999).

Several variations of the CCM, including the *Expanded Chronic Care Model* and the *Innovative Care for Chronic Conditions,* have focused on the importance of the broad determinants of health (Barr et al. 2003; WHO 2002). They stress the importance of coordinated interventions that cut across the primary, secondary and tertiary levels of care and beyond the boundaries of the healthcare system to cover issues such as public health (i.e. population health promotion, prevention, screening and early detection), management of diagnosed cases, rehabilitation and palliative care).

For example, the *Expanded Chronic Care Model* identified a number of additional domains to the original CCM including: community resources and policies (such as healthy public policy, a focus on influencing the socio-determinants of ill-health through the living environment and strengthening community action); self-management support; decision-support to professionals through evidence-based guidelines; a focus on quality of life and holistic needs rather than just clinical outcomes; and the importance of data systems that integrate information across sectors (Barr et al. 2003).

The *Innovative Care for Chronic Conditions,* developed by the WHO as part of a 'road map' for countries and their health systems to deal with the rising burden of chronic illness, placed a specific premium on prevention through 'productive partnerships' between patients and families, community partners and healthcare teams to create informed, prepared and motivated communities. Eight strategies for action were presented to support the model become reality (WHO 2002; see Fig. 1.5). Other framework developments have included the *patient-centred medical home (PCMH)* that represents an evidence-based model of enhanced primary care developed in the USA that can provide care which is accessible, continuous, comprehensive and coordinated and delivered in the context of family and community (National Committee for Quality Assurance 2016). PCMH evolved as a response in how to manage *all* patients in a particular community, rather than those with chronic illness as in CCM, and was particularly targeted at children and adolescents and other people requiring more holistic care and treatment. PCMH was piloted as an approach within Medicare and Medicaid insurance programmes,

Fig. 1.5 Innovative care for chronic conditions framework (adapted from WHO 2002)

including the creation of new payments and incentives for group practices that meet the core criteria associated with being designated as a PCMH. The key domains of the approach include: having a personal physician (continuity of care); physician-directed medical practice; whole person orientation; care that is coordinated and/or integrated around a person's individual needs; quality and safety targets; and enhanced access (to primary care).

The frameworks and models for care systems described above have primarily evolved from the USA and been confined in their thinking to *within* health systems and not sought to identify the wider range of actions that decision-makers would need to adopt to enable integrated care to be adopted. One knowledge synthesis conducted in Canada, however, that sought to address this was able to develop 'ten principles of successful integrated systems' (Suter et al. 2007) from which some care systems in Canada derived a simple scorecard to reflect on their capabilities (see Box 1.3). The research was updated and validated through a series of Delphi exercises, and a revised version was published in 2017 (Suter et al. 2017).

Box 1.3 Ten Principles for Successfully Integrated Systems (Suter et al. 2007)

1. *Care across the continuum*. Recognising the importance of providing seamless health care despite the multiple points of access
2. *Patient focus*. Encouraging active participation by the patients, families or informal caregivers while focusing on population-based needs' assessment
3. *Geographic coverage and rostering*. Rostering to maximise accessibility and minimise duplications
4. *Standardised care delivery through inter-professional teams*. Using provider-developed and evidence-based clinical care guidelines and protocols
5. *Performance measurement*. Evaluating the process of integration and measuring system, provider, and patient outcomes
6. *Appropriate information technology and communication*. Collecting data through electronic patient records systems to effectively track utilisation and outcomes
7. *Organisational culture and leadership*. Sharing a vision of an integrated healthcare delivery system through strong leadership and cohesion
8. *Physician engagement*. Integrating physicians, particularly primary care physicians, by a variety of methods such as compensation mechanisms, financial incentives and non-financial ways of improving quality of life
9. *Strong governance structure*. Implementing a strong governance structure that includes community and physician representatives;
10. *Sound financial management*. Encouraging fiscal responsibility.

Of the range of interpretations and conceptual frameworks through which to understand and study the complexities of integrated care, it is the comparatively recent work by Valentijn et al. that provides one of the more elegant approaches (Valentijn 2016; Valentijn et al. 2013 and see Fig. 1.6). By placing people-focused and population-based coordinated care as the guiding principle or objective of integration, their research describes the range of different integration processes at the macro-level (system integration), meso-level (organisational and professional integration) and micro-level (clinical, service and personal integration). Functional integration (e.g. communication and the use of ICT) sits alongside normative integration (e.g. shared cultural values) to ensure effective connectivity between the functioning of the integrated care system between various levels. Hence, information and communication is regarded as a key transversal issue with a role as a ‘connector’ of processes that has the dual quality of both being the ‘glue’ through which people and organisations come together to provide more integrated services, but also the ‘grease’ in making these relationships dynamic through creating effective channels of communication and data sharing.

Valentijn et al.’s *Rainbow Model* of integrated care (Fig. 1.6) is a very useful way to conceptualise the inter-relationships among different dimensions of integrated care though it does drive a ‘process-driven’ rather than ‘user-centred’ understanding. In a final taxonomy of integrated care elements positively associated with each of the different levels (see Box 1.4), the research did not focus on core issues related to person-centred care nor on the wider issues that other frameworks had identified regarding the ability to tackle the socio-determinants of ill-health or integrate public health approaches into integrated care strategies. This is not to

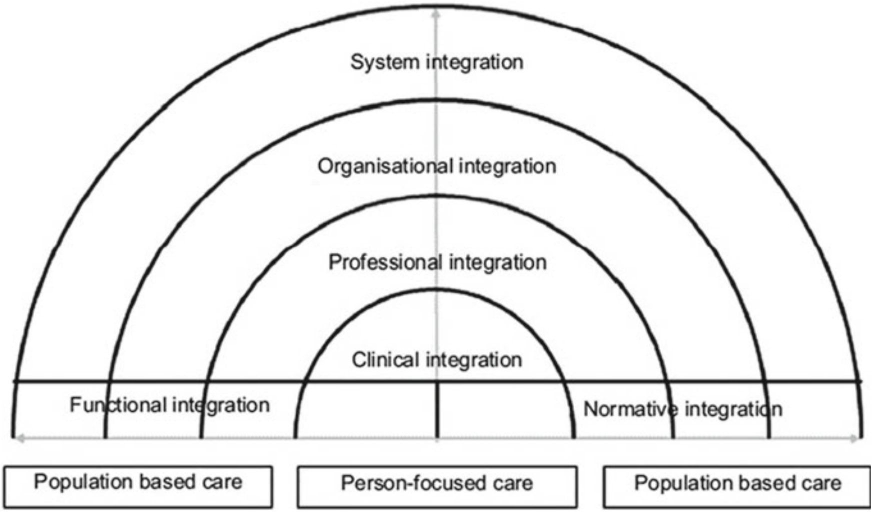

Fig. 1.6 Rainbow model of integrated care (after Valentijn et al. 2013)

criticise the *Rainbow Model* but demonstrates the problems in developing a generic template or tool through which to judge the key success factors across what is a complex service innovation. This leads to the recognition that the concept of integrated care should be seen as so much more than the sum of complex organisational and systemic processes but be regarded as a fundamental design principle in the future of care systems (Goodwin 2013a).

Box 1.4 The Rainbow Model of Integrated Care: Final Taxonomy Summary (from Valentijn 2016).

Clinical integration: case management, continuity of care, multi-disciplinary care plans, supportive relationship with client	*System integration*: aligned regulatory frameworks to support care coordination and team work
Professional integration: inter-professional education, inter-disciplinary teams	*Functional integration*: shared information systems; collective learning and joint research; regular feedback on performance measures
Organisational integration: shared governance and accountability; shared strategy; trust	*Normative integration*: shared vision; reciprocity of behaviour; mutual gain; visionary leadership; distributed leadership; shared norms and values

Most recently, the World Health Organisation has published a series of papers examining the transformational processes necessary to achieve people-centred and integrated health services delivery. WHO Europe, for example, has published its European Framework for Action on Integrated Health Services Delivery (WHO Regional Office for Europe 2016). The Framework provides an ‘implementation package’ designed for people and institutions in political and technical roles responsible for integrated care policy and practice.

In parallel to this, and based on its own examination of the evidence internationally, the WHO at the global level has since published its *Framework on Integrated People-Centred Services* (WHO 2016). Having been ratified by WHO’s General Assembly in May 2016, it implies that all WHO member states (including across the EU) have signed up to the formal commitment to implement integrated care. In terms of implementation, the Framework sets out five interwoven strategies that need to be implemented for health service delivery to become more integrated and people-centred: empowering and engaging people and communities;

strengthening governance and accountability; reorienting the model of care; coordinating services within and across sectors; and creating an enabling environment.

1.6 Conclusions

> Without the full alignment of political, regulatory, organisational and professional support for the goals of integrated care, a significant degree of local leadership and commitment is needed at a clinical and service level to make change happen. This does not appear to be a sustainable proposition for the long-term future of integrated care, nor will it allow the widespread uptake of these approaches. Perhaps all countries need to re-evaluate and recalibrate their health and social care systems such that local service innovations can be supported to integrate services that can better meet the growing needs of [older] people with complex and multiple conditions (Goodwin et al. 2014, p. 22).

Integrated care is difficult to define and understand since it represents a complex service innovation in the way health and care services should be redesigned around people's needs. Consequently, integrated care has come to mean different things to different people and the resulting conceptual 'soup' has often acted as a barrier when it comes to developing commonly understood strategies to support implementation and change. However, as this chapter has attempted to outline, there are three distinct dimensions to what integrated care means in practice:

- First, integrated care is a necessary response to overcome fragmentations in care delivery where this adversely impacts on the ability to coordinate care effectively around people's needs and so leads to sub-optimal results in terms of people's care experiences and outcomes.
- Second, integrated care represents an approach to improve the quality and cost-effectiveness of care by ensuring that services are well coordinated around people's needs. Integrated care is by definition, therefore, both 'people-centred' and 'population-oriented'.
- Third, it is this people-centred focus that becomes the organising principle for integrated care as a service innovation, whether this be related to individual patients, the carer/family or the wider community to which they belong.

However, our understanding of integrated care, its complexities, its components and the ways to implement it remains an emerging scientific discipline. There is a significant and emerging body of knowledge that helps us understand and appreciate the building blocks that need to be put in place for the effective development of integrated care in policy and practice. Yet, as the next chapters in this Handbook make clear, what appears to be more difficult is our understanding of the impact of integrated care programmes and the relationship between the component parts of an integrated care solution that contributes to improving outcomes.

It has been observed that the implementation science to integrated care remains weak (Goodwin 2013b). In part, this is a reflection on how many integrated care programmes are immature, often ill-defined and lacking in focus. Much still needs to be done through research to broaden our conceptual and empirical understanding, but in a way that pro-actively supports adoption to meet the ‘Quadruple Aim’ goals that have been adopted as the core hypothesis behind the integrated care movement.

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Refocussing Care—What Does People-Centredness Mean?

2

K. Viktoria Stein and Volker Amelung

2.1 Introduction

From the very beginning, integrated care set out to transform care systems and shift the focus from organisations and structures to patients and communities. The IOM (2001) defined patient-centredness as one of the six elements of high-quality health care, and the WHO has emphasised the importance of responsiveness, patient- and people-centredness and community involvement in several reports over the last 2 decades, starting with the World Health Report 2000 (e.g. WHO 2000, 2007, 2015, 2016; WHO and UNICEF 2018). But after decades of putting theory into practice, the inclusion of patients, families and communities on all levels and in all aspects of care is still far from the norm and often an afterthought (Goodwin 2016; Stoop et al. 2019). 'We can't include people yet! We don't know ourselves what we want to do, so how could we invite others to join the discussion?' This argument is frequently used by professionals, managers and decision-makers when answering the question whether they had already reached out to the people, who should 'profit' from integrated care. The prevailing culture is still that we do integrated care TO people and not WITH them. The COVID-19 pandemic is only the latest crisis showcasing the abyss between formal and informal care, community resilience and political ineptitude, when it comes to making sure that people receive the care and support they need, when they need it and where they need it. This chapter will frame the

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concept at the heart of integrated care and outline the many possibilities to involve patients, families and communities in the design, implementation and delivery of integrated care.

2.2 Theoretical Underpinnings

As outlined in Chap. 1 of this Handbook, integrated care aspires to address the ‘Quadruple Aim’ (Bodenheimer and Sinsky 2014) of health systems by improving coordination, collaboration and management of health and care systems. At the heart of the movement lies the rediscovery and development of the principle of a healthy mind, which lives in a healthy body, and was first formulated in Ancient Greece and Rome some 3000 years ago. In modern times, this was epitomised by WHO’s definition of health as ‘a state of complete physical, mental and social wellbeing, and not merely the absence of disease’ (WHO 1946). In clinical-practical terms, the bio-psycho-social model developed by Engel (1977) tried to introduce this holistic understanding of health and well-being, which focusses on the needs of the whole person, and not on the isolated treatment of a symptom. Both concepts emphasise the relationship between body and mind of an individual in the context of their social environment in order to successfully treat and support a person. The concept of salutogenesis was borne out of these reflections. Underneath this umbrella term, very different theories are subsumed, but which all deal with the strengthening and empowerment of the person. Some of these concepts specifically address the importance of social connectedness and being a member of a healthy community in order to be able to fulfil ones potential and feel truly well (Fig. 2.1).

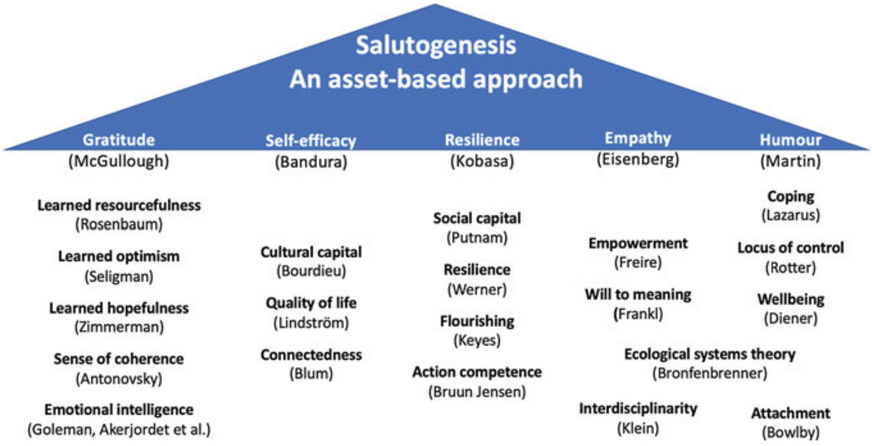

Fig. 2.1 Concepts and theories of salutogenesis. *Source* Own illustration, based on Lindström and Eriksson (2010) and Eriksson and Lindström (2010)

The theories represent so diverse fields as economics (e.g. social capital), philosophy (e.g. cultural capital) or psychology (e.g. will to meaning), but they all serve a common purpose: in contrast to pathogenesis, which is still prevalent in our health systems today and which deals with the development and combat of illness, salutogenesis looks at the development and maintenance of health and well-being. As such, it is at the core of what people-centredness is all about.

This understanding of health and well-being still represents a major paradigm shift, which needs to happen on all levels of the system. People and civil society need to take a more active part in the decision-making process about their own health, professionals need to let go of their paternalistic treatment of patients and families, and organisations and systems need to change the funding, regulatory and monitoring frameworks to achieve outcomes important to people and communities (Horne et al. 2013).

2.3 What Does 'People-Centred' Mean?

'The people-centred approach meets these broader challenges by recognising that before people become patients, they need to be informed and empowered in promoting and protecting their own health. There is a need to reach out to all people, to families and communities beyond the clinical setting. In addition, health practitioners are people, and healthcare organisations and systems are made up of people. Their needs should also be considered, and they must be empowered to change the system for the better. That is, a people-centred approach involves a balanced consideration of the rights and needs as well as the responsibilities and capacities of all the constituents and stakeholders of the health care system' (WHO 2007).

As with most other concepts associated with integrated care, there are a plethora of terms used synonymously and simultaneously for those receiving services (Miller et al. 2016; The Health Foundation 2016). Depending on the perspective and the system, the terms 'patients', 'service users', 'clients', 'consumers' or 'persons with lived experience' may be used. These terms come with different connotations, but in effect all talk about people who access health and care services from a variety of service providers and organisations (Miller et al. 2016). Similarly, integrated care has been described as being 'patient-centred', 'person-centred', 'people-centred', and more recently, 'people-powered' or 'people-driven'. These terms can be seen as representing a continuum of inclusivity and a growing understanding of who needs to be involved and to what degree in integrated care, where 'patient-centred' signifies the first, still clinically driven, realisation that individual patients need to be involved in clinical decision-making about their health and care. On the other end of the spectrum, recent developments reflect the broader demand of communities and populations to take active part in the design and policy-making about public services and systems. 'People-powered' and 'people-driven' thus represent a 180° shift in perspective, putting people and communities in the driver's seat of public policies (WHO 2007; Ferrer 2015; Horne et al. 2013; Thompson 2019).

Box 1. Some Denitions

Patient-centred care means 'providing care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions' (IOM 2001; Gerteis et al. 1993).

Person-centred care 'depends on the needs, circumstances and preferences of the individual receiving care' (The Health Foundation 2016).

People-centred care is 'an approach to care that consciously adopts the perspectives of individuals, families and communities, and sees them as participants as well as beneficiaries of trusted health systems that respond to their needs and preferences in humane and holistic ways' (WHO 2015).

'The *People Powered Health* approach draws on the expertise and commitment of the people it serves, and supports them to change behaviours and create social networks that improve health' (Horne et al. 2013).

'People-driven care is based on people's needs and their strengths. People-driven care centres on the ability to engage and empower people to take control of the factors that influence their health and wellbeing, including addressing social determinants of health' (Based on Marmot et al. 2008).

These definitions give an overview of what can be understood by the different terms, but it should be recognised that there is no universally accepted definition for any of them. As mentioned above, they represent a fluid, but continuous evolution of how far reaching the involvement of individuals and communities may go and how many aspects of life and public administration should and need to be included. The commonalities in all these concepts, approaches and definitions echo the principles of integrated care in general: it is about changing perspectives, taking a holistic and inclusive approach to health and care, building trusted relationships and respecting each other as equal partners in care (Stoop et al. 2020; Ferrer 2015; Miller et al. 2016; The Health Foundation 2016).

As it is well established by now, that 90% of our health and well-being are influenced by factors outside the clinical–medical realm, whether it be personal life choices, the built environment and infrastructure or education, the need for people-centred policy-making and system design is ever more pressing (Gnadinger 2014; Hood et al. 2016; Kindig 2008). However, while all these terms essentially call for the same thing, they are not synonymous, and thus it is important to determine, at what level involvement and engagement of people happen and what the purpose of it is. Is it the focus on individual patients and families to support their day-to-day care, or is it to include civil society representatives in the management of an integrated care system? As always, it is necessary to clearly identify the purpose of involvement and engagement and the roles, to determine which tools are adequate to achieve people-centredness and whom one needs to involve (Miller et al. 2016). Arnstein's 'Ladder of Participation' (1969) established a clear

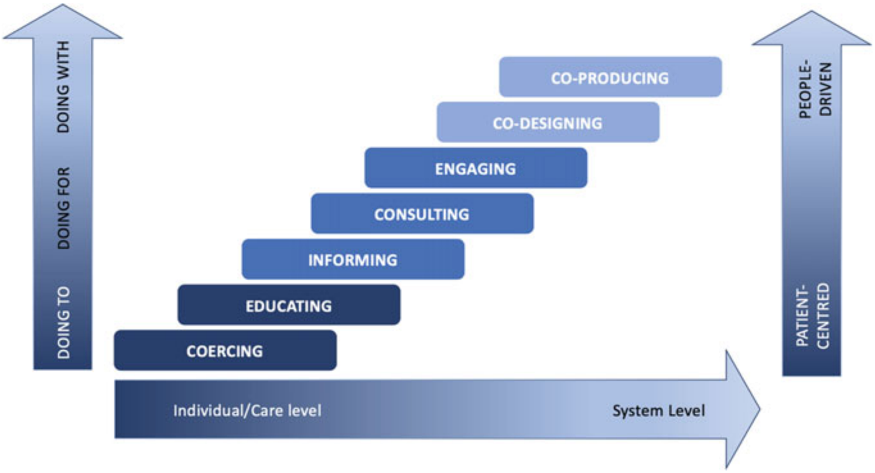

Fig. 2.2 Ladder of participation for integrated care. *Source* Own illustration, based on and adapted from Arnstein (1969)

hierarchy from ‘doing to’ to ‘doing with’, which is still very useful in distinguishing whether the policies, strategies and activities designed and implemented in the guise of integrated people-centred service delivery, actually are what they claim to be. Combining it with the terms defined in Box 1 illustrates the intensity of involvement needed (Fig. 2.2).

Many systems have already come some way from the paternalistic, coercing attitude towards patients and families, implementing some measures of shared decision-making and shared care planning, supporting self-management and involving informal caregivers, but a truly people-centred or people-driven system will need a more fundamental change than these local, stepwise and half-hearted efforts of recognising the growing need and demand for a more inclusive health and care system on all levels.

2.4 Strategies and Instruments to Support People-Centred Services and Systems

As outlined in the introduction of this book, integrated care aims at improving the quality of life, quality of care and satisfaction of people and communities with their services. Thus, people-centredness can be seen as fulfilling a dual purpose: (a) it can be an end in itself, i.e. in the democratic sense of having civil society representation throughout the system (people-powered, people-driven care), or (b) it can be a means to an end, i.e. by involving people and families in their own care, this will better meet their needs and lead to better outcomes (patient-centred, person-centred, people-centred care) (Miller et al. 2016). These different aspects, roles and perspectives are reflected in the definitions and frameworks put forward over the last two decades, but again, a common thread can be made out through all of them. Again, Box 2 only represents examples of definitions and does not purport to represent the ultimate versions.

Box 2. Denitions for Engaging Individuals and Communities

People empowerment refers to 'the process by which people develop their intrinsic capabilities to increase control over the factors, decisions and actions that affect their health and care and the process of gaining power externally over them' (Ferrer 2015).

People engagement is 'the process by which people increase their degree of active involvement in caring for themselves and in shaping their health determinants' (Ferrer 2015).

Co-design enables people to make a creative contribution in the formulation and solution of a health-related challenge. The approach focusses on addressing people's needs rather than those of institutions. It goes beyond consultation since it seeks to build equal collaboration between all those affected by, or seeking to resolve, such challenges. A key tenet of co-design is that people are 'experts of their own experience' and so the process involves the active facilitation of engagement between people to communicate, share insights and test out new ideas (IJIC 2020).

Co-production represents care and support that is delivered in an equal and reciprocal relationship between clinical and non-clinical professionals, individuals using care services, their families and the communities to which they belong. Co-production implies a long-term relationship between people, providers and healthcare systems where information, decision-making and service delivery become shared (IJIC 2020).

Another way of thinking through the different involvement and engagement activities to achieve people-centred services and systems is to distinguish between improving health and well-being for individuals or communities versus designing and implementing policies with individuals or populations. Ferrer (2015) compiled a comprehensive set of tools, strategies and evidence to achieve these different levels of engagement and empowerment, from the individual patient-centred approaches of self-management and shared care planning, to population and system-level public benchmarking of system performance, as evidenced by the example of the state of Vermont. One reason why a sustainable and system-wide shift to people-centred thinking and working has not happened yet is the fact that the implementation of self-management does not stop at the interface of patient/family and professional, i.e. the micro-level. It needs to be supported by a culture and strategy of shared governance and management on the meso-level and lead by supportive and shared values and principles on the system level (see Table 2.1). Only then will the efforts on the micro-level not evaporate when dedicated professionals run into barriers, e.g. of information sharing or patients face the problems of unconnected health and social services.

Along the same lines, Ferrer (2015), in her seminal report for the WHO Regional Office for Europe, outlined four key strategies for patient engagement and four key strategies for population empowerment. For each strategy, she identified tools and examples for patients and families, professionals and policy-makers, as well as for supporting implementation, and provided the overwhelmingly positive evidence for all of them.

Tables 2.1 and 2.2 give cursory examples of how people-centredness may be realised on all levels, but it also highlights the subtle differences in understanding of what engagement, empowerment and co-design mean. Ultimately, it is not important to agree on the definitions, but on the actions, which need to be taken in order to move from a disease focussed to people-driven system of health and care. And there is clear evidence available that a more engaged and actively involved population, with adequate health literacy levels, along with a better educated workforce experiences better health and well-being outcomes and uses less resources than a passive population (Ferrer 2015).

Underlying these discussions is also an ethical question of rights and responsibilities. If applied correctly, shared decision-making and care planning will enable individuals and families to articulate what they can and cannot do, e.g. through goal-oriented care. Integrated people-centred services will also support marginalised groups to receive access to the necessary care services and help professionals share responsibilities across services. On the system level, this calls for clear regulatory frameworks and the enforcement of the human right to health and health care, among other things (Cohen and Ezer 2013; Gruskin et al. 2007).

Table 2.1 Selected activities of involvement to achieve people-centred systems

Micro (care or service integration)	Meso (professional and organisational integration)	Macro (system integration)
Self-management	Shared governance and management	Establishing values, principles and strategies
Evaluation, e.g. feedback	Quality improvement and management, e.g. lay advisory boards	Transparent monitoring and benchmarking systems
Patient and family researchers	Evidence-based practice and integrated care guidelines	Evidence-based policy making
Shared decision-making and care planning	Interdisciplinary teams including informal care givers	Civil society representation in decision-making bodies
Co-production of services	Co-design of services and organisations	Co-creation of integrated care systems

Source Adapted from Miller et al. (2016)

Table 2.2 Examples of strategies and tools for patient engagement and population empowerment

Strategies for patient engagement	For patients	For professionals	For policymakers	For implementation
Self-management	Raising awareness about available resources, e.g. apps	Identifying and tailoring self-management support according to health literacy levels, e.g. through standardised questions	Raising awareness and understanding of the importance of self-management, e g. through pubic campaigns	Creating platforms for knowledge exchange, e.g. the Self-Management Network Scotland
Shared decision-making	Decision aids to support patients in considering why one option is better than other and what is important for them about their decision, e.g. the Ottawa Personal Decision Guide and the Guide for Two	Education and training: when health professionals participate in education, they are more likely to use patient decision aids and share decision-making with patients (Legare et al. 2010)	Developing frameworks and strategies to support shared decision-making, e.g. the Ottawa Decision Support Framework	Support research projects and knowledge exchange, e.g. monitoring and evaluation
Peer-2-peer support	Setting up and training peer support networks, e.g. in the NUKA system (Alaska)	Connecting patients with peer support networks	Supporting the establishment of community health workers as promoted by WHO	Joining the Global Network of Peer Support
Supporting patients and families	Respite care for carers	Including informal caregivers in the decision and planning of care	Improving support for informal caregivers, e.g. through paid leave	Using carer assessments as part of an evaluation and monitoring strategy
Strategies for population empowerment				
Protecting peoples' rights and fostering shared responsibilities	Active involvement in citizen's panels or lay advisory boards	Training to understand the implications of patient's rights and how to address them in every day practice	Mandating people representation with voting rights on all levels of the system	Using a health-related human rights impact assessment for service and system design

(continued)

Table 2.2 (continued)

Strategies for patient engagement	For patients	For professionals	For policymakers	For implementation
Enabling informed choice	Using consumer reports and healthy choice guides	Taking time to explain alternative choices and resources available	Supplying culturally adapted guidebooks	Monitoring and evaluation frameworks
Strengthening health literacy	Developing skills for health and attending educational programmes	Improving patient–provider communication and simplifying language and tools	Raising awareness and developing targeted campaigns and programmes	Using implementation framework, toolkits and strategies, such as provided by Health Literacy Europe
Supporting community development	Getting involved in community groups or volunteering	Using communities as assets and engaging with local support networks	Developing coalition and community coalition-driven interventions	Using community implementation programmes and assessment, e.g. the CDC Community Health Assessment and Group Evaluation (CHANGE)

Source Adapted from Ferrer (2015)

2.5 Prerequisites for People-Centred Services and Systems

Throughout this chapter, barriers and challenges have been mentioned, which still impede the radical cultural and systemic change necessary to implement integrated people-centred systems at scale. Given how long the interplay of body, mind and social environment has already been recognised as essential for the health and well-being of people, it is at first glance astonishing that so little has changed in our systems thus far. However, upon closer scrutiny, the shift from patho- to saluto-genesis represents a profound paradigm shift, which touches at the cultural, financial and structural core of our systems (see various chapters in this Handbook). While politicians, professionals and civil society may concur that such a shift is necessary, this would necessitate painful behaviour changes for all of us (WHO 2007; Horne et al. 2013; TransForm 2019):

- We need to change what and how we measure and value health and well-being. The current systems of clinically driven, process-oriented indicators are inadequate to capture the complex interrelating factors the influence health and well-being (see chapters Nolte and Suter).
- We need to change how we pay for services, as episodic, disease-related payments to not reflect the catalogue of services and processes needed to treat complex and chronic conditions, or incentivise healthy behaviour (change) (see chapters Tsiachristas).
- We need to change the dominant culture in our workforce and organisations, to reflect the interdisciplinary, cross-sectoral and holistic values and principles, which found the basis of integrated people-centred care systems (see chapters Goodwin, Stein, Miller and Busetto).

In Part II of this book, stories of such changes illustrate that it is possible, albeit locally or piecemeal. The journey from static disease repair system to complex adaptive health system is long and arduous, and it needs a lot of personal courage and dedication to get it started. There is still no health and care system in the world, which can claim to be truly people-centred, and it may be that it needs another 50 years for this concept to gestate and become ingrained in our structures, processes and culture. After all, it took the WHO definition for health that long to find a concept, which would take its aspiration seriously.

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Evidence Supporting Integrated Care

3

Ellen Nolte

3.1 Introduction

An ageing population coupled with a rising burden of chronic diseases, growing user expectations and technological advances challenge health care delivery in many countries. Against a backdrop of increasing financial constraints, this creates a pressing need for more efficient use of resources. There is increasing concern about health systems' continued focus on acute, episodic illness with their dependence on hospital-based care delivery. Apart from being very costly, there are questions about the suitability and efficiency of such services in the light of the changing disease burden (Rechel et al. 2009) and the rising proportion of people with multiple health problems (Barnett et al. 2012). Chronic conditions create a spectrum of long-term and fluctuating needs. In combination with increasing frailty at old age, these conditions require the development of delivery systems that bring together a range of professionals and skills from both the cure and care sectors, as well as active service user engagement (Holman and Lorig 2000; Nolte and McKee 2008a).

Yet, service delivery has developed in ways that have tended to fragment care both within and between sectors. For example, structural and financial barriers dividing providers at the primary and secondary care and at the health and social care interface, distinct organisational and professional cultures, and differences in terms of governance and accountability all contribute to care fragmentation (Glasby et al. 2006). As a consequence, people typically receive care from many different providers, often in different settings or institutions; they are frequently called upon to monitor, coordinate, or carry out their own care plan, often with limited guidance

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on how to do so (House of Commons Health Committee 2014; Nolte et al. 2008). Failure to better coordinate services along the care continuum may result in suboptimal outcomes, such as potentially preventable hospitalisations, medication errors, and other adverse events (Vogeli et al. 2007).

It is against this background that, globally, systems have set out to explore new approaches to health care delivery that can bridge the boundaries between professions, providers, and institutions and so provide appropriate support to people with long-standing health and care needs (Nolte et al. 2008; WHO Regional Office for Europe 2016; World Health Organisation 2015). At the policy level, countries have sought to create regulatory and policy frameworks to promote approaches that better integrate care and improve coordination between sectors and levels of care. This often occurs alongside efforts to shift specialist services from hospital into the community as a means to increase the accessibility of services and the responsiveness of the system, and, potentially, reduce costs (Ettelt et al. 2006; Nolte et al. 2014; Winpenny et al. 2016). In Europe, this development has been supported by the 2011 European Council Conclusion recommending countries introduce innovative approaches and models of health care to move towards more integrated care systems, enhance equitable access to high quality care, and reduce inequalities (Council of the European Union 2011).

The move to more integrated care systems is often associated with high expectations and a goal of increasing the effectiveness, efficiency, and sustainability of service delivery more broadly. This chapter provides an overview of available evidence supporting integrated care. We begin by briefly describing conceptualisations of integrated care against which to assess the evidence, followed by an overview of the literature that examines the impacts of integrated care. We then discuss some of the key challenges of interpreting the existing evidence base and the extent to which it permits drawing robust conclusions on the effects of integrated care approaches on various outcomes. We close with a set of overarching observations.

3.2 Conceptualising Integrated Care

Depending on the context, strategies to integrate care are sometimes driven by a need to contain cost, sometimes by the need to improve care, and often by both. Central to the development of integrated care is an expectation that it might support achievement of the ‘Triple Aim’ of a simultaneous focus on improving health outcomes, enhancing patient care experience, and reducing the per capita costs of care for populations (Berwick et al. 2008). Available evidence points to a positive impact of integrated care programmes on the quality of patient care and on selected outcomes (Martinez-Gonzalez et al. 2014; Ouwens et al. 2005). However, the effectiveness and consequences of different forms of care integration, including their economic impacts, remain uncertain (Nolte and Pitchforth 2014). This is in part because of the lack of a common understanding of what is being referred to as 'integrated care', as well as inconsistencies in describing component approaches and interventions (Martinez-Gonzalez et al. 2014; Nolte and Pitchforth 2014; Ouwens et al. 2005). This section provides a summary of ways to think about integrated care; a detailed review of relevant conceptualisations is presented in Chap. 1.

Integrated care is a concept that has been widely used in many ways by different scholars and in different health systems (Nolte and McKee 2008b). Traditionally, it has been discussed in the health and social care fields, with reference to linking the cure and care sectors (Kodner and Spreeuwenberg 2002). Some authors also suggest linking in broader human services systems such as education and housing in order to improve outcomes (Leutz 1999). The application of the concept of integrated care to health and social care is not clear cut, however, and different conceptualisations have been put forward emphasising, for example, the health care perspective ('a concept bringing together inputs, delivery, management, and organisation of services related to diagnosis, treatment, care, rehabilitation, and health promotion' (p. 7) (Groene and Garcia-Barbero 2001), or interpreting integration in terms of financing and delivery functions in the context of managed care (Ovretveit 1998; Shortell et al. 1994).

The common denominator of integrated care concepts and approaches is their primary aim of improving outcomes for, traditionally, frail older people, and other population groups with diverse and complex needs who require assistance with activities of daily living (Nolte and McKee 2008b). It is important, however, to recognise that integration is a much broader concept that applies to many other areas such as urgent care, maternity and child health care, and public health, among others. A common element is the notion that integrated care should be centred on the needs of service users, their families, and the communities to which they belong (Shaw et al. 2011). Lewis et al. (2010) highlighted that a user-centred vision for care delivery is more likely to overcome the tendency to opt for structural or organisation-based solutions, and it also provides a compelling logic regarding the objectives for integrated care and how success might be evaluated.

Systematic understanding of the evidence of the impacts of integrated care has long been hampered by the absence of a 'sound paradigm through which to examine the process' (p. 311) (Goodwin et al. 2004), and it has only been more recently that more formal analytical frameworks have been proposed (Minkman et al. 2013; Valentijn et al. 2013; van der Klauw et al. 2014). For example, in an attempt to develop a typology of integration in health and social care that enables systematic assessment of the structures and processes involved, their prerequisites, and their effects on service organisation, delivery, and outcomes, analysts have identified different dimensions of integration. The most commonly used dimensions differentiate the *type*, the *breadth*, the *degree,* and the *process* of integration (Nolte and McKee 2008b). Valentijn et al. (2013) brought these different ways of conceptualising integration together in the form of the Rainbow Model of Integrated Care, which sees integrated care as a person-focused and population-based care approach across the care continuum. In the model, integration occurs at the micro (clinical integration), meso (professional and organisational integration), and macro (system integration) levels, along with functional and normative integration linking the different levels (see Chap. 1) (Valentijn et al. 2013). It is important to recognise that the process of integration typically requires simultaneous action at the different levels and across different functions, which develop in distinct phases (Minkman 2011). Thus, care integration is not likely to follow a single path and variations will be inevitable.

3.3 The Evidence Supporting Integrated Care

There is now a series of reviews, and reviews of reviews, of the published and grey literature on integrated care models or strategies for people with (specific) chronic conditions (Busetto et al. 2016; Kruis et al. 2013; Martinez-Gonzalez et al. 2014; Ouwens et al. 2005), those with mental health co-morbidity (Lemmens et al. 2016; Rodgers et al. 2016), or for broader population groups (Nolte and Pitchforth 2014). Reviews typically consider a range of approaches that can be subsumed under the heading of integrated care, such as collaborative care, case management, care coordination, or disease management. Indeed, in a review of systematic reviews by Ouwens et al. (2005), which sought to assess the effectiveness, definitions, and components of integrated care programmes for chronically ill patients, the majority of the studies assessed disease management programmes (see Chap. 24) (Ouwens et al. 2005). Similarly, in a meta-review of integrated care programmes for adults with chronic conditions, two-thirds of included studies were reviews of disease management interventions (Martinez-Gonzalez et al. 2014).

Both reviews found evidence of beneficial effects for some outcomes, such as functional health status, clinical outcomes, patient satisfaction, and quality of life. Frequently, there was evidence of a positive trend only, rather than of statistically significant improvements (Martinez-Gonzalez et al. 2014; Ouwens et al. 2005). Evidence of impacts on mortality tended to be mixed. There was also evidence of reduced health care utilisation but again observed trends were often not statistically significant. Evidence of beneficial impacts of integrated care programmes on costs tended to be weak. Based on these observations, review authors concluded that integrated care programmes can lead to improvements in the quality of care and in selected health and resource use outcomes. At the same time, authors also reported a lack of precision among reviewed studies in describing programmes, with variation in definitions and components of care analysed, which made it difficult to arrive at overarching conclusions about the 'best approach'. Indeed, as Ouwens et al. (2005) noted, such heterogeneity might lead to inappropriate conclusions about programme effectiveness and the application of findings.

This raises the question about the usefulness of seeking to assess the effectiveness of integrated care as such and, more specifically, whether the concept lends itself to evaluation in a way that would allow for the generation of definitive evidence given its complex and polymorphous nature. Indeed, if integrated care is seen as a means to improve outcomes by overcoming issues of fragmentation through linkage or coordination of services of different providers along the continuum of care, related initiatives will have to be targeted to the needs of a given population, which in turn will be highly context-dependent. Therefore, while it may not be possible to generate clear-cut evidence as to the effectiveness of integrated care as a whole, there is potential for transferable lessons to be learned across different studies to identify core elements that will support better outcomes.

Such an approach was taken in the World Health Organisation's global strategy on people-centred and integrated health services. Published in 2015, work presented in support of the strategy focused on the evidence of effects of interventions and approaches within each of five key strategic directions (World Health Organisation 2015). These strategic directions were: empowering and engaging people, strengthening governance and accountability, reorienting the model of care, coordinating services, and creating an enabling environment. For example, under the heading of 'empowering and engaging people', the most common and effective interventions were identified to be in the areas of health education, shared decision-making, supporting self-management, and personalised care planning (Ferrer 2015).

Similarly, there is good evidence that coordination, described as a strategy, or rather a range of strategies that can help to achieve integrated care (Leutz 1999; Van Houdt et al. 2013), can positively impact selected outcomes. For example, a systematic review by Powell-Davies et al. (2006) examined the effects of different strategies of coordination within primary care and other sectors (Table 3.1). The review assessed outcomes in terms of the percentage of studies that reported significant positive results. It showed that, generally, strategies that helped build relationships between service providers, through co-location, case management, or the use of multidisciplinary teams tended to be the most successful in achieving positive health outcomes and service user satisfaction. Also, strategies that involved providing systems and structures to support coordination tended to be more effective in terms of health outcomes than those providing support for service providers. The review by Powell-Davies et al. (2006) highlighted the need to recognise the context within which approaches are being implemented, whether individually or as part of a broader strategy, as well as the populations that are being targeted, in order to assess their impact and likelihood of success. This will be of particular importance where individual strategies can themselves be considered complex interventions.

This context specificity can be illustrated by the example of case management. Powell-Davies et al. (2006) noted that this may be a promising coordination strategy for some populations and settings, particularly in mental health and aged care (Powell-Davies et al. 2006). A 2015 Cochrane review of the effectiveness of case management approaches to home support for people with dementia found, based on 13 randomised controlled trials, that it was beneficial for some outcomes at certain time points. There was evidence of a significantly reduced likelihood of being institutionalised among those with dementia in the short and medium term, reduced carer burden, and reduced overall health care costs (Reilly et al. 2015). Conversely, a systematic review and meta-analysis of the effectiveness of case

Table 3.1 Summary of the evidence on the effectiveness of interventions to improve coordination in health care

Strategy	Proportion (%) of studies with positive outcome for health	Proportion (%) of studies with positive outcome for service user satisfaction	Proportion (%) of studies with positive outcome for cost saving
Coordination of clinical activities			
Structured arrangements for coordinating service provision between providers, including joint consultations, shared assessments and priority access to another clinical service (*n* 1/4 37 studies)	19/31 (61.3%)	4/12 (33.3%)	3/15 (20%)
Communication between service providers			
Interventions designed to improve communication between service providers, such as case conferences (*n* 1/4 56 studies)	26/47 (55.3%)	12/22 (54.5%)	3/21 (14.3%)
Support for service providers			
Interventions include support or supervision for clinicians, training (joint or relating to collaboration), and reminder systems (*n* 1/4 33 studies)	16/28 (57.1%)	8/14 (57.1%)	1/12 (8.3%)
Support to service users			
Interventions include joint education, reminders and assistance in accessing care (*n* 1/4 19 studies)	6/17 (35.3%)	3/6 (50.0%)	1/7 (14.3%)
Systems to support coordination			
Interventions include shared care plans, decision support, proforma, service user held or shared records; shared information or communication systems; register of service users (*n* 1/4 47 studies)	23/38 (60.5%)	7/19 (36.8%)	2/13 (15.4%)
Relationships between service providers			
Structured relationships between service providers including co-location, case management, multidisciplinary teams or assigning service users to a particular primary care provider (*n* 1/4 33 studies)	19/29 (65.5%)	8/12 (66.7%)	2/12 (16.7%)
All studies (*n* 1/4 80)	36/65 (55.4%)	14/31 (45.2%)	5/28 (17.9%)

Source Adapted from Powell-Davies et al. (2006)

management of patients in primary care that are ‘at risk’ of hospitalisation failed to demonstrate significant differences in service utilisation, mortality, or total cost among those receiving the intervention compared to usual care (Stokes et al. 2015). There was, however, some evidence of a (small) benefit for self-reported health and patient satisfaction.

It is beyond the scope of this chapter to assess the evidence base for case management, or indeed other strategies, tools, and instruments supporting integration, which are reviewed in greater detail elsewhere in this book. However, the example of case management provides a useful illustration of how a given approach or strategy seeking to enhance coordination and support integration may not always provide the most suitable strategy to enhance outcomes. Practitioners need to carefully consider the appropriateness for the target population. The review of case management of ‘at-risk’ patients also demonstrated that its effectiveness may be increased when delivered by a multidisciplinary team, when a social worker was involved, and when delivered in a setting rated as low in initial ‘strength’ of primary care (Stokes et al. 2015). These observations concur with the aforementioned review by Powell-Davies et al. (2006), which showed that coordinated care strategies that used multiple strategies tended to be more successful in enhancing health outcomes than those using a single strategy only. Specifically, those that helped structure relationships between providers and between providers and patients through, for example, co-location or multidisciplinary teams, were more likely to be successful.

3.4 The Economic Impacts of Integrated Care

As noted in earlier sections of this chapter, the move to more integrated care systems is often driven by the need to contain costs and associated with expectations of improved efficiency of service delivery. Yet, reviews that have also assessed the impacts on cost that can be attributed to integrated care programmes tend to report weak effects only (Martinez-Gonzalez et al. 2014; Ouwens et al. 2005). The following summarises the findings of our 2014 review of reviews, which sought to systematically assess the economic impacts of approaches and strategies supporting integrated care (Nolte and Pitchforth 2014). That review considered 19 systematic reviews and meta-analyses of diverse strategies that targeted a diverse group of people or populations. Reviewed studies focused on adults with specific chronic conditions including pain (Brink-Huis et al. 2008), depression (Gilbody et al. 2006a; van Steenbergen-Weijenburg et al. 2010), stroke (Langhorne et al. 2005), asthma (Maciejewski et al. 2009), heart failure (Phillips et al. 2004), COPD (Steuten et al. 2009) or those with multimorbidity (Smith et al. 2012). Others considered strategies for older people in the community considered to be frail (Oeseburg et al. 2009), who had long-term medical or social care needs (Tappenden et al. 2012), or who were to be discharged from hospital (Chiu and Newcomer 2007). Three reviews focused on adults with dementia or memory loss (Pimouguet et al. 2010), those with severe mental health problems (Smith and Newton 2007), or those who received mental health care services (Steffen et al. 2009), while the remainder addressed populations defined by patterns of health service utilisation (Althaus et al. 2011; Shepperd et al. 2008; Simoens et al. 2011).

Strategies frequently targeted the interface between hospitals and primary care or community services, most often in the context of discharge planning or care transition (Althaus et al. 2011; Chiu and Newcomer 2007; Langhorne et al. 2005; Phillips et al. 2004; Simoens et al. 2011; Steffen et al. 2009). Several studies examined initiatives that sought to coordinate primary care and community services, often, although not always, involving medical specialists (Brink-Huis et al. 2008; Gilbody et al. 2006a; Smith et al. 2012; van Steenbergen-Weijenburg et al. 2010) or extending further into social care services (Pimouguet et al. 2010; Smith and Newton 2007; Tappenden et al. 2012; van Steenbergen-Weijenburg et al. 2010). The latter type of interventions tended to target older people with multiple care needs, those with dementia or with mental health problems. About half of primary studies considered by reviews were set in the USA, followed by the United Kingdom, Australia, Canada, New Zealand, the Netherlands, Spain, Italy, and Sweden.

The most common economic outcome measures were utilisation and cost, but reporting of measures was inconsistent and the quality of the evidence was often low. The majority of economic outcomes focused on hospital utilisation such as (re) admission rates, length of stay or admission days, and emergency department visits. For example, among reviews that considered care coordinating activities at the hospital-primary care or community services interface the majority reported evidence of reduced hospital utilisation (Chiu and Newcomer 2007; Langhorne et al. 2005; Phillips et al. 2004; Simoens et al. 2011; Steffen et al. 2009).

Most studies reported cost in terms of health care cost savings, most frequently in relation to hospital costs. Avoided costs or cost savings were typically derived from reduced hospital and emergency room utilisation. There was some evidence of cost reduction in a number of reviews although findings were frequently based on a small number of original studies, or studies that only used a before-after design without control, or both (Althaus et al. 2011; Brink-Huis et al. 2008; Chiu and Newcomer 2007; Phillips et al. 2004; Shepperd et al. 2008; Simoens et al. 2011; Steffen et al. 2009). Philips et al. (2004) highlighted the impact of health system setting on costs, demonstrating that pooled cost differences of comprehensive discharge planning for those with heart failure ranged from $359 compared to usual care in non-USA based trials to $536 in USA trials. Tappenden et al. (2012) further noted, in a review of structured home-based, nurse-led health promotion, the importance of differentiating between initial and longer-term costs (Tappenden et al. 2012). They reported that a community-based nursing programme for patients with Parkinson's disease had initially increased costs but over two years costs were lower.

Reviews also assessed the cost-effectiveness of selected integrated care approaches but again the evidence base was weak, frequently relying on single trials of a given intervention. For example, one review of approaches targeting frequent hospital emergency department users found only one trial that reported the intervention to be cost effective (Althaus et al. 2011). One other review of structured home-based, nurse-led health promotion for older people at risk of hospital or care home admission concluded, based on three economic studies, that there was a high likelihood of cost savings associated with the intervention (Tappenden et al. 2012). However, one of the three primary studies suggested that there was little or no evidence for gains in quality-adjusted life years over usual care. Overall the evidence was difficult to interpret.

3.5 How to Interpret the Evidence Supporting Integrated Care

There is a wide and diverse evidence base, which appears to support a range of strategies and methods towards achieving more integrated care. However, it remains difficult to arrive at overarching conclusions about what works best in what composition and in what context. This is in part because the available evidence captures a wide range of, at times, very varied strategies and care approaches, which are not necessarily equivalent or comparable in relation to the type of service model, or the health and social care system context within which they are embedded. This challenge is greater where more complex combinations of interventions and service delivery changes are being implemented.

We have argued elsewhere that the interpretation of evaluation findings such as those presented here needs to be placed in the broader context of programme implementation specifically and issues around evaluation more widely (Nolte et al. 2012). For example, where an evaluation finds improvements in health outcomes but not in economic impacts, this might be because the length of evaluation was not sufficient to demonstrate economic gain. Indeed, a recent review of integrated care found statistically significant effects for studies that lasted longer than 12 months only (Rocks et al. 2020). Likewise, an evaluation might find that a given care approach improved outcomes for a subgroup of participants only; this might indicate that the intervention was suboptimal or not sufficiently targeted at those who would benefit most. Also, intervention effects will differ by target population and, importantly, by setting, in particular where initiatives involve a complex interplay of different actors as is the case with integrated care approaches.

Against this background, it will be particularly important to understand the quality of the available evidence in order to make sense of the variation in findings. Concerning economic evaluations for example, several authors highlighted their low quality as a major impediment to arrive at a robust evidence base suitable to inform decision making. Studies frequently rely on before-after studies without appropriate control, reducing the ability to attribute observed cost reductions to the actual intervention (Althaus et al. 2011). Other challenges include small sample sizes (Chiu and Newcomer 2007), the type of costs and cost categories considered (de Bruin et al. 2011), and whether these are limited to the health care sector or also consider the wider societal impact of (successful) integrated care strategies

(Gilbody et al. 2006b), alongside lack of reporting on reliability of estimates. All of this highlights the need for higher quality studies.

At the same time, to support this process, there may be a need to revisit the way in which evidence in the field of integrated care is being generated to advance our understanding of ‘what works’. This requires a clear definition of what constitutes effectiveness (or ‘success’) and, perhaps more critically, of the hypothesised mechanism(s) of expected effect(s), which, in turn, requires good theoretical understanding of how the intervention causes change and of the links within the causal chain (Craig et al. 2008). Much of the available evidence on outcomes rests on explicitly quantitative methods. However, as Cretin et al. (2004) have suggested in the context of chronic care, the complexity and variability of related interventions and programmes call for the use of mixed-method research. While there is an increasing body of work in this field, there remains relatively little research on methodological, analytical, or conceptual aspects of the use of qualitative approaches in the evaluation of complex care programmes. Recently, there has been a move towards emphasising ‘realistic evaluation’ (Pawson and Tilley 1997), which uses pluralistic quasi-experimental methods for evaluating complex interventions that are highly influenced by contextual factors. Realistic evaluation involves understanding what works for whom under what circumstances and places equal emphasis on external validity, generalisability, and cumulative learning.

3.6 Conclusions

This chapter has provided an overview of available evidence supporting integrated care. It highlights that evidence of the impacts of integrated care as a whole is difficult to derive, given the complex and polymorphous nature of a concept that has been approached from different disciplinary and professional perspectives. Instead, it may be more instructive for decision-makers and practitioners to draw on evidence of impact of core elements and strategies that can help to achieve integrated care. One such element is care coordination which in itself can be seen to comprise a series of strategies, including case management, co-location, and the use of multidisciplinary teams, along with support strategies such as shared care plans and decision support, which have been shown to enhance processes and the quality of care as well as health outcomes although the evidence of impact on cost remains weak.

A fundamental question that remains is whether integrated care is to be considered as an intervention that, by implication, ought to be cost-effective and support financial sustainability, or whether it is to be interpreted, and evaluated, as a complex strategy to innovate and implement long-lasting change in the way services in the health and social care sectors are being delivered and that involve multiple changes at multiple levels. Evidence reviewed here and in other sections of this book strongly supports the latter. This means that initiatives and strategies underway will require continuous evaluation over extended periods of time that will enable assessment of their impacts on both economic and health outcomes. Such an approach will require sustained investment in research and in the development and implementation of integrated care initiatives to ensure that evaluation will inform service development in particular (Goodwin et al. 2012).

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Values in Integrated Care

4

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4.1 Introduction

Over the past few years, the attention to the normative aspects of integrated care has grown (Hujala and Oksman 2018; Poulsen et al. 2019). Both in academic debate and in its application in practice, integrated care is now seen as more than 'just' a technical intervention for organizing and governing care services. For example, in their frequently used typology of healthcare integration, Fulop and colleagues (2005) present normative integration (addressing the role of values in the coordination of work and collaboration) as one of the two key dimensions of care integration. Similarly, Valentijn and colleagues' Rainbow Model of Integrated Care (RMIC) distinguishes normative integration from functional integration, with the former referring to 'the development and maintenance of a common frame of reference (i.e., shared mission, vision, values and culture) between organizations, professional groups and individuals' (Valentijn 2015, p. 30). While the importance of effective collaboration and commitment has been widely acknowledged (Minkman 2012), practice experience demonstrates that more is needed to take integrated care forward. In addition to making arrangements, normative aspects such as the human factor and the underlying basis of commitment becomes

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increasingly important. By emphasizing this normative dimension, such frameworks provide a broader perspective on integrated care—stressing that it entails more than the 'systematic integration' of rules and policies (Fulop et al. 2005) or the 'functional integration' of funding, information and management mechanisms and practices (Valentijn 2015).

Other integrated care research also increasingly recognizes the role of values in services organization and governance. In integrated care research, values have been connected to organizational culture and performance of teams (Tietschert et al. 2019) and the decisions made by professionals (Miller et al. 2017). Values are increasingly seen as an important factor in explaining strong staff commitment (Goodwin 2013), informal coordination mechanisms (Valentijn 2015), teambuilding processes (Lette et al. 2019) and effective collaborative governance (Minkman 2012). On the other hand, values may also explain constraints to care integration, e.g., when collaborating partners pursue conflicting values, which may affect motivation and trust negatively (Kaehne 2018), or when stakeholders interpret values differently, which may complicate collaboration (Miller et al. 2017). The recent report of the International Foundation for Integrated Care 'Realising the true value of integrated care: beyond covid-19' defines nine building blocks for integrated services, of which the first one is shared values and vision (Lewis and Ehrenberg 2020).

The insights above have in common that values are seen as helpful in the explanation of less tangible mechanisms that play a role under the surface, such as commitment, trust and informal processes. These underlying mechanisms and processes may help explain why integrated care initiatives sometimes work and sometimes do not work. In this way, understanding the role and influence of values in integrated care initiatives can support their further improvement and development.

But although we know that values can play an important role in the explanation of less tangible mechanisms in integrated care, insight into which values play a role and how they can work is still missing. In order to further improve and develop integrated care initiatives, a shared frame of reference to discuss values is necessary. This chapter provides this frame of reference, by presenting a systematically developed list of values underpinning integrated care. First, we will explain values as a broader theoretical concept. We will then elaborate on which values are specifically relevant in integrated care and its different levels. Subsequently, we will conclude with a discussion on the practice implications of values in integrated care.

4.2 What Are Values?

Despite their presence in our everyday lives, values are intangible and they are defined in various ways. Following the sociological theorists that have been working on values in the past decades, values can be defined as conceptions of the desirable (Kluckhohn 1951), moral compasses (Spates 1983) or beliefs that a particular end-state is preferable to the opposite (Hitlin and Piliavin 2004).

Sociologists also stress that values can determine our identity (Hitlin 2003) and actions (Ajzen and Fishbein 1980). In short, five characteristics of values can be distinguished. Values (a) are concepts or beliefs, (b) refer to desirable goals, (c) transcend specific situations, (d) are guiding principles for action, and e) are ordered by relative importance (Schwartz and Bilsky 1987). As Miller et al. (2017) also state, values can be summarized in layman terms as ‘what people see as important and want to pursue’.

Since values refer to what is considered as important, the personal values of people can differ. In fact, people often vary in the relative importance they attach to certain values. In values theory this is also called a value hierarchy (Schwartz 2012). People often link values to particular aspects of their identity and/or group membership. Consider, for instance, the common values of colleagues, relatives or people from the same country of origin. This brings us to the question how the value hierarchies of people and groups are constructed. A variety of determinants influences people’s value orientations. On the one hand, personal factors play a role. Factors such as gender, age and family background can have a major effect on the value hierarchy of a person (Fung et al. 2016; Kalleberg and Marsden 2019). On the other hand, the values of people develop throughout their lives. Experiences related to education, interaction with people and cultural development can influence the value priorities of people. Translating this to the work context, many people take their personal values to work (Altun 2002). At the same time, employees often internalize organizational and professional values through socialization processes (Suar and Khuntia 2010).

Although values are intangible constructs, they are also often explicitly used. Organizations and institutions such as service providers and governments, for example, use values to create an image of their identity. Vision and mission statements or professional codes often consist of lots of values. In Boxes 1 and 2, two examples of these statements are shown. Values like trust, responsibility and transparency pass by. In this way, values are used to create a particular image of ‘who we are’ and ‘how we do things’ as an organization, regardless of whether this image is actually shared by employees.

In sum, values are abstract concepts that describe what people find important and want to achieve. The values of different people often vary and are linked to their identity and/or group membership. Personal factors such as family background determine the values of a person, but values also keep developing throughout their lives. In practice, we also often see organizations using values to frame their identities.

Box 1. Vision Statement Home Care Provider Buurtzorg in The Netherlands

“In our vision trust and responsibility should be leading instead of supervision and control. Nurses can do their job much better, if we do not control but trust. Our professionals are responsible for their own planning and activities. Our core values are: reliability, simplicity, thinking in solutions, practically and collegiality. In the care we provide, we strive for the best solution for clients, sustainable and effective. Because we work with self-organizing teams, we can tailor our services to the specific needs of our clients.”

Box 2. Mission Statement Local Integrated Multidisciplinary Teams

"Empowerment. We believe in empowerment and self-management. Our professionals look at what a person is still able to do, and what the social contacts of the person could do.

Proximity. Our professional work on neighborhood level, visit places where service users are located, are visible and can easily be found.

Transparency and clarity. Our service users should always know why, from whom and when she or he receives services.

Efficient. Our professionals are aware what services cost. They will do what is necessary, but take the costs of a solution into account."

Knowing that people often differ in their prioritization of values, how does this then explain their actions and behaviors? In daily life, many issues are implicitly underpinned by values. Decisions, both important and trivial, are often a trade-off between competing values. In such a trade-off, values are being ordered by their relative importance. In dementia care for example, professionals have to often make trade-offs between the safety and freedom of their clients. A decision on whether or not to open the doors in a dementia care home has implications for both the freedom and the safety of the residents. In several situations, professionals need to balance between these two values; ensuring the residents' safety at all cost or the protection of their freedom (Driessen et al. 2017). These trade-offs may influence choices, decisions, actions and behavior in many situations.

The role of values is specifically relevant in integrated care because many different stakeholders are involved. First, service users, informal caregivers, professionals, policymakers and managers all have different roles, values and interests. Second, as integrated care transcends traditional sectors and domains, people from diverse backgrounds, cultures and traditions are cooperating and/or coordinating their work. They will therefore often have different value orientations. Third, integrated care programs and networks often consist of both public and private parties with different tasks and responsibilities such as funding, policy, implementation or service delivery. This also can lead to a difference in values. Consider, for example, the roles and responsibilities of governments, health insurers and health services providers. Whereas governments may highly value population health and the sustainability of the health system as a whole, health providers may attach more importance to the experience of their clients and the efficient delivery of services. In the following chapter, we will elaborate on what values are specifically relevant in integrated care.

4.3 Values Underpinning Integrated Care

Although people often differ in their value orientations, the concept of integrated care is often driven by a common philosophy. This philosophy is underpinned by a number of frequently appearing core values. In recent years, much important work has been done on the explication of integrated care values by fellow researchers. First, a set of core guiding principles has been proposed by the International Foundation of Integrated Care (IFIC) (Ferrer and Goodwin 2014). These principles of integrated care were developed by reflecting on the perspectives and views of stakeholders from different countries. In their 'Global strategy on people-centred and integrated health services' report, the World Health Organization (WHO) pleads for a unifying values framework (WHO 2015) and presents this set of guiding principles as items for this framework. This list, which was based on expert opinion and a large amount of practice experience, formed the basis for further development of integrated care values.

In order to study the values underpinning integrated care more systematically, a systematic review of literature has been conducted. This study identified the most frequently appearing values in integrated care literature (Zonneveld et al. 2018). Subsequently, this list of values was assessed and refined by a panel of 33 integrated care experts from 13 countries, following Delphi consensus methodology. This resulted in a refined list of eighteen values of integrated care. This list is shown in Box 3. The list of values underpins integrated care as a concept, across different countries and health systems.

Box 3. Values Underpinning Integrated Care (Zonneveld et al. 2020)

Collaborative	*Establishing and maintaining good (working) relationships between users, informal carers, professionals and organizations—by working together across sectors, and in networks, teams and communities*
Comprehensive	*Users and informal carers are provided with a full range of care services and resources designed to meet their evolving needs and preferences*
Continuous	*Services that are consistent, coherent and connected, that address user's needs across their life course*
Co-ordinated	*Connection and alignment between users, informal carers, professionals and organizations in the care chain, in order to reach a common focus matching the needs of the unique person*
Co-produced	*Engaging users, informal carers and communities in the design, implementation and improvement of services, through partnerships, in collaboration with professionals and providers*
Effective	*Ensuring that care is designed in such a way that outcomes serve health outcomes, costs, user experience and professional experience*

(continued)

(continued)

Efficient	*Using resources as wisely as possible and avoiding duplication*
Empowering	*Supporting people's ability and responsibility to build on their strengths, make their own decisions and manage their own health, depending on their needs and capacities*
Flexible	*Care that is able to change quickly and effectively, to respond to the unique, evolving needs of users and informal carers, both in professional teams and organizations*
Holistic	*Putting users and informal carers in the centre of a service that is 'whole person' focused in terms of their physical, social, socio-economical, biomedical, psychological, spiritual and emotional needs*
Led by whole-systems thinking	*Taking interrelatedness and interconnectedness into account, realizing changes in one part of the system can affect other parts*
Person-centered	*Valuing people through establishing and maintaining personal contact and relationships, to ensure that services and communication are based on the unique situations of users and informal carers*
Preventative	*There is an emphasis on promoting health and wellbeing and avoiding crises with timely detection and action by and with users, informal carers and communities*
Reciprocal	*Care is based on interdependent relationships between users, informal carers, professionals and providers, and facilitates cooperative, mutual exchange of knowledge, information and other resources*
Respectful	*Treating people with respect and dignity, being aware of their experiences, feelings, perceptions, culture and social circumstances*
Shared responsibility and accountability	*The acknowledgment that multiple actors are responsible and accountable for the quality and outcomes of care, based on collective ownership of actions, goals and objectives, between users, informal carers, professionals and providers*
Transparently shared	*Transparently sharing of information, decisions, consequences and results, between users, informal carers, professionals, providers, commissioners, funders, policy-makers and the public*
Trustful	*Enabling mutual trusting between users, informal carers, communities, professionals and organizations, in and across teams*

In addition to the list of 18 values and descriptions, the results of the Delphi study also reveal differences in value priorities on different levels of integration based on the Rainbow Model of Integrated Care (Valentijn 2015). Four levels of integration are distinguished. The personal level (in the RMIC: clinical integration) refers to the process of person-centered care delivery for a person with complex needs. The professional level (in the RMIC: professional integration) comprises interprofessional teamwork to deliver integrated services. The management level (in the RMIC: organizational integration) refers to issues within and between collaborating organizations. The system level (in the RMIC: system integration) refers to the role of policies and systems in integrated care. We do not see these levels as separate worlds, but believe they should be interacting.

Figures 4.1, 4.2, 4.3 and 4.4 display the differences in relevance for each value. On the personal level, values referring to relationships and interactions with service users and informal caregivers are found to be relevant, such as trustful, reciprocal, preventative, respectful, person-centered, holistic and collaborative. On the professional level, the most relevant values are mainly connected to cooperative and multidisciplinary aspects of integrated care, such as reciprocal, co-ordinated, flexible, collaborative and trustful. When looking at the management level, the values efficient, effective and shared responsibility and accountability are seen as most relevant. These values refer to the governance side of the delivery of integrated care. Lastly, on the systemic macro-level, the most relevant values relate to implications for health systems such as led by whole systems thinking, comprehensive, effective and efficient. Summarized, 'softer' relational values are considered as relevant on the personal and professional level of integrated care, while more 'hard' rational values are seen as important on the management and system level where also has to be dealt with contextual factors like restrains in resources and budgets (Zonneveld et al. 2020).

In conclusion, research on integrated care values illustrates that despite the differences in context, health systems and interventions across countries, a set of common integrated care core values can be defined. At the same time, the study also shows that certain values may be more or less relevant on particular integrated care levels. On the one hand, this may explain why these integrated care levels are often not well connected. Service users, professionals, managers and policy and decision-makers, all acting at different integrated care levels, may find different

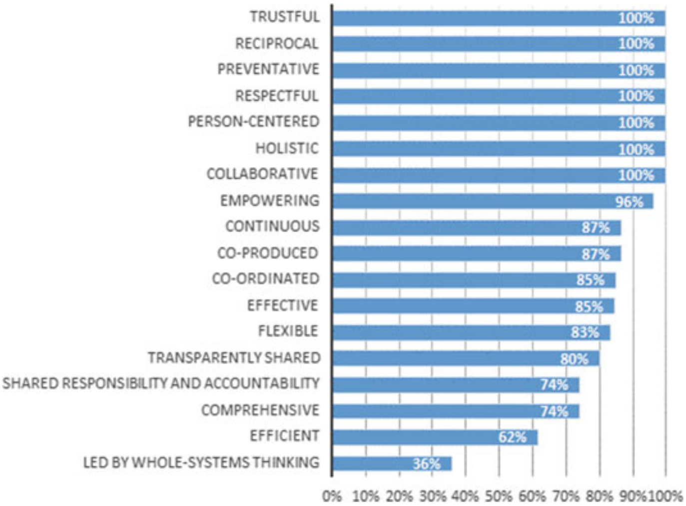

Fig. 4.1 Relevant values on personal level

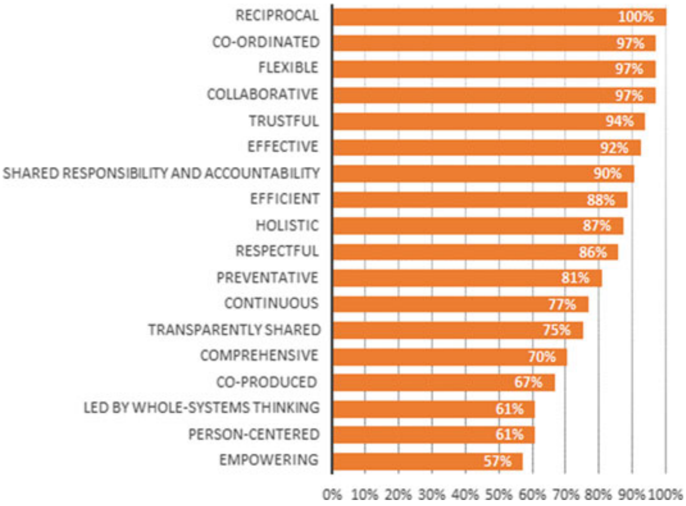

Fig. 4.2 Relevant values on professional level

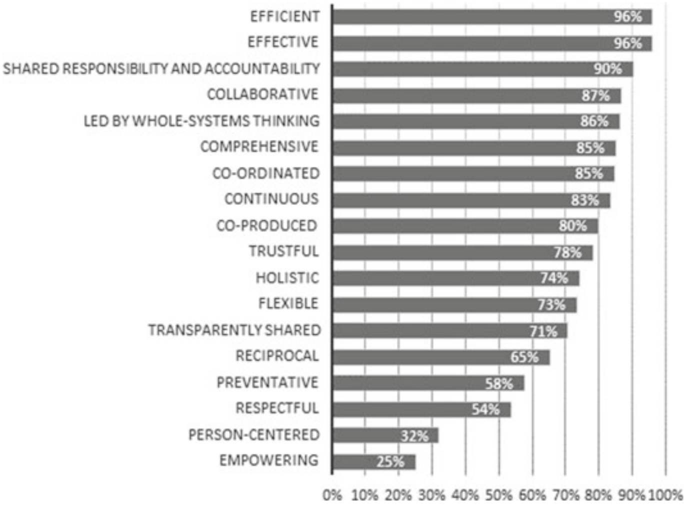

Fig. 4.3 Relevant values on management level

values important and base their behavior on these values. They may not understand or support the actions and behaviors of ‘the other.’ This may complicate the connectivity between levels and people. On the other hand, these insights offer us the opportunity to improve this connectivity. The awareness that different stakeholders on different integrated care have different roles and values can form the basis for a first step toward a better mutual understanding. A better understanding of one

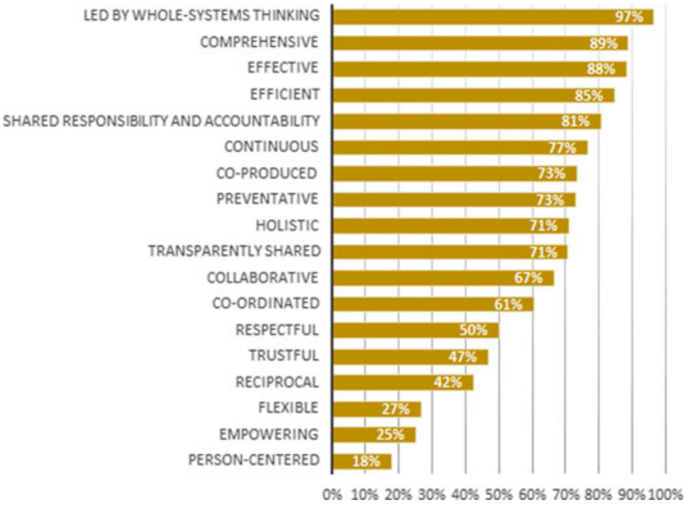

Fig. 4.4 Relevant values on system level

another's behavior, actions and motives, in order to better align and coordinate these—from service users to professionals, from governments to health insurers. The following chapter will elaborate on how this can be done in integrated care practice (Fig. 4.5).

4.4 Practice Implications

In the previous section, we presented a list of frequently appearing values underpinning integrated care. Values theory, however, also teaches us that the value orientations of people often differ, which may explain their actions and behaviors. In this section, we will elaborate on the implications of such diverse orientations for integrated care practice.

Integrated care is a collective undertaking in which people and organizations with different roles, backgrounds and interests work together. In pursuing such a collective undertaking, it is important to take account of stakeholders' potentially different value orientations. The roots of these differences may be found on various levels. First, people take their personal values to work. Such personal values may be shaped by, e.g., age, social background or past experiences. Second, people's various professional backgrounds also shape what they find important, being socialized in different professional fields and having internalized particular value orientations throughout their education. Third, people's position and role within their organization may also affect their value orientation, e.g., as a board of directors may have a somewhat different outlook on 'what matters' than a front-line professional worker. Fourth, and

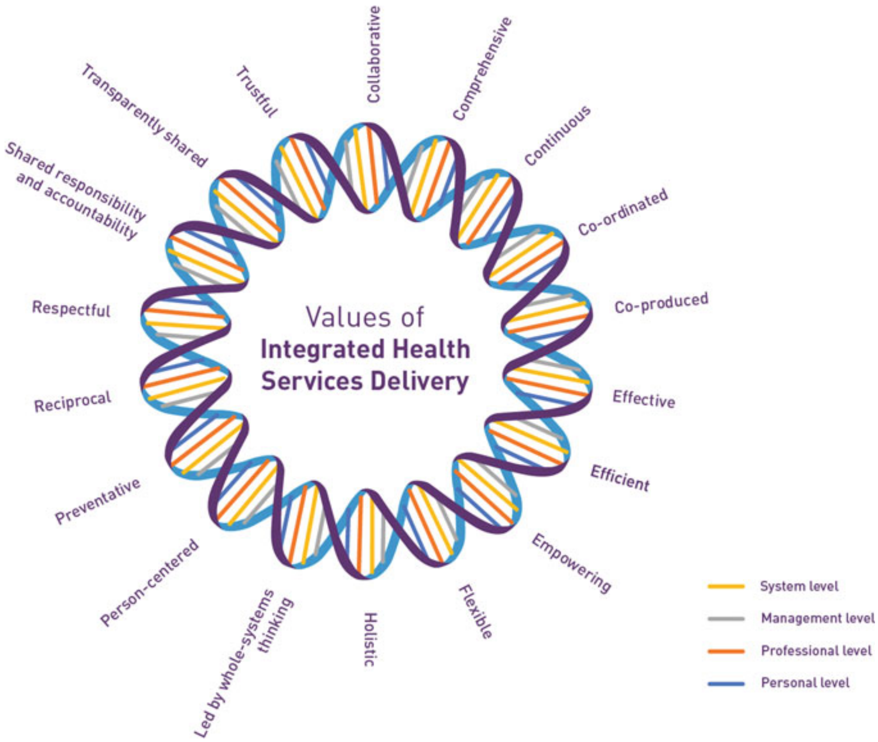

Fig. 4.5 Values underpinning integrated care

last, an organization may itself espouse particular values that can be reflected by its mission statement or within its organizational culture. These organizational values may not always be the same as people's personal value orientations, and they may also be different from the core values of other organizations. For example, even when both parties are pursuing integrated care, health insurance companies and patient advocacy organizations may prioritize and weigh particular values differently. In sum, within integrated care initiatives, various value orientations on the personal, professional and organizational level come together. These may not always be entirely congruent, which might complicate collaboration and coordination. This challenge needs to be addressed when pursuing the shared, overarching objective of delivering person-centered care across the care continuum.

Nevertheless, we should not forget that the diversity of perspectives also forms a key asset of integrated care. As integrated care programs and networks consist of people and organizations with various backgrounds, different value orientations will presumably always exist. This is not necessarily a bad thing—in many cases, such differences may complement each other. In integrated care, each partner brings its own values, expertise and knowledge to the table. Often, the whole is greater than the sum of its parts. It is important to note here that collaborating partners do not have to change their own values or hide their personal, professional or organizational backgrounds.

At the same time, to collectively take the next step toward sustainable integrated care, it is important that stakeholders do establish a shared set of values as a basis for their joined-up efforts. While value differences will persist on a personal or organizational level, it is important for all parties involved to identify themselves with a shared set of integrated care values that they can translate to their everyday work practices. In other words, a shared set of values can provide the common ground on which stakeholders can build their collective efforts. Identification and explication of values may therefore be an important step to take in any integrated care initiative, program and network. Exploring shared values, acknowledging differences and being able to step into each other's shoes can be a first step in the development of a joint normative basis.

Box 4. Practice Example

A new regional integrated health care service was developed in the Eastern part of the Netherlands. In their first meeting, representatives of a hospital, two home care providers and multiple GPs discussed how to organize their joint service delivery. The collaborating partners swiftly agreed on tasks, roles and a project structure. A steering group was composed, key performance indicators were determined and a future development agenda was developed. However, after a couple of weeks, the first issues arose. It became clear that the professionals of the different partner organizations had different opinions and thoughts on how to work together or interact with service users. For example, some professionals were used to working autonomously and did not automatically share information, while others were used to a collaborative and transparent culture. And while some professionals were used to lots of intensive contact with service users and their informal caregivers, others were used to a more distant attitude towards their clients. At this moment, an important reflection was made: "We have to talk. I do not think we have ever really talked about our values and what is important to us. We never discussed our joint vision, its underlying values and how we want to achieve our objectives."

The list of integrated care values that we presented and discussed in this chapter can be used for such an assessment of stakeholder value orientations. The list offers a vocabulary for making these values explicit. It can, for example, be used as a value mapping tool to make personal, organizational and possible shared values more tangible. In a working session, integrated care stakeholders can 'map' values by prioritizing the eighteen values on a prioritization map. Thereafter, stakeholders share their value maps and orientations within the group of participants of the initiative. In order to take integrated care to the next level, it is important to engage in a fundamental discussion within integrated care initiatives. In this discussion, preferably moderated by an experienced facilitator, similarities and differences in orientations can be identified, interpretations of values can be uncovered, and the most relevant personal, organizational and shared values can be unraveled. Core questions could be: What values matter most to the people and organizations involved? What do these values mean to them and how do they translate them to their own work setting? How can these abstract values form a concrete basis? What values should be leading within the collective initiative? And how does this relate to the individual people and organizations' priorities? What values are currently insufficiently addressed? These core questions can unravel both similarities and differences between people, between organizations and within the initiative as a whole. These similarities and differences in value orientations need to be addressed for the further alignment and development of integrated care initiatives. Defining a basic set of shared values can form a common starting point for integrated care leadership, policies and strategies.

4.5 Normative and Functional Aspects

The list of values presented in this chapter can contribute to the identification of values in integrated care initiatives, and subsequently to a discussion about normative aspects among stakeholders. When looking again at the earlier mentioned healthcare integration typology of Fulop and colleagues (2005) and the RMIC of Valentijn and colleagues (2015), normative integration and functional integration are positioned as the two essential mechanisms that ensure consistency between the micro (clinical)-, meso (professional, organizational)- and macro-levels (system) of integrated care. For the further development of integrated care, it is relevant to reflect on how these two mechanisms interact. Because in practice these mechanisms are intertwined and subsequently cannot be separated, we believe that we should not see them as separate worlds but as mutually influencing mechanisms. Consider, for example, the influence of functional aspects on normative integration. When professionals with different backgrounds are functionally located under one roof, their social interaction will increase. This may drive normative aspects of integration such as the development of a shared culture with common values. The other way around, normative aspects can also influence functional integration. A group of collaborating partners that, for instance, attach a high priority to values as 'collaborative' and 'trust' may be more likely to base their rules and decision making processes on horizontal relationships and mutual trust than on control and hierarchy. The relationship between normative integration and functional integration emphasizes the relevance of the presented list of values for the development of integrated care. Functional activities, rules and agreements should be normatively underpinned by values. For example, the requirements of an IT system for a multidisciplinary team need to be determined by the values of its users. When the end users see 'co-produced' and 'transparently shared' as leading values, they might use a file sharing tool more often.

In sum, the value orientations and interpretations of stakeholders in integrated care often differ. However, because values are rarely explicated, this is not always visible or tangible. The presented list can be used as a vocabulary tool to identify and explicate values, after which differences and similarities can be discussed and/or acknowledged. Thereafter, the values list can be used to underpin many functional activities in integrated care such as policies, decision making and implementation processes.

4.6 Conclusion

In this chapter, we have focused on the values in integrated care. As values often play a role in underlying integrated care processes and mechanisms, they may help us explain why integrated care initiatives work or do not work. However, values are not always tangible or visible and their role is often implicit. This chapter therefore presents a list of eighteen frequently appearing values underpinning integrated care, including insight into their relevance on the levels of integration. The list forms an international normative basis for the integrated care concept. Furthermore, it can be used for the identification and explication of values in integrated care practice, while also enabling discussion among stakeholders that appear to prioritize or interpret values differently.

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Patients' Preferences

5

A. Mühlbacher and Susanne Bethge

5.1 Patients' Priorities for Integrated Healthcare Delivery Systems

Integrated care (IC) suits patient needs better than fragmented health services. It is needed to organize care around the patient (Davis et al. 2005) and is seen as a critical factor in a high-performance healthcare system (McAllister et al. 2007). Care coordination is a process that addresses the health needs and wants of patients, including a range of medical and social support services (Rosenbach and Young 2000; Tarzian and Silverman 2002). Still there are problems in defining care coordination (Wise et al. 2007) which may be caused by the lack of knowledge about patient priorities. Hence, patients must play a major role in designing the infrastructure and policies that will support the care coordination and integrated care approaches (Laine and Davidoff 1996).

If current trends continue, healthcare spending will leave governments bankrupt within decades (Henke et al. 2002). The problem is not lack of knowledge, nor is it the peoples' unwillingness to spend money. Rather, the difficulties lie in the understanding of peoples' priorities and preferences. Porter and Teisberg state "health care is on a collision course with patient needs and economic reality"

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(Porter and Teisberg 2006). This is one of the biggest problems policymakers are facing in the coming years, and it raises questions of how services should be provided. The Institute of Medicine Report "Crossing the Quality Chasm" (2001) emphasizes that health decisions should be customized based on patients' needs and values. Most, if not all, newly developed programmes so far are conceptualized in a "top-down" manner by the government and healthcare administration with little involvement of the general public (Wismar and Busse 2002). "Healthcare systems are challenged to effectively meet the wants and needs of patients by tailoring interventions based on each person's (…) preferences as well as personal and social context" (Sevin et al. 2009). In health policy terms, this refers to services "closely congruent with, and responsive to patients' wants, needs and preferences" (Laine and Davidoff 1996). The most powerful structural innovation will be based on a paradigm shift—patient-centred care. Patient-centred care takes numerous forms and should be based on patient evidence as provided by preference data.

Patient Preferences The term "patient preferences" still lacks a consistent definition; despite this, there appears to be convergence in the view that patient preferences are statements made by individuals regarding their needs, values and expectations and the relative importance of treatment properties. Therefore, these preferences refer to the individual evaluation of dimensions of health outcomes, treatment characteristics or health system attributes. Based on the existing literature, integrated care can be differentiated into attributes, such as:

(1) Organization of care: The organization of care can be seen as a function that helps to ensure that patients' preferences for health services and information are met (National Quality Forum 2006). It is widely acknowledged that care coordination across all healthcare settings and related disciplines will improve the quality of health care and therefore satisfy the preferences of the patients involved (Adams and Corrigan 2003). Physicians in larger medical groups, particularly those who are part of integrated care programmes, perform more favourably on all patient experience measures than those in smaller, less-integrated practice settings (Rodriguez et al. 2009). Some findings have shown that individuals within an integrated care system had shorter average hospital stays and lower costs than comparison groups (Criscione et al. 1995; Liptak et al. 1998). When addressing different social, developmental, educational and financial needs, the design of services has to take heterogeneity of patients and families into account. One of the biggest challenges in care coordination and integrated care is identification of the necessary set of attributes that are needed to obtain optimal results. Clinicians need to understand and tailor care to the wider whole-person context—including whatever non-medical factors may affect the success of medical care (Peek 2009).

(2) Interpersonal care: In integrated care, physician–patient communication is the fundamental platform for health service delivery. An important component is the creation of individualized care plans "that establish a partnership among practitioners, patients and their families (when appropriate), to ensure that decisions respect patients' needs and preferences" (Institute of Medicine 2001).

Patients placed the highest value on seeing a physician who knew them well, followed by seeing a physician who was interested in their ideas, one who asked about social and emotional issues and one who involved them in decisions (Cheraghi-Sohi et al. 2008). Preference studies using discrete choice experiments have shown that communication is highly valued (Vick and Scott 1998; Scott and Vick 1999; Morgan et al. 2000; Chapple et al. 2002; Scott et al. 2003; Gerard and Lattimer 2005; Rao et al. 2006; Al Mulley et al. 2012). Although patients with chronic diseases valued shared decision-making, it was of lower relevance than whether the physician seemed to listen (Longo et al. 2006). Longo et al. question the high-priority patients place on communication issues and suggest critical examination (Longo et al. 2006).

(3) Technical care: Technical care—the quality of clinical care—is another key dimension (Campbell et al. 2000). A discrete choice experiment reported that technical care was the most important factor in determining patient choice of a physician (accounting for 27% of the variance), compared with waiting time (15%), billing problems (20%), time to get a referral (18%) and who made healthcare decisions (20%) (Markham et al. 1999). Cheraghi-Sohi et al. (2008) argue that attributes used to test the priorities placed on patient-centred care in published studies have not accurately reflected the complexity of the patient-centred care concept. Little is known about patients' assessment of technical care and how these assessments correlate with other objective measures (Rao et al. 2006). A study conducted in the USA asked patients to choose between physician report cards with different scores for interpersonal and technical care. Findings showed that more patients preferred the physician with high technical care scores (Fung et al. 2005). The three described meta-dimensions of IC can further be explained by seven sub-domains. In qualitative and quantitative research, these seven preference dimensions with three attributes each could be evaluated and identified as patient relevant in respect of IC (Juhnke and Mühlbacher 2013).

1. Access described by waiting time for an appointment, travel time care provider, out of pocket costs
2. Service and facilities described by guidance within the facility, medical devices and furnishings, friendliness and helpfulness of staff
3. Data and information described by patient's health record, information about performance, accurate health information
4. Professional care described by treatment guidelines, experience of care provider, patient education
5. Coordination and continuity described by multidisciplinary care, care transition, clinical information exchange
6. Individualized healthcare described by proactive care, case management, attention to personal situation
7. Personal care described by trust and respect, attentiveness of care providers, shared decision-making.

The Question What do patients want from integrated care? Much work remains to be done for care coordination to become a standard feature of health care.

Integrated care aims to achieve higher-quality care, lower costs and greater patient satisfaction. Individual preferences on integrated care must be considered for a range of attributes, such as technical and interpersonal care. Designing services that are sensitive to patients' preferences in the context of limited resources may require policy- and decision-makers to choose between attributes (Wensing et al. 1998; Campbell et al. 2000; Coulter 2005). Two of the core contributions needed to achieve this goal are: assessment of the value of integrated care for different patient populations and development of measures for integrated care quality (Antonelli et al. 2009). The published literature does not clearly specify the relative importance patients place on these attributes. In order to promote integrated care, policymakers need to understand patients' priorities and preferences.

In order to make integrated care more congruent with patients' needs, patients' preferences for different attributes need to be analysed (Laine and Davidoff 1996). Moreover, meeting expectations on a range of attributes may be difficult within the constraints of limited budgets; this has led to interest in methods for assessing priorities (Ryan et al. 2001a). "One promising method is the discrete choice experiment, used in psychology, marketing and economics" (Ryan et al. 2001a). McFadden (1973) introduced feasible techniques for estimating a complete characteristics-based model of demand.

5.2 Stated Preference Studies: Method and Study Design

Discrete Choice Experiment The value of goods and services depends on the nature and level of the underlying attributes (Lancaster 1966, 1971). Healthcare interventions, services or policies can be described by their attributes (Hauber 2009). A key feature of these methods is the specification of utilities associated with the alternatives in terms of choice characteristics and individual preferences (Ben-Akiva and Lerman 1985). Stated preference studies focus on investigating the trade-offs between crucial attributes (Ryan and Hughes 1997; Ryan and Farrar 2000; Ryan and Gerard 2003). Discrete choice experiments are the most important form of stated preference studies and determine whether consumers are willing to trade off some of the attributes against others (Ryan et al. 2001b). DCEs have recently gained importance in the study of innovative health technologies and non-market goods (Lancsar et al. 2007; Lancsar and Louviere 2008; Ryan et al. 2008) or where market choices are severely constrained by regulatory and institutional factors (Ryan and Farrar 2000). The US Food and Drug Administration (FDA) has already considered preference data within a regulatory decision for medical devices (US Food and Drug Administration (FDA) 2014), and the German Institute for Quality and Efficiency in Health Care (IQWiG) has conducted two pilot studies to preference methods (Danner et al. 2011; Mühlbacher et al. 2016).

The discrete choice technique is already used to elicit preferences in primary care (Vick and Scott 1998; Scott and Vick 1999; Morgan et al. 2000) and gaining more and more importance (de Bekker Grob et al. 2010; Clark et al. 2014). The application of DCEs has been extended to take account of providers preferences (Ubach et al. 2003) or insured preferences for health system attributes (Telser et al. 2008). Moreover, the technique has been used to evaluate patient-centred outcomes in the provision of care (Mühlbacher et al. 2008, 2009, 2014; Mühlbacher and Bethge 2014, 2015; Ostermann et al. 2015). For policy analysis, it might be interesting to calculate how choice probabilities vary with changes in attributes or attribute levels, or to calculate secondary estimates of money equivalence [willingness to pay (WTP) or willingness to accept (WTA)] (Kleinman et al. 2002), risk equivalence [maximum acceptable risk (MAR)] (Johnson et al. 2007) or time equivalence for various changes in attributes or attribute levels (Johnson et al. 2009). Findings on the reliability and validity of DCEs in healthcare settings are encouraging (Bryan et al. 2000; Bryan and Parry 2002). A DCE can be described in terms of detailed checklists (Bridges et al. 2011; Johnson et al. 2012, 2015; Mühlbacher et al. 2013).

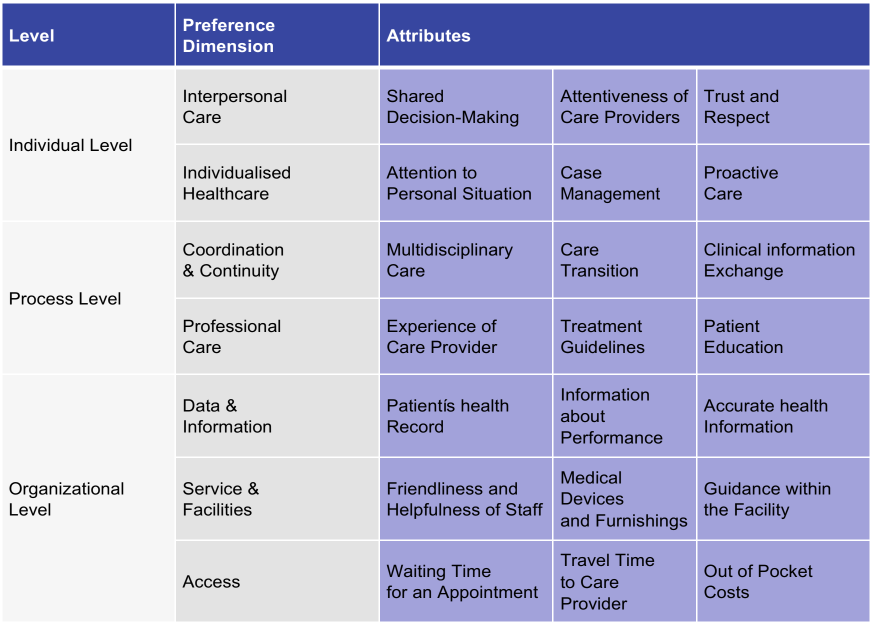
To analyse patient and insured preferences in IC, two very similar studies have been conducted in USA (Mühlbacher et al. 2015a) and Germany (Mühlbacher et al. 2015b) and should help to illustrate preference measurement in IC. An identical stated preference method was used to assess patient preferences in different healthcare systems and cultural backgrounds. Furthermore, a study was realized that explored the impact of the contextual factor of the communicator of IC programmes and the resulting effects within choice behaviour (Bethge et al. 2015).

5.3 Preference for Integrated Healthcare Delivery Systems

Qualitative Methods Both studies in the USA and in Germany included an identical conceptual framework linking organizational structure to potential preferences. The framework was developed by systematic literature reviews as well as quantitative surveys and factor analysis about the very differentiated needs and expectations in respect of integrated care (Juhnke and Mühlbacher 2013). The final framework included the specification of different organizational levels of healthcare delivery and corresponding preference dimensions as described in the first part of this chapter and as can be seen in Fig. 5.1.

Quantitative data were obtained by means of two identical discrete choice experiments (DCEs) integrated in online surveys. Within the experiment, participants were presented two alternative scenarios of hypothetical healthcare delivery systems and asked to choose between them. Each scenario included six attributes with three specific levels.

Based on the assumption that patients' choices are influenced by latent concepts such as sociodemographic characteristics, experience, knowledge and attitudes, it was also important to elicit respondent-specific experiences, attitudes and



Level	Preference Dimension	Attributes		
Individual Level	Interpersonal Care	Shared Decision-Making	Attentiveness of Care Providers	Trust and Respect
	Individualised Healthcare	Attention to Personal Situation	Case Management	Proactive Care
Process Level	Coordination & Continuity	Multidisciplinary Care	Care Transition	Clinical information Exchange
	Professional Care	Experience of Care Provider	Treatment Guidelines	Patient Education
Organizational Level	Data & Information	Patientís health Record	Information about Performance	Accurate health Information
	Service & Facilities	Friendliness and Helpfulness of Staff	Medical Devices and Furnishings	Guidance within the Facility
	Access	Waiting Time for an Appointment	Travel Time to Care Provider	Out of Pocket Costs

Fig. 5.1 Framework: patient-centred healthcare delivery (Mühlbacher et al. 2015a)

sociodemographic information. These characteristics may influence preferences in a systematic way, and heterogeneity within subgroups can be analysed. Therefore, these additional data were included in the survey.

Sample Characteristics Within the two studies, n 3900 participants (only patients assigned in healthcare system) in the USA as well as n 1322 participants (insured sample) in Germany could be included within the final preference estimations. Table 5.1 presents some sociodemographic characteristics of both study samples.

US Preference Results The feature “out of pocket costs” was a very important attribute within the DCE in the US study. In DCE 1 regarding patient involvement, “trust and respect” (0.65600) was slightly higher than cost. “Attention to personal situation” (0.42178) was as well of great importance. In DCE 2 addressing preferences at the point of care, “shared decision-making” (0.71058) and “access to patient health record” (0.46432) were highly valuable to patients. In DCE 3 focusing on personnel in healthcare delivery systems, “multidisciplinary care” (0.74096) was ranked highest. Lastly, in DCE 4 analysing features of the organization of healthcare delivery systems, “treatment guidelines” (0.44834), “clinical information exchange” (0.38334) and “case management” (0.37689) were of almost equal value to patients. Differences in individual living conditions influenced respondents’ preferences.

Table 5.1 Respondent characteristics of US and German participants

Characteristic	US patient sample (*N* 1/4 3900) No. (%)	German insured sample (*N* 1/4 1322) No. (%)
Sex		
Men	1347 (34.5)	652 (49.3)
Women	2553 (65.5)	670 (50.7)
Marital status		
Married	2431 (62.3)	605 (45.8)
Single	568 (14.6)	278 (21.0)
Divorced or separated	432 (11.1)	143 (10.8)
In a committed relationship, but not married	311 (8.0)	277 (21.0)
Widowed	158 (4.1)	19 (1.4)
Self-rated health		
Excellent	408 (10.5)	34 (2.6)
Very good	1249 (32.0)	252 (19.1)
Good	1270 (32.6)	708 (53.6)
Fair	741 (19.0)	295 (22.3)
Poor	216 (5.5)	33 (2.5)
Not sure	16 (<0.1)	–

German Preference Results The additional costs (out of pocket costs) were again of highest relevance in patients' choice. Next to the "costs" attribute, in DCE 1 (patient involvement) "patient education" (coef.: 0.2196) was of great importance, and in DCE 2 (point of care) it was "waiting for an appointment" (coef.: 0.335). In DCE 3 (personnel), "experience of care provider" (coef.: 0.289) had strong influence on decisions. In the fourth DCE (organization), "medical devices and furnishings" (coef.: 0.464) were highly relevant. [*Detailed results of the German study can be found at* Mühlbacher et al. (2015a), *and details for the US study are available at* Mühlbacher et al. (2015b)].

Comparison of Results The inclusion of an identical cost attribute across all content blocks provides the means to compute a common metric across all 21 attributes. Figure 5.2 represents the comparison of the relative importance of the attributes for the US and the German study (not discussing the issue of scale heterogeneity). The estimates are sorted in relation to the US results beginning with the highest important attribute. It can be seen that the US participants were most influenced by shared decision-making, multidisciplinary care and trust and respect within their decision for an integrated care programme. These are attributes that relate to individual or process aspects of integrated care. On the contrary, the German participants valued medical devices and furnishings, waiting time for an appointment as well as the experience of care provider highest. This means the German population is more focused on organizational aspects of healthcare delivery and puts a high value on the state of medical equipment.

The differentiation of the first five ranks in comparison between both study groups can be seen in the following chart (Fig. 5.3).

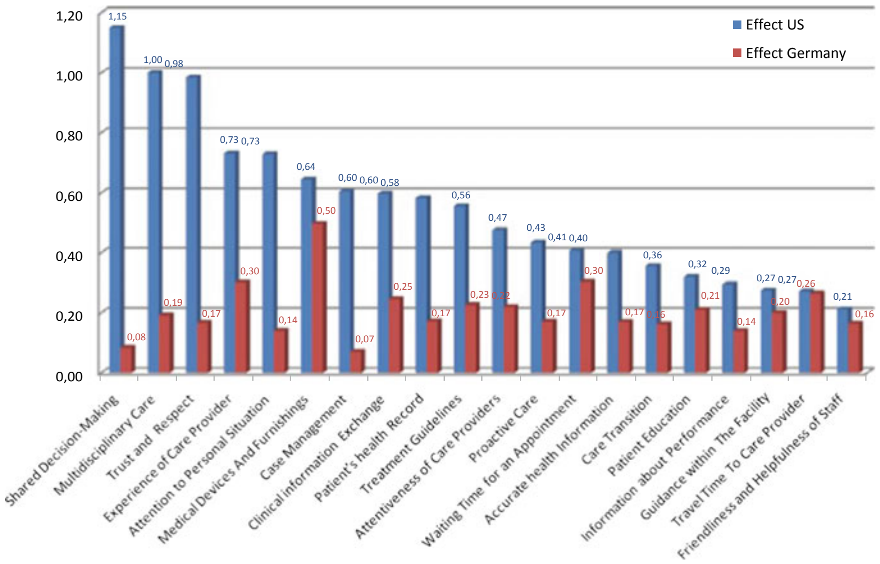
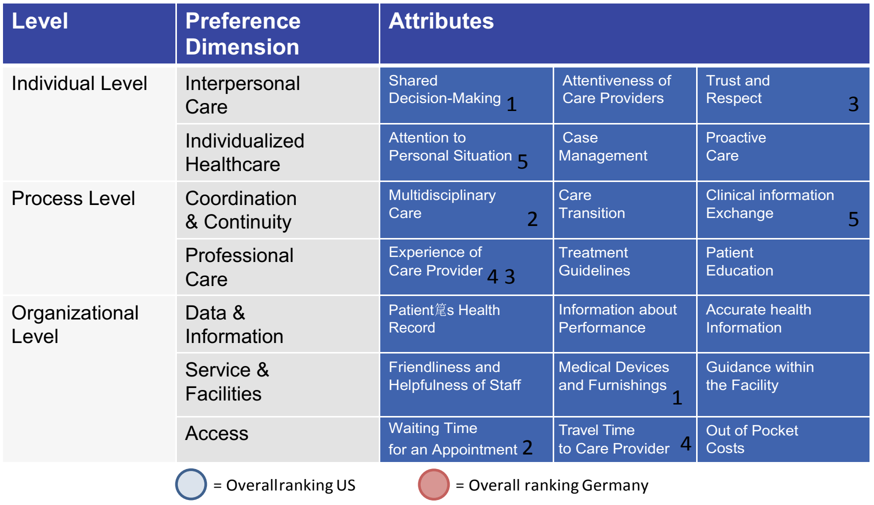


Fig. 5.2 Overall assessment of all attributes in relation to cost attribute



Level	Preference Dimension	Attributes		
Individual Level	Interpersonal Care	Shared Decision-Making 1	Attentiveness of Care Providers	Trust and Respect 3
	Individualized Healthcare	Attention to Personal Situation 5	Case Management	Proactive Care
Process Level	Coordination & Continuity	Multidisciplinary Care 2	Care Transition	Clinical information Exchange 5
	Professional Care	Experience of Care Provider 4 3	Treatment Guidelines	Patient Education
Organizational Level	Data & Information	Patient's Health Record	Information about Performance	Accurate health Information
	Service & Facilities	Friendliness and Helpfulness of Staff	Medical Devices and Furnishings 1	Guidance within the Facility
	Access	Waiting Time for an Appointment 2	Travel Time to Care Provider 4	Out of Pocket Costs

○ = Overallranking US ● = Overall ranking Germany

Fig. 5.3 Rank order comparison USA and Germany, place 1–5

Conclusion The presented results display the complexity of preferences and their dependency on cultural and healthcare system differences. As stated by the WHO "*There is no perfect combination or a "one size fits all" solution*" for patient-centred and integrated health services. Nevertheless, the person with its needs and expectations is/and needs to be in the centre of integrated care (World Health Organization (WHO) 2015).

The novelty of the presented results is the combination of qualitative and quantitative methods for building a conceptual map of patient-centred outcomes that can be used to plan comprehensive assessment of patients' preferences in integrated care. The framework concludes important attributes and endpoints and allows sorting them in categories and subcategories. Further research is needed to distinguish the possible interpretations of the presented attitudes or preference dimensions and to take notice of heterogeneity within patient population. In addition, the development of a conceptual framework can be used as foundation of further stated preference measures.

It is necessary to evaluate what patient preferences are to help researchers, payers, regulators, physicians and patients to understand the relative importance of each treatment attribute and the willingness of patients to trade among treatment attributes. Designing integrated care around patients' preferences has the potential to improve the effectiveness of health care by improving adoption of and adherence to clinical treatments or public health programmes. An important area for future research is the question: What are the implications of patient-centred care? Understanding how patients and other stakeholders perceive and value different aspects of integrated care is vital to the optimal design and evaluation of programmes.

5.4 Discussion and Outlook

Patient-centred outcomes will provide objective information about the impact on patient involvement, the experiences of patients, and their needs and wants. The publication of patient preference data will help insurers, policymakers and others to promote patient-centred integrated care as the new standard of primary care. The data can be communicated through medical and economic journals, congresses and media.

Because of the lack of information on patient needs in the decision-makers' assessment of health services, the individuals' preferences often play a subordinate role at present. The patients' perspectives and desires in healthcare decisions are often not sufficiently considered. However, shared decision-making with the involvement of patients in treatment decisions has been encouraged in recent years.

Though not examined in this chapter that has focused on patient preferences, it should be noted that a key aspect in the development of interpersonal care is the ability to engage and empower patients as partners in their own care. There is good evidence to demonstrate the value of empowerment strategies with patients suggesting that approaches such as health literacy, shared decision-making and self-management support should be better embedded in integrated care programmes than currently seems to be the case (Ferrer 2015). The recent publication of a Global Strategy on Integrated People-Centred Health Services by the World Health Organization presents evidence that enabling individuals to make informed choices and supporting them to understand their responsibilities as well as their rights can significantly enhance health outcomes. The WHO goes further to argue that an equal and reciprocal relationship between health professionals and patients is required to support more sustainable care systems (World Health Organization (WHO) 2015).

The findings of such studies supply important information on the benefits of integrated care from the patients' point of view. If patient needs are taken into account adequately, it is safe to assume that this will increase their satisfaction with integrated care programmes. Heterogeneity within preferences due to racial and ethnic disparities, age or illness can be documented and considered in the design of healthcare services. Integrated care schemes will not work unless it is accepted that different patient groups need different care programmes and that sensitivity to cultural factors and the local context of application are important to engage patients and support their needs and preferences effectively.

The presented studies reviewed in this chapter also support efforts for increased consideration of patient benefit as an essential quality criterion in the assessment of integrated care. Especially where it is difficult to clearly differentiate between services in terms of medical and financial aspects, comprehensive information on patient benefits (and to that of communities as well) can be very useful in prioritizing approaches to care and treatment. Studies of this type can thus help to stimulate fresh discussion and lead to the formulation of increasingly person-centred care concepts in the long term.

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Integrating Health- and Social Care Systems

6

John Eastwood and Robin Miller

6.1 Introduction

It has long been recognised that social issues have a strong bearing on people's health and well-being. Whilst medical treatments are essential to address underlying infections and physical malfunctioning, these are insufficient by themselves to maintain and promote the health of a population. Wider social contexts such as poverty, housing, hygiene, employment and education play a fundamental role in the incidence of disease. These must be considered and connected issues addressed to achieve better health for all. Vaccines can provide important immunity that will help to eradicate a disease, but it is only by societal coordination and development of associated social norms that vaccines are successfully introduced. Health interventions may be able to prolong the life of people with a long-term health condition, but social issues enable life to be of better quality—i.e. a life worth living and acute care can only successfully operate if people are supported post-crisis to return or access support in the community. In relation to mental health, social networks and access to employment are often the most influential in achieving better well-being.

Given that health and social care should be at the heart of all integrated care it could therefore be questioned as to why there is a need for a separate chapter on this topic within this compendium. And yet practitioners of integrated care are well aware that we are far from achieving integration of health and social care in either

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policy or practice. Integrated care is often still interpreted as being about integrating primary and secondary medical services, and attempts remain disconnected from the social system upon which people rely for the essentials of living. This narrow view of integrated care should be challenged and the principles of integrated care systems extended across sectors in partnership with communities and their citizens. Integration of health and social care has been difficult to achieve using structural and organisational approaches given the significantly different funding streams, regulatory frameworks and professional and organisational cultures. Given the demonstrated importance of the social determinants of health, it is only by putting the social needs of individuals, and their families, at the centre, can we achieve the integration we strive for.

In taking a person-centred approach to the provision of care and support, it is necessary to keep 'all matters in scope' including biological, psychological, physical and social environments and life-course. In this chapter, we will consider integration of health and social care in relation to the direct delivery of support to individuals and their families (i.e. clinical and service integration) and integration of health and social care in relation to addressing the social determinants of health (i.e. population and system integration). We will then focus on the importance of workforce and what practically can be done to enable health- and social care professionals to collaborate better. We will begin though by considering what is meant by social care.

6.2 What Do We Mean by Social Care?

Whilst the individual concepts of 'social' and 'care' are ones that transcend boundaries, the term 'social care' is not widely used or consistently understood internationally. In relation to the delivery of services, in the UK (which has been influential in relation to integrated care developments), social care refers to a range of direct support to people who are vulnerable and/or have lost independence due to age, disability, mental health or other issue. Classically, this involves support such as tending to personal care (i.e. washing, toileting and dressing), maintaining a household (i.e. cleaning and shopping), supervision (through staff and/or electronic devices) and support for informal carers (i.e. home- or residential-based respite). The support can be provided in the person's own home or in designated facilities such as residential care or supported housing. In many other countries, such services are not separately denoted as 'social care', but rather included within the concept of 'long-term care'. The OECD (2019) defines this as a 'range of medical, personal care and assistance services that are provided with the primary goal of alleviating pain and reducing or managing the deterioration in health status for people with a degree of long-term dependency' (OECD 2019, p. 1). Long-term care therefore includes community-based health services as well as the UK-defined social care. Other terms are also deployed—in Australia—for example, 'aged care' denotes long-term care for older people. Alongside long-term care, another commonly used terms are 'social services' or 'human services'—this incorporates the support outlined above but also wider services to promote someone's well-being, such as those related to employment, education, leisure and financial support. These sectors also often have responsibilities in relation to safeguarding people who are vulnerable from exploitation and/or abuse.

However one denotes such provision (and we shall refer to them as 'direct social care services'), an important context is that much of the non-health components of long-term care are provided by families and other informal networks, rather than by formal agencies. Furthermore, such care is largely provided by women. This can restrict women's ability to access paid work and progress careers of choice. Informal care giving is also related to higher poverty rates and prevalence of mental health problems. Formal direct social care services are commonly provided by a mixed economy of public, private and charitable organisations and public funding routes include social insurance, taxation and/or user charges. Whatever the funding model, there are common concerns regarding the capacity of formal provision to cope with increasing demand, ensure the quality of care due to tensions between funding and pressures and manage the economic impacts of populations living longer and with multiple conditions (Spasova et al. 2018). In response to the latter, one common strategy being pursued by many countries is to reduce reliance on institutional care through strengthening home-based care.

Many countries experience challenges relating to the recruiting of a skilled workforce due to restricted pay, unsociable hours and low status of such roles. Such concerns are not limited to advanced market economies. For example, the (WHO 2017) has estimated that in Ghana, more than 50% of people between the ages of 65 and 75 years require some assistance with daily activities. For those 75 years and older, the percentage jumps to more than 65%. This compares with Switzerland in which the proportion is less than 5% and 20%, respectively.

Alongside direct services to individuals and their families are 'activities that address health-related social risk factors and social needs' (National Academies of Sciences 2019, p. 28). Social variation in health outcomes has been long studied and appreciated. A historical social epidemiological perspective is provided by Berkman and Kawachi (2000). The authors discuss several relevant concepts including a population perspective, the social context of behaviour, multilevel context, a developmental and life-course perspective and the possibility of a general susceptibility to disease linked to the cumulative effects of stress. Pearlin (1981) hypothesised that health disparities arose to a substantial degree from differences in life-time exposure to social stress (Turner 2010). Social determinants of health can be defined as the economic and social conditions that influence both individual and group differences in health and well-being. The 2011 World Conference on Social Determinants of Health affirmed that health inequities are unacceptable and noted that these 'inequities arise from the societal conditions in which people are born, grow, live, work and age, including early childhood development, education, economic status, employment and decent work, housing environment and effective prevention and treatment of health problems' (World Health Organization 2011).

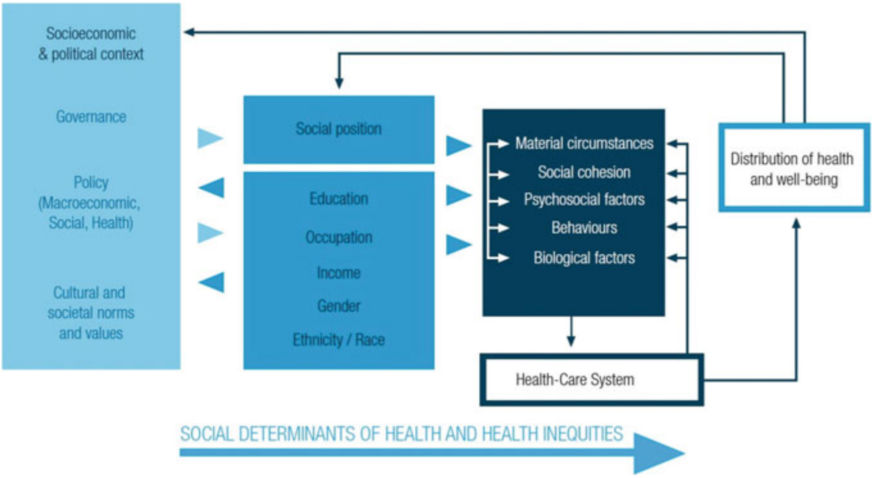

Fig. 6.1 Commission on social determinants of health conceptual framework (WHO 2011)

Whilst the determinants are primarily rooted in macro-resource allocation, the effects are experienced by individuals and families in their daily lives and across generations (Fig. 6.1).

Lantz and colleagues observe that “public health activities in the late nineteenth and early twentieth centuries focused on ‘upstream’ causes of poor health, including poor sanitation, overcrowded and squalid housing conditions, work-related hazards, food security and nutrition” with consequential sharp declines in mortality. Coming from a *population health* perspective the authors argue for continued attention to key social and economic causes and caution against the medicalisation of the social determinants of health (Lantz et al. 2007). The US Healthy People 2020 Plan (Health and Services 2001) identifies four key aspects of society to be addressed in regards to the social determinants alongside healthcare services: economic stability, education, social and community context, neighbourhood and built environment. Social care from this perspective refers to activities that seek to address these wider determinants of health. There is increasing recognition in such approaches that all communities, even those which face considerable disadvantage, will have their strengths based on local social and cultural networks. Building on these local assets, rather than solely problematising the people and their communities, provides a more constructive, enabling and sustainable solution to underlying and embedded challenges.

6.3 Integrating Health- and Social Care for Populations

6.3.1 Population Health Improvement Approach

Lantz and colleagues (2007) observe that healthcare and public health professionals may have different interpretations of the term population health, with healthcare leaders using the term to describe cohorts of individuals served by health plans or clinical services. By contrast, for public health leaders, the population of interest is all people living in a geographical area, such as country or region. The differences between these two views may be more profound and influenced by quite different beliefs and values.

The modern population health approach has a pedigree that includes the Alma-Ata Declaration on Primary Health Care (WHO 1978) and the Ottawa Charter of Health Promotion (WHO 1986). The Alma-Ata Declaration of 1978 was a major milestone in the field of public health, and it identified primary health care as the key to the attainment of the goal of 'Health for All' around the globe. It was based on the principles of equity and community participation in health planning and policy making, through an inter-sectoral approach. The Ottawa Charter for Health Promotion incorporated five key actions of: (1) building healthy public policy; (2) creating supportive environments for health; (3) strengthening community action for health; (4) developing personal skills; and (5) re-orienting health services.

This population health 'improvement' approach to the social determinants of health (SDOH) seeks to address the underlying structural factors such as economic, education, housing and income security policy and the broader values, cultural and institutional contexts that shape the distribution of resources. The approach is intended to improve the health and well-being of the whole society and not just the poorest or most marginalised. When integrating health and social service systems, this approach is operationalised through a whole of society approach to 'health in all policies', universal health care, housing, education and full employment. At a local level, population-based initiatives may be represented by safe communities and healthy city initiatives. Through such approaches, all citizens benefit from reduced crime, strong social cohesion and clean air.

The relevance of the population health 'improvement' approach to integrated care may not be immediately apparent, but it can be advanced that integrated health and social care will benefit from strong community social cohesion, health literacy, coordinated services and shared governance. This is what the Ottawa Charter calls 'Supportive Environments for Health'. The recently ratified WHO framework on integrated people-centred services (WHO 2016) takes a similar population health approach and has echoes of both the Alma-Ata Declaration and Ottawa Charter. The framework has five interwoven strategies: (1) empowering and engaging people and communities; (2) strengthening governance and accountability; (3) re-orienting models of care; (4) coordinating services within and across sectors; and (5) creating enabling environments. As with the Alma-Ata Declaration, the WHO framework on integrated people-centred services, places a strong emphasis on the role played by other sectors as illustrated in the conceptual framework (Fig. 6.2).

Fig. 6.2 WHO conceptual framework for people-centred and integrated health services (WHO 2016)

6.3.2 Population Health Management Approach

By contrast, the population health 'management' approach is a person-centred approach to meeting the needs of those with identified health- and social care needs. This approach focuses on groups of patients included in insurance plans, hospital patient cohorts, accountable-care organisations or other health- and social care organisations. In its narrowest conceptual form, the population health 'management' approach will focus on medical conditions with little consideration for the social or prevention dimensions. Of particular significance, here is the population health 'management' approach developed by Kaiser Permanente (KP) which includes health promotion and disease prevention elements. The approach was modified by the Kings Fund (UK) for the Barcelona Integrated Care Strategy (Ham 2003) to include the social dimension (Fig. 6.3).

6.3.3 Combined Population Health Improvement and Management

Some healthcare systems, by contrast, will pursue both population health improvement and population health management strategies at the same time. In this way, they collaborate with other sectors for both: improving the care of their patient population and improving the health and well-being of the wider geographical population. A further aspect of more mature systems is strong advocacy to address the upstream macro-structural determinants of health and well-being. This approach has been incorporated into the National Academy of Sciences (USA) report: *Integrating social care into the delivery of health care: Moving upstream to improve*

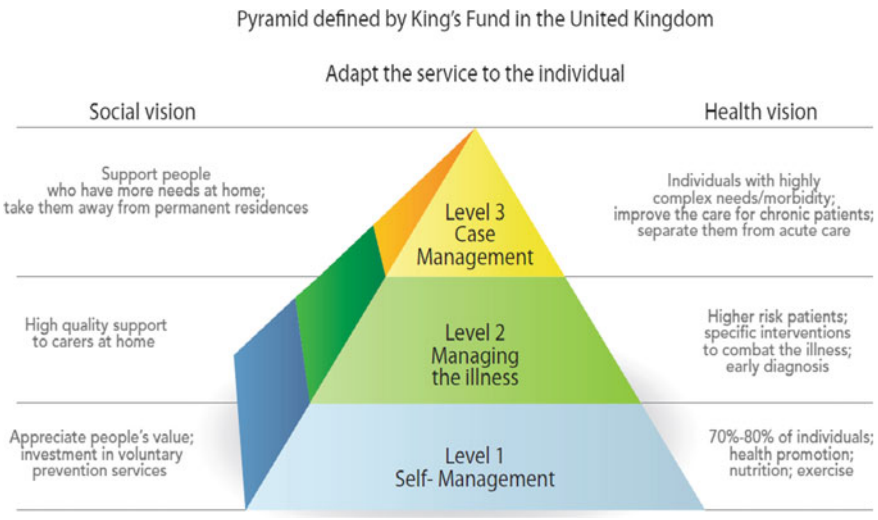

Fig. 6.3 Kaiser Permanente (KP) pyramid as adapted by the Kings Fund (UK) (Ham 2003)

the nation's health (National Academies of Sciences 2019*).* The report identifies five complementary activities in the healthcare setting to facilitate the integration of social care (defined as activities that address health-related social risk factors and social needs) into the delivery of health care (Table 6.1) (Bibbins-Domingo 2019). Bibbins-Domingo (2019) further note that the activities of 'alignment and advocacy recognise that some social needs may broadly affect a community and the most effective role for the healthcare system is to tackle these needs collectively and not just one patient at a time'.

It is becoming increasingly clear to health funders that social risk factors are impacting on their health costs as evidenced by longer length of stay, frequent representations and more complex morbidity. It is in this context that population health management systems are increasingly asking their patients about the SDOH in clinical settings.

An alternative to the top-down structural approach to the integration of health- and social care services is to adopt a bottom-up person-centred and locally driven approach that puts individuals and their families at the centre and incorporates place-based and local system change elements. Such an approach draws on the foundations of the Alma-Ata Declaration in the context of person-centred integrated health (and social) services.

An example is the *Healthy Homes and Neighbourhoods* Integrated Care Initiative in Sydney, Australia, which was collaboratively designed as part of a local district 'whole of system' approach to child, youth and family health and well-being. The design intentionally drew on both population health improvement and population health management approaches as discussed above. The design elements included: identification of vulnerable family cohorts; care coordination;

Table 6.1 Five categories of healthcare activities that facilitate addressing social needs applied to a transportation-related example

Activity	Definition	Transportation-related example
Awareness	Activities that identify the social risk and assets of defined patients and populations	Ask patients about their access to transportation
Adjustment	Activities that focus on altering clinical care to accommodate identified social barriers	Reduce the need for in-person healthcare appointment by using other options such as telehealth appointments
Assistance	Activities that reduce social risk by providing assistance in connecting patients with relevant social care resources	Provide transportation vouchers so that patients can travel to healthcare appointments; vouchers can be used for ride-sharing services or public transit
Alignment	Activities undertaken by healthcare systems to understand existing social care assets in the community, organise them to facilitate synergies and invest in and deploy them to positively affect health outcomes	Invest in community ride-sharing
Advocacy	Activities in which healthcare organisations work with partner social care organisations to promote policies that facilitate the creation and redeployment of assets or resources to address health and social needs	Work to promote policies that fundamentally change the transportation infrastructure within the community

Source Bibbins-Domingo (2019)

evidence-informed intervention(s); general practice engagement and support; family health improvement; placed-based neighbourhood initiatives; interagency system change and collaborative planning; monitoring of individual and family outcomes; and evaluation (Eastwood et al. 2019a). The person-centred intervention is supported by other tiered components that function at professional and organisational levels (see Box 1).

Box 1: Healthy Homes and Neighbourhoods Key Features (Eastwood et al. 2019b)

Healthy Homes and Neighbourhoods

The Healthy Homes and Neighbourhoods Integrated Care Initiative uses a stratified population-based approach to address the needs of families who are experiencing adversity, whilst supporting parallel interventions for families more generally. The approach to identifying the most vulnerable families who are disconnected from key services has been developed using existing perinatal risk-assessment systems, developing new cross-agency assessment and referral pathways, and improved hospital recognition of the needs of families using an e-health solution.

The initiative has the following key features:

1. Multiple core and non-core agencies **working together over a sustained period of time** (i.e. 5 years) with families with complex health and social needs
2. Co-design and co-production of the initiative in **partnership** with families and service partners
3. **All the needs of enrolled families are in scope** for the intervention, including housing, employment, income support and legal advice
4. An **early intervention and public health approach** to interrupting cycles of family disadvantage, poor health and psychological trauma
5. A **focus on efficiency** through the maximum use of, and leverage from, existing family, societal and government resources, including Medicare scheduled services
6. Use of **evidence-informed integrated care methods** by service partners, including family case conferencing, and 'wrap-around' care delivery
7. Encouraging families to have a **'health home'** for all their health needs and supporting progress towards self-efficacy
8. **Providing a supporting structure to general practice** providers to care for families that are often seen to be 'too difficult'
9. Development and implementation of **shared assessment tools and referral criteria**
10. Implementation of **family assessment and engagement tools** that can be used over the long-term to monitor the health and well-being of family members.

A central element of the initiative is targeted long-term sustained cross-agency care coordination. The design acknowledges the need for significant system redesign and commitment from partners. The initial model required a care coordination team with both project-funded and partner-funded components as a means of ensuring sustainable 'collaboration'. The initiative also includes local elements through deliberate recruitment of families and service partnerships in the City of Canterbury and City of Sydney local government areas. This last component enabled the development of 'demonstration-site' place-based partnerships with local general practice, schools, family support agencies, local government, religious and faith-based organisations and community members.

6.4 Integrating Health and Social Care for Individuals

Coordination between health and social services reflects the general challenges found within all forms of integrated care that seek to bring together professionals, services and organisations from different backgrounds and sectors around the needs of individuals and their families (Hujala et al. 2017; Auschra 2018; Seaton et al. 2018). Research highlights that the particular contexts and cultures of health- and social care services result in such general challenges being commonly experienced in distinct ways (Petch 2012; Cameron et al. 2014; Miller et al. 2016). The distinctive challenges within health- and social care integration include:

(1) Professional rivalry between social workers and doctors based on the perceived conflicts between their traditional philosophies of care (i.e. 'medical' and 'social' models). Furthermore, these professions are dominant in their own sectors and therefore not familiar with their professional judgements being challenged by another profession of 'equal' standing.
(2) The high proportion of staff within social care who do not have the formal status of a 'registered professional'. This can lead to them having lower status to more professionalised health colleagues and excluded from decision making, despite often having a detailed knowledge of a person and their day-to-day life.
(3) Healthcare receives more funding than social care. This results in disparities in technical capabilities, standard of facilities and accommodation and overall workforce capacity. Health care is often more able to lead on integrated care initiatives due to their greater infrastructure. This can result in their perspective dominating the objective setting and implementation process.
(4) Public interest in health care is greater because it is accessed by all of a population at some point in their life, and its professions have traditionally been held in high esteem. This leads to its prioritisation by politicians over the less popular social care sector which is accessed only by a proportion of the population, is not always seen favourably, and which supports stigmatised and excluded groups.
(5) Social care services are delivered by a myriad of agencies from private and non-governmental organisations. The fragmentation of the sector can give it less influence than the large provider organisations within health care such as hospitals and the powerful professional colleges.
(6) The policy development and governance of health- and social care services commonly fall under different parts of government and/or public entities. Social care is commonly coordinated at a local level while health care is often led nationally. Performance targets and inspection regimes may be therefore different leading to organisations focussing on their own sector's objectives and requirements to the detriment of a local system as a whole.
(7) Reflecting in part the financial differentials, there has been much less research in social care than health care, and in particular clinical care and pharmaceuticals. This can result in healthcare interventions being seen as better supported by evidence and therefore more worthy of investment than the under investigated social care support.

There are important consequences for individuals and their families from direct health- and social care services not collaborating. Social care support is often central to people being discharged from hospital following admissions for physical and/or mental health crisis and/or planned treatment. A lack of coordination results in people having to remain longer in such settings, which can result in frustration and uncertainty for them and their informal carers. Similarly, those with long-term physical and/or mental health conditions are admitted into crisis and/or hospital care because their social issues have not been addressed. Difficult social contexts can result in people's health deteriorating and reduce their resilience to cope with their health condition. Particular difficulties in relation to integration between health and social care are experienced at times of transition. For example, when young people with disabilities and/or mental health difficulties are moving into adulthood, this will often involve them leaving behind the health, education and care services that have supported them through childhood and adolescence to access an unfamiliar range of support. This process commonly involves them also losing their care coordinator and this further complicates navigating this new environment. Social work's central role in many countries in relation to safeguarding means that good collaboration with health professionals is vital to identify concerns at an early point and ensure that interventions are in the best interest of the child or young person.

Box 2: Example of Benefits of Better Integration Between Health and Social Care (Cornell et al. 2020)

Social care within Patient Aligned Care Team

The Veterans Health Administration describes itself as America's largest integrated healthcare system, providing care at 1255 healthcare facilities, including 170 medical centres and 1074 outpatient sites of care of varying complexity (VHA outpatient clinics), serving 9 million enrolled Veterans each year (https://www.va.gov/health/). The Patient Aligned Care Team (PACT) was launched by VHA in 2010 to introduce the primary care medical home model to improve patient-centredness, coordination and continuity of care. PACTs involve 'teamlets' of professionals including primary care physician, nurse, clinical associate and administrative staff member supporting around 1.200 patients. Social workers were seen as bringing expertise in responding to psychological needs of veterans, supporting informal carers, arranging support in the home and addressing wider social issues including isolation and housing. VHA recognised that many of the PACTs in rural settings did not include social workers and therefore introduced a programme to recruit social workers for these teams in 2016. Between 2016 and 2019, ninety-five social work positions were created which enabled ninety-three primary care sites to have social workers present on a full- or part-time basis. Cornell et al. (2020) undertook a study of the programme which exploited the staggered implementation to identify comparison groups (i.e. early implementers and late implementers). They found that visits to emergency departments by veterans decreased following the introduction of a new social worker. This appeared to be due to reductions in the number of visits connected with preventable causes such as non-urgent concerns and those that could be addressed through more thorough management of their conditions. In addition to the reduction in use of costly hospital resources, they highlight that veterans having better access to social workers could result in other benefits including reducing stress, improved coordination and wider social supports.

Fragmentation between health- and social care services also has major implications for efficiency and productivity. Acute health services are generally more expensive than community-based social care and therefore avoiding unnecessary admissions and securing timely discharge has become a major focus for governmental policy. Similarly, insufficient collaboration can result in people becoming admitted to long-term institutional settings following a time of crisis. Hospitals can apply pressure for patients to be discharged as soon as they deemed medically fit in order to free up ward capacity. This can result in older people moving into care homes on a permanent basis when a longer period of rehabilitation could have enabled them to return to a community setting. Such inefficient use of resources due to fragmentation between health and social care is also recognised for other populations. For example, people with a learning disability and/or complex mental health difficulty may be subject to long admissions to assessment and treatment facilities due to a failure of community-based health- and social care services to provide intensive support during a time of crisis (Miller et al. 2018).

This combination of improving outcomes for people and families and ensuring that resources are used more effectively has convinced policymakers that better integration between health- and social care services should be a priority. This has only heightened with ageing demographics and increasing proportion of populations with multiple long-term conditions. Reflecting the distinct challenges outlined above and our understanding of how to support integrated care in general, it is evident that better integration between health and social care will require change at all levels of the health and care system. Whilst often seen as an amorphous whole, health and care policy in the UK has been devolved to the home nations (i.e. Northern Ireland, Wales, Scotland and England) which lead to differences in how they frame similar challenges for their populations and the solutions that they propose (Kaehne 2017; Miller 2019). Health- and social care integration is though a common aspiration, and all of the home nations have introduced over the past decade a similar blend of policy and practice approaches to facilitate more coordinated care (Table 6.2). These include system-level outcomes and population-based planning, integrated organisations and/or partnership boards, multidisciplinary health- and social care teams, an overall narrative of community based and person-centred care and addressing functional barriers such as siloed budgets and workforce planning. Some progress has been made, for example in relation to slowing increasing rates of hospital admissions within the UK regions

Table 6.2 Examples of development to promote integration between health and social care in the four home nations of the UK

	Scotland	Northern Ireland	Wales	England
System	National health and well-being outcomes	Integrated Care Partnerships	National Outcomes	Integrated Care Systems
Organisational bodies	Lead Agency for delivery of health and social care	Joint health and social care trusts	Regional Partnership Boards	Transfer of public health to Local Authorities
Professional	House of Care	MDTs in Primary Care	Primary Care Clusters	Multi-Speciality Community Providers
Service	Lead professionals	Family Support Hubs	Integrated Family Support Teams	Integrated personal budgets
Normative	Live longer healthier lives at home (or in homely setting)	New model of person-centred care	Healthier and happier lives through whole system approach	*"I can plan my care"* I statements
Functional	Pooled budgets for social care and primary care Workforce Plan	Patient e-Portal Electronic Patient Record	National Transformation Fund	Better Care Fund Health and Care Record Exemplars

Source Miller (2019)

that adopted multi-speciality community providers and reducing delayed transfers of care in Scotland. However, it is clear that despite all of the attention and investment, there remains fundamental divisions and more must be done to achieve sustained integration between health- and social care services (Box 3).

Box 3: Examples of Criticisms of the Extent of Health- and Social Care Integration From National Audit Reports in the Home Nations (UK)

"The Integrated Care Fund has helped to bring organisations together to plan and provide services …. The fund has provided an impetus for partners to develop integrated services and to move to joint funding arrangements in the context of wider policy and legislation … [however] the overall impact of the fund in improving outcomes for service users remains unclear, with little evidence of successful projects yet being mainstreamed" (Welsh Audit Office 2019).

> "The HSC system continues to be under mounting pressure and the costs associated with maintaining existing models of service continue to increase at a pace which cannot be sustained within the budget available. There is a clear need for successful transformation of service delivery models … However the successful delivery of this vision will require new ways of working, including with partners outside of HSC Trusts" (Northern Ireland Audit Office 2018).
>
> "Integration Authorities (IAs) have started to introduce more collaborative ways of delivering services and have made improvements in several areas, including reducing unplanned hospital activity and delays in discharging people from hospital … Financial planning is not integrated, long term or focused on providing the best outcomes for people who need support … [making] it difficult for IAs to achieve meaningful change" (Audit Scotland 2018).
>
> "[Government] expectations of the rate of progress of integration are over-optimistic. Embedding new ways of working and developing trust and understanding between organisations and their leaders are vital to successful integration. This can take many years because the cultures and working practices in the health and local government sectors are very different" (National Audit Office 2018).

6.5 Integrating Health and Social Care Through the Workforce

When approaching integrated care from a medical perspective the workforce considerations focus often on interdisciplinary teams where the members are subspecialty doctors and nurses with perhaps some consideration of the allied health professions that support treatment modalities of care. Professional and regulatory agencies provide in these circumstances clear clinical governance regarding matters such as accreditation, scope of practice and clinical standards. To address the complex social needs of patients and families, there is a requirement for collaboration beyond the traditional healthcare teams to include staff from social care services, housing, schools, residential institutions, correction facilities, local government and community-based organisations. The ability of these interdisciplinary teams to function effectively is dependant of a wide range of factors many of which relate to workforce capacity, relationships and governance. Furthermore, it is important to recognise that it is not only those working in the frontline who have to adapt their practice to achieve better integration. Those who are responsible for the planning, funding, policymaking and managing of the health- and social care sectors must demonstrate new collaborative behaviours in order to address these long-standing and embedded barriers and missed opportunities to address inequalities.

6.5.1 Inter-Professional Competence

As highlighted above, there are long-standing challenges in relation to the ability of health- and social care staff to collaborate constructively due to professional tensions and/or perceived differences in status and expertise. One issue is the willingness of this workforce even to consider such engagement on the basis that it is out of their area of concern and/or they are sceptical that it will lead to any benefit. A second issue is that even if they do recognise the importance of working better with those from the different sector they may not have the underlying competence to do so successfully (Xyrichis and Lowton 2008; Mangan et al. 2015; Carpenter and Dickinson 2016). This is despite the underpinning values, skills and knowledge necessary for health- and social care integration to be well recognised at a practice level and receiving greater attention for those within management and leadership roles (see below) (CIHC 2010; IPEC 2016; Miller and Stein 2020).

One approach to support the development of such competencies is through inter-professional education (IPE) in which health- and social care professionals learn alongside and from each other (Baker 2010; Carpenter and Dickinson 2016; Miller et al. 2019). IPE is becoming more common within education settings delivering qualifying/post-qualifying programmes and within on-going professional education. Often though, this is limited to health professionals and further limited to formal ‘professionals’ rather than involving those with other roles and backgrounds. Reflecting the wider context of integration between health and social care, such limitations can reflect a lack of awareness from educators rather than an opposition to opening up training wider as such. Engaging multiple professions in a learning process can be extremely challenging, and this is amplified if (as can be the case with social care) the students or staff are based in or employed within different colleges or organisations. There is also an issue of appropriate design and quality of delivery in relation to inter-professional education with health and social care (Mertens et al. 2018). Simply getting sufficient funding, institutional agreement, timetable co-ordination and faculty support can be enormously challenging. This can then result in insufficient capacity to develop learning opportunities that will facilitate changes in professional behaviour into the long term despite the enablers of inter-professional education being recognised in research and practice (Table 6.3).

6.5.2 Professional Accountabilities

Practice governance frameworks are well developed within most of the sectors that will partner in the integrated health- and social care setting. The funding mechanisms will usually include requirements for accreditation against national and international standards that include workforce-related standards. Complications begin to occur when health practitioners are employed by non-health organisations where supervisors are either not from a health background or not from that specific clinical speciality. Clinical supervision arrangements may not be sufficient to

Table 6.3 Enablers of inter-professional education

Aspect	Description
Involved patients	Patient stories, home visits, co-designed, patient led
Holistic focus	Multi-professional assessment, patient experience, determinants of health
Practical orientation	Supporting individuals. Undertaking shared project, community action
Multi-modal	Lectures, on-line learning platforms, group discussions, team tasks, collective reflections, observations
Multi-professional	Professions, disciplines, agencies, sectors
Robust evaluation	Formative and summative, impact, mixed methods

Source Miller (2019)

adequately support that staff member. Similar situations occur within the health sector when a sub-speciality practitioner is deployed away from their core team (i.e. community social worker in a dental hospital). Even more difficult challenges can occur where non-licensed social care staff work in close partnership within healthcare teams. That workforce includes: (1) community workers and community health workers; (2) case managers, care coordinators and care navigators; (3) home health aides and personal care aides; (4) family caregivers; and (5) other professionals such as community lawyers (Table 6.4).

Apart from the legal profession, many of the above categories of workers are not registered by statutory professional regulatory agencies. Consequently clinical governance concerns are often raised in relation to scope of practice. This then becomes a barrier to full integration of the social care workforce into transdisciplinary care teams. It is also used as reason for not sharing both personal and clinical information even when the practitioner is closely involved in a shared-care relationship with a patient.

6.5.3 Information Sharing

Information sharing among agencies and practitioners is essential for the provision of high quality health and social care. As noted above modern high-quality health care has moved towards utilisation of integrated systems that include multidisciplinary teams, bio-psycho-social interventions and follow-up care often by other professionals and agencies. Such approaches are considered to be part of an evidence-informed ‘duty of care’. But an approach that aims to act in the best interest of patients is also in tension with the principle of respect for patient autonomy.

Central to clinical integration is the sharing of clinical information between providers of care to patients. Some of those providers will be known to the patient whilst others (i.e. clinical supervisors, pathology and imaging services) will not. A further complexity is that some practitioners may not be considered members of the traditional healthcare team (i.e. school educational psychologists, security staff,

Table 6.4 Non-licensed social care workforce examples

Category	Description
Community Health Workers	Community health workers (CHWs) provide linkages among health, social services and the community. Often recruited from the communities they serve CHWs work in health systems, social service agencies and community-based organisations. They are engaged in awareness, assistance and advocacy activities
Social Service Navigators, aides and assistants	Social service navigators, aides and assistants and also trained volunteers often work outside of the healthcare sector in awareness, assistance and advocacy roles in social service agencies and community-based organisations. Examples include housing and transportation experts, people who work at food banks, people who provide employment assistance, outreach and enrolment workers, navigators and trained volunteers
Home Health Aides and Personal Care Aides	Within the healthcare sector, home health aides and personal care aides provide extensive social support services to assist older adults and disabled and post-acute care patients in their homes. These direct care workers have close contact with the country's most disadvantaged patients
Family Caregivers	People who provide care for their family members (family caregivers) are another critical part of the care team and provide assistance to many individuals. Because they spend time in the home, family caregivers, similar to home health aides and personal care aides, have a valuable perspective on the social needs of patients. I
Case Managers	Case managers (and care managers) work intensively with individuals with complex social needs, whether in the healthcare system or with social service agencies. They can be based in hospitals, at home care agencies, in skilled nursing and rehabilitation facilities, or with community-based organisations. Case managers also are found in social services agencies, such as foster care agencies, child welfare agencies, senior centres and homeless shelters. Often, the role of case managers is filled by licensed clinical social workers and licensed nurses
Lawyers	Lawyers who address the social needs of patients and families are increasingly being used in community-based organisations, including some federally qualified health centres, to assist patients and families with legal matters that can compromise health, such as inadequate housing or a loss of housing

Adapted from National Academies of Sciences (2019)

religious counsellors, disability support workers and practitioners working in the criminal justice sector). Thus, the provision of excellent integrated clinical care requires the sharing of clinical information with a multidisciplinary healthcare team of clinicians from across a wide range of sectors and disciplines.

With the development of digital technology, clinical information can be rapidly shared between healthcare teams, institutions and actors involved in system management and evaluation. At the agency and system levels of an integrated service system, there is also an increasing focus on personal health data integration within health care as evident by the implementation of the various forms of shared health records. The sharing of information is often problematic and is often reported as a barrier to integration of health and social services. Barriers exist for both identifiable and non-identifiable information sharing.

Cross-agency sharing of de-identified personal information is usually for advancing a shared understanding of population health and well-being and for improving the delivery of health and social services. Despite this common purpose, the sharing of de-identified information can be difficult in some jurisdictions. The challenges of sharing identifiable personal and clinical information are many. That cross-agency sharing of identifiable personal information can be for: (1) clinical care of individuals who have consented for the shared use of their information; (2) clinical care of individuals who have not consented for the sharing of their information but where the use is covered by that jurisdictions privacy codes; or (3) protection of the individual and others as is covered in that jurisdiction's statutory legislation (i.e. mental health, child protection, public health and criminal legislation).

Each country and statutory jurisdiction will have different statutory provisions. Within New South Wales (NSW), Australia, for example, it seems clear that both the Australian Privacy Principles and NSW Health Privacy Principles make provision for clinicians to share information within the 'healthcare' team, and with closely affiliated clinicians where there has been informed consent from the patient. It is also clear that where informed consent has not been obtained, health information can be used and disclosed (shared) for the purpose for which it was collected (the primary purpose) and for other purposes that are related to the primary purpose and that are within the individual's reasonable expectations.

It seems, therefore, that multidisciplinary interagency healthcare teams can collect and share health information, without consent, provided the purpose is closely related to the primary purpose for which it was collected. Given that the holistic nature of health and social care is not always fully appreciated, the 'sharing' of sensitive information with others in the 'team' will not always be fully understood. It is, therefore, appropriate to inform patients of the nature of the 'multidisciplinary health- and social care team' and to advise them of the practice of sharing health information among team members. The sharing of health information between health- and social care team members is an important component of the drive to improve the quality and safety of care. Barriers to such information exchange are often advanced as the underlying reasons for mishaps in the provision of care and the failure to implement change.

6.5.4 Leadership and Followership

Clinical leadership is now seen an important enabler of quality practice by health professionals (Ezziane 2012; Daly et al. 2014; Mulla et al. 2014). Such leadership builds on socialisation processes within professional training, registration and bodies and the powerful influence of peers and 'esteemed' colleagues. Whilst in many ways a strength of health care, clinical leadership can reinforce an isolation mentality if focussed on the preservation and status of the profession rather than the interests of individuals and their families. Professions are particularly susceptible to separatist behaviour when they perceive that aspects of their traditional scope of practice are being encroached upon, or they believe that their professional autonomy is being diluted through more shared and open decision-making (Braithwaite 2013; MacMillan and Reeves 2014). Integrated care can of course introduce both such dynamics, with multidisciplinary team structures being a common vehicle to bring together different professionals (Jelphs et al. 2016). The addition of social care to such teams can add further disruption, due to the lack of traditional professional hierarchy and/or an unfamiliarity of health professions and practice roles within social care. Similar challenges can be experienced within senior management and governmental roles with leaders familiar with their own health- or social care contexts finding it difficult to engage and influence those from an alternative sector (Miller and Stein 2020).

There is therefore a need for leaders at a clinical and senior level to demonstrate a new form of leadership. Rather than being limited to their own profession or organisation, this must instead be able to connect and inspire those within different roles and sectors (Ghate et al. 2013). Systems leadership is being promoted in other areas than health and social care, but there is increasing recognition that it is a necessary component of achieving the benefits of integration (Senge et al. 2015; SCIE 2018). There is not one model of system leadership as such, but there are common elements: system leaders are best placed to tackle 'wicked' issues which involve many stakeholders and uncertain solutions; system leaders work collaboratively with others to encourage a sharing of resources and creative thinking; system leaders are focused on goals of collective interest and are willing to sacrifice personal benefits to achieve this greater good; and system leaders enable those with lived experience and communities to participate in decision-making and contribute as partners (Miller 2020). System leaders at a senior level will often work through partnership structures and management networks, whereas system leaders at a clinical level will work through care pathways, multidisciplinary teams, and professional networks. Both will need a similar set of skills, values and facilitative style of leadership (Evans et al. 2016). Whilst sometimes overlooked, as important as the system leaders is the readiness of 'followers' who are willing to follow this new vision and alternative ways of working.

6.6 Conclusion

In this chapter, we have examined the impact of social issues on people's health and well-being and presented the argument that integration at both population-level and in delivery of direct services are necessary to achieve better outcomes and address inequalities. Different approaches to responding to social need are taken within and between countries and regions. This is influenced by macro-economic, funding and delivery structures, and also their cultural traditions of how best to care for those with social needs. Despite such differences, there are common lessons that can be shared internationally. Common challenges include: professional rivalry between professionals, perceived lower status of consumers and 'unregistered' workers, siloed funding structures; multiple agencies and performance frameworks non-incentivising integrated working. Arrangements that on paper offer a one-stop solution are not successful in isolation. The existence of a single agency for health and social care does not mean that people will experience person-centred and coordinated care. Population health improvement and population health management approaches fail due to the lack of a common vision, strong leadership and appropriate governance structures. Addressing the long-standing fragmentation between health and social care requires a fundamental shift in the recognition of professionals and those in senior leadership regarding the potential for better working between these sectors and their own contribution to achieving this in practice. Identifying what will work in a locality requires open and honest debate of the policy and practice context, including underlying assumptions about the relative merits and the historical tensions and differences that need to be addressed. Whatever arrangements are introduced, 'trust', 'partnership' and 'working in teams' will be central to the solutions.

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Integrated Community Care—A Community-Driven, Integrated Approach to Care

7

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7.1 What is ICC?

Integrated Community Care (ICC) is moving to the forefront of an international policy and practice agenda. At first sight, ICC bundles three generic concepts: ‘integrated’, ‘community’ and ‘care’. In its most rudimentary form, ICC is recognised as a much-needed and valuable expansion of the more typical notions of integrated care, with explicit recognition of the value, potential and power of communities, citizens and informal caregivers. Or, as a formula: ICC = IC + C. However, this is a rather shallow vision on ICC. The present chapter highlights the distinctiveness of the approach beyond a community-flavoured version of ‘integrated care'. It is an approach that takes a person’s and community’s strengths, goals and needs as a start point and focuses on tackling inequities in health (Dahlgren Göran 1991). There is a wide diversity in the landscape of ICC practices. Integrated Community Care is not a prescriptive approach, or a managerial toolbox, but rather a set of principles that wholly or partially manifest themselves in a range of existing practices and have the potential to evolve to a paradigmatic and dialectic change in the way health and care are organised.

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This chapter is structured as follows:

(a) A broad description of Integrated Community Care in the form of a 'root definition';
(b) An emerging set of 'effectiveness principles' to act as a compass to guide implementation of ICC;
(c) An overview of three existing practices that exemplify the essential elements of an ICC approach;
(d) A reflection on the link between Integrated Community Care and community resilience;
(e) A conclusion that ties various themes together.

This chapter draws to a significant extent on findings from a series of conferences organised by the TransForm partnership (Transnational Forum for Integrated Community Care). TransForm is a joint initiative of Foundations in Europe and Canada that aims to inspire and mobilise policy-makers and practitioners to foster Integrated Community Care.[1]

7.1.1 A Root Definition

The contours of the field of Integrated Community Care can be captured by formulating a phrase that synthetically captures the what, how and why of ICC:

Integrated Community Care encompasses a range of strategies to support professionals, organisations, policy-makers and members of a community in a continuous process of co-developing health, care and social support infrastructures and services with the aim to enhance the quality of life, social cohesion and resilience of a territorially defined community.

Integrated Community Care in many respects represents a paradigm shift. Certainly, ICC shares the ambition of integrated care to enhance the quality, value and experience of care, improve population health and wellbeing, and increase job satisfaction in the workforce. It also reflects the understanding that health and care services are delivered through co-productive partnerships and intersectoral and interdisciplinary collaborations. The key difference is the move beyond 'delivery' to genuine 'co-creation' with the individuals and communities that are traditionally seen as recipients.

Integrated Community Care is strongly aligned with the principles underlying the vision for primary health care (PHC) put forward by the World Health Organisation (WHO). This vision sees primary care as a foundation for a resilient, equitable and efficient healthcare system as it integrates three key functional components (UNICEF 2018):

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[1] TransForm initiative. Information available online: https://transform-integratedcommunitycare.com/.

- Meeting people's health needs through comprehensive, integrated health and care services, throughout their life course;
- Systematically addressing the broader determinants of health through evidence-informed policies and actions across all sectors; and
- Empowering individuals, families and communities to optimise their health.

Integrated Community Care builds upon the WHO vision for primary health care. ICC:

- *Goes beyond 'care'*. It is just as much about activating and reinforcing the social ties between people. ICC is an investment to *improve both health and social cohesion*. ICC views health as a public good.
- Pivots on greater integration between primary care, specialised care, public health functions, social work and neighbourhood development. Network governance is a crucial competence to continuously form new constellations of service providers that can respond to changing and spatially differentiated needs.
- Is *goal-oriented in nature*, *supporting people's priorities and life goals*. Such a goal-directed approach represents a more positive view on care, characterised by a greater emphasis on individual strengths and resources. This is a fundamental shift from the traditional, disease-specific, problem-solving approach.
- Is *place-based*. A place-based community is a reservoir of possibilities and assets that can be re-appropriated and replenished on an ongoing basis and leveraged in a range of societally relevant projects. Place-based governance is a participatory, empowering and trust-based alternative to a traditional model that focuses on centrally defined and measurable targets as a guarantee of accountability.
- Assumes *accountability towards a territorially defined population*. This ensures that resources are equitably and efficaciously allocated to where the most acute needs are, ensuring no one is left behind. The involvement of local actors (including local authorities) in the decision-making process is required.
- Inscribes itself in an *enabling perspective on public services*, beyond taking care of infrastructural needs and material safety to creating opportunities for community members to fulfil a larger role in society.
- *Reaches underserved and marginalised groups* to tackle social exclusion, social isolation and help overcome problems related to discrimination, stigma and violence.
- *Engages and empowers people* in local communities and thus plays a central role in valuing the position of the *informal care sector* and of *peers with lived experience*. ICC requires a dynamic, assets-based approach to community development, characterised by non-hierarchical processes, highly engaged communities and distributed leadership
- Comes down to a *continuous process of 'whole system innovation'*. ICC points towards a paradigm shift at the citizen, community and system levels. Lived experience, a shared vision on the fate of the community, distributed power and collective learning are the cornerstones of this comprehensive perspective on health and care.

7.2 Advancing the ICC Agenda

How can Integrated Community Care move from an aspiration into reality? The collection of reflections from experts and practitioners in the setting of the Trans-Form learning journey has led to an initial set of seven effectiveness principles that provide guidance for thinking and acting towards a future in which ICC is the norm. The principles are not prescriptive but meant as a compass for those aiming to bring Integrated Community Care to life in a variety of contexts (Patton 2017).

Co-develop health and wellbeing, enable participation

1. Value and foster the capacities of all actors, including citizens, in the community to become change agents and to co-produce health and wellbeing. This requires the active involvement of all actors, with an extra sensitivity to the most vulnerable ones.
2. Foster the creation of local alliances among all actors which are involved in the production of health and wellbeing in the community. Develop a shared vision and common goals. Actively strive for balanced power relations and mutual trust within these alliances.
3. Strengthen community-oriented primary care that stimulates people's capabilities to maintain health and/or to live in the community with complex chronic conditions (Art et al. 2007). Take people's life goals as the starting point to define the desired outcomes of care and support.

Build resilient communities

1. Improve the health of the population and reduce health disparities by addressing the social, economic and environmental determinants of health in the community and investing in prevention and health promotion.
2. Support healthy and inclusive communities by providing opportunities to bring people together and by investing in both social care and social infrastructure.
3. Develop the legal and financial conditions to enable the co-creation of care and support at community level.

Monitor, evaluate and adapt

1. Evaluate continuously the quality of care and support and the status of health and wellbeing in the community by using methods and indicators which are grounded within the foregoing principles and documented by participatory 'community diagnosis' involving all stakeholders. Provide opportunities for joint learning. Adapt policies, services and activities in accordance with the evaluation outcomes.

The next section presents three examples of initiatives that embody ICC in different ways, reflecting their specific community's context, strengths and needs.

7.3 Exemplars

Examples of ICC in action can be found all over the world. It is important to note that due to the content in this chapter being largely based on the findings from a European and Canadian initiative, the material is drawn from the 'global North'. The ICC approach could be considered as more common and potentially stronger in the 'Global South' (albeit not necessarily formally described as such). This is because public resources tend to be scarcer and community assets are informally relied upon more heavily. Indeed, the WHO PHC approach is based on the experiences of Panamerican Health Organisation (PAHO) in Latin America and the community health worker programmes in Asia and Africa.

The three emblematic exemplars described below were selected to provide a flavour of the wide range of existing ICC practices. The three examples embody the ICC effectiveness principles described in the previous section, and each reflects different drivers (who initiated the project), different focuses (care provision, community building or on spatial-environmental development) and different ingredients. More information on these three examples and others can be found in the collection of ICC case studies on the TransForm website.[2]

7.3.1 Community Health Centres

Community health centres (CHCs) aim to meet a territorially defined group of citizens' needs by offering accessible, high quality and integrated primary care from a biomedical, psychological and social perspective. The intention is to approach patients by taking into account their whole context: family, community, work and socio-economic circumstances.

CHCs usually bring together several healthcare providers (general practitioners/family physicians, nurses, physiotherapists, social workers, psychologists, etc.) under one roof. These professionals form part of what is commonly known as the 'primary care' network, and they work in an interdisciplinary team. In terms of their legal status, CHCs range from collaborative groups of organisations to single legal entities. Governance models also vary (e.g. elected members from each organisation, volunteer boards of directors or clinical management team), but they often engage community members in governance structure. This helps inform a more population health-focused approach. CHCs can be financed with an 'integrated needs-based capitation', whereby the centre receives an amount of money per patient on a regular basis, based on the average care needs of the population for care provided by family medicine, nurses and physiotherapists.

CHCs organise and provide care following the principle of proportionate universalism where care is qualitatively and quantitatively attuned to the goals and care needs of patients and local residents. Community health centres are well placed to

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[2] TransForm international case studies. Available online https://transform-integratedcommunitycare.com/casestudy/?category=international-case-studies.

provide comprehensive primary and preventative care and health promotion with the potential to offer better coordinated, goal-oriented care and access to a wider variety of disciplines in their team and to community services.

Community Health Centre Botermarkt (Belgium)

What makes the difference? Patients, the community and the interprofessional team truly knowing each other and working together

Soon after its establishment in 1978, Community Health Centre (CHC) Botermarkt managed to place the social determinants of health on the agenda of local authorities. A multi-sector partnership in the community was born that included care providers, schools, police, social institutions, informal caregivers, and civil society and organisations, to tackle the root causes of ill health.

Community Health Centre (CHC) Botermarkt is now one of 175 not-for-profit CHCs providing integrated primary care to 4% of the Belgian population. These centres offer primary health care for all inhabitants living in a specific geographical area who subscribe to the patient list of the CHC. The centre is responsible for the health and wellbeing of the enrolled patients, but also engages to protect and promote the health of all citizens living in the community in which they are embedded.

CHC Botermarkt is located in a deprived urban neighbourhood in Ghent and takes care of approximately 6500 patients with a relatively large burden of chronic diseases and high ethnic diversity (95 nationalities). CHC Botermarkt's mission is to ensure accessible, high-quality and comprehensive primary care for all and to contribute to intersectional actions aimed at tackling health inequities. It achieves this by focusing on patient empowerment, social cohesion and local participation.

With 40 years of the presence in the community, CHC Botermarkt's offers an interprofessional team to listen and learn from the community and to strengthen resilience. The interdisciplinary team includes family physicians, nurses, social workers, dieticians, dentists, receptionists, health promoter and psychologists. The services offered include an interdisciplinary sub-team focused on health promotion, managed by a 'manager of health promotion'. The services offered include prevention, curative care, social care, palliative care, rehabilitation and health promotion. The service delivery focuses on accessibility (with no financial, geographical or cultural threshold) and quality. The centre refers patients to secondary care providers, physiotherapists, specialised mental health care, specialised social care, within the framework of an integrated care system. The centre offers a tailored service for people with multimorbidity (including longer consultations with the practitioner most suited), starting from the patient's life goals. This is used as the basis for designing a range of subsequent services and interventions by the broader care team that will meet patients' specific needs.

The community-oriented primary care strategy within the centre aims to adapt services to needs in the community, identified via a stepwise process:

(1) Identification of care needs and underlying social determinants in individual care provider-patient contacts (e.g. through info in the electronic patient records);
(2) Interdisciplinary patient meetings in the centre to identify relevant topics for a larger part of the population;
(3) Prioritisation and validation in the population using data and experiences of relevant stakeholders at regional and city level. The centre actively participates in 'community diagnosis' meetings with local actors (local schools, welfare organisations, etc.) These meetings—initiated and organised by the local government—help to give a voice to the community residents' needs and aspirations.

Performance of CHCs in Belgium was compared to the usual (fee-for-service) care system in 2008 and 2018. The major findings included that CHC is more accessible, especially for vulnerable people than practices in the usual system; they do not cost more and provide at least as good care as in the usual system, with better results in prevention, antibiotic prescription, use of technical investigations and referral to secondary care.

Other examples include: Foundry, Canada; Bromley by Bow Centre, UK; and more generally primary care centres, team-based primary care, community clinics, community mental health centres, headspaces, medical homes, maisons médicales.

7.3.2 Caring Communities

Caring communities (CCs) promotes collaboration between patients, citizens, professionals and decision-makers to bridge informal and professional care for people with complex health and social needs. It capitalises on the ability of patients and citizens to create social connections and take care of each other. The caring community model is anchored on three core activities: (1) *listening* to patients and citizens as people and community member, beyond labels about their disease or social condition; (2) *coaching* them to clarify and achieve their life project; (3) *connecting* them other community members, health and social resources.

The idea of a 'caring community' can represent an enormous diversity of practices, drivers, target groups and aspirations. An example is 'compassionate communities'—a global movement that recognises that caring for one another is everyone's business. Some focus on palliative and end-of-life care or on older people, while others embrace an asset-based approach to participation, wellbeing and healthy neighbourhoods. In other cases, CC originates within a primary care setting, where project co-leaders start caring together for patients in situations perceived as ‘clinical gridlocks’ by professionals.

Caring Community Project (Canada)

Taking care of one another—a bridge between professional and community care

Caring community started as a small-scale experiment within the Centre-South neighbourhood in Montreal. The project’s co-leads started working together to care for patients in situations perceived as ‘clinical gridlocks’ by professionals because of the complex interaction between medical and social issues. The rationale for the project is that people often feel excluded from society once they become sick. Conversely, socially marginalised groups have challenges accessing health care. The project is co-led with patients, health professionals and community members, with shared funding from the municipal government, healthcare institution, social innovation philanthropy and research.

Based on a partnership model of care, caring community mobilises experienced patients (with deep experiential knowledge of health conditions and healthcare navigation) and citizen partners (with intimate knowledge of their own community) to bridge health and community care, in partnership with local health professionals and community organisations. Caring community members help people navigate and connect with their local health and community resources. Interventions are grounded in people’s life goal project: a patient partner can guide other patients to better communicate their symptoms, pain and objectives regarding his treatment, facilitate relationships with his care team and family members and guide them towards self-management and healthcare resources. As experts of the community, citizen partners can invite people to take part in activities, use services available in the neighbourhood (e.g. art therapy sessions, support groups, food banks) and promote their social participation in their own community (e.g. engage as volunteer) to break social isolation and reintegrate society as a full citizen.

The project demonstrated its potential to integrate patient and citizens as members of extended community-based primary care teams. Establishing a caring community takes time, mutual trust, structured recruitment, role clarification and sensitivity to professional and institutional barriers. Improvements in care outcomes (e.g. reduced hospitalisation and emergency room visits) and social wellbeing (e.g. improved connections with family members and community resources) have been noted, particularly for individuals with most complex needs. The initiative is embedded in an ongoing action research project (Boivin 2020).

Other examples include: Vibrant Communities, Caring Neighbourhoods, Quartiers Solidaires, Caring School Communities, Compassionate Communities.

7.3.3 Healthy Place-Making

The places we live in have a profound impact on our health and wellbeing. Significant gains in population health can be achieved by working in partnership with allies across sectors to improve the built, natural and social environments. Health-promoting infrastructure, activities and opportunities need to be accessible to all, with a targeted focus on groups with the poorest health outcomes.

Healthy place-making works in part by acting as a connector and catalyst in local systems. Participating sites often start with creating a small team of people with explicit responsibility for bringing partners together and facilitating dialogue across sectors. There needs to be concerted action on health inequalities as part of efforts to create healthy places, informed by data on the specific health needs of local communities.

The idea of 'healthy place-making' encompasses various layers. On one level, 'place-making' refers simply to the planning, design and management of public spaces. However, it is also used to describe a broader perspective that emphasises not just the spaces themselves but how people use them, based on the belief that thriving neighbourhoods and inviting public spaces play a profoundly important role in community life. When put into practice, the approach often places significant value on collaboration and co-design between professionals and local people. The concept of 'healthy place-making' builds on this by asserting that an explicit goal of those involved in place-making should be to improve the health and wellbeing of the local population.

Habitat Microaree—HM (Trieste, Italy)

The programme is a result of a memorandum of understanding (2006) which was signed by three public entities: the Trieste Local Health Authority, the Trieste City Council and the Regional Public Housing Organisation. The city of Trieste has a population of 204,234 inhabitants characterised by a substantial ageing, significant family fragmentation and moderate levels of incoming migrants creating a more diverse population. There is also a high proportion of one-person households, often elderly women.

The HM is a social, health and housing joint programme with the intent to address the broader determinants of health, to create effective and concrete integration between policies and sectors and to positively influence life contexts, actively involving the local community to reinforce social cohesion. The programme targets the local community living in a 'Micro-area', a small municipality or housing cluster (500–2500 residents), characterised by a high proportion of public housing, socio-economic vulnerability and over 75 inhabitants.

The programme approach promotes community development through matching at a 'micro' level the demand for services with the available public and/or private resources, thus reinforcing the active participation and resilience of citizens in addressing social and health needs. Every micro-area has a professional team responsible for contact and activation, as well as for the coordination of activities (both at individual and community levels) and the local management of resources. Every micro-area also has a multi-functional centre with a dual function: contributing to the decentralisation of health care and social services and to the promotion of participation and social cohesion. They are 'local laboratories' where not only the needs but also the skills/assets expressed by the citizen are combined with the integrated intervention.

The main activities can be divided into:

1. Knowledge area—(a) "door-to-door" home visits to meet the resident population, (b) joint home visits recommended by sociosanitary services and (c) proactive visits to specific population groups
2. Community development area—(a) enabling community-based (and driven) activities (socialisation activities, informal thematic groups, etc.), (b) promoting mutual caring and support, (c) valuing inhabitants' skills (e.g. time bank)
3. Health intervention areas—(a) monitoring the health of those most vulnerable, (b) improving health literacy, (c) planning and providing integrated continuing health and social care on individual cases.

Over 10 years, the comparison of HM and non-HM population (using regional data warehouse) showed a decreasing ratio of incidence for the first hospitalisation, especially when urgent. The decrease of urgent hospitalisation is significant for a number of pathologies: psychosis—85% for women, 28% for men; respiratory acute infections—56% for women; cardiovascular pathology—28% for men.

Other examples include: Healthy New Towns Programme, NHS, UK; Healthy Communities Corridor Project, USA; Good Places, Better Health, Scotland.

7.4 ICC and Community Resilience

The world seems to be moving into a new era characterised by systemic shocks that place global systems and local communities under severe pressure. The COVID-19 pandemic has underlined the fragility of our infrastructures and systems, serviced by both private sector actors and public authorities, in advanced and emerging economies alike. It is to be expected that the existing megatrends (EEA 2015)—such as an expanding global population, more severe impacts of climate change, widening social inequality, increasing transgression of planetary boundaries (The Stockholm Resilience Centre 2020), surging migration streams and impacts of advanced technologies on the workforce—will confront communities with additional challenges in the short- and medium-term future. Traditional, static 'measures of progress of societies' such as 'quality of life' are not able to capture the ability of communities to successfully withstand these pressures. The realisation is quickly dawning that policies across sectors need to be designed to contribute to community resilience (Giovannini et al. 2020).

Broadly, there are two conceptions of resilience (Davoudi et al. 2012):

- The notion of 'engineering resilience' implies the capacity of a system to return to an equilibrium or steady state after a disturbance. This view of resilience is very prominent in emergency and disaster contexts to respond to sudden, large and turbulent events.
- Alternatively, the notion of 'evolutionary resilience' is not conceived as a return to 'normality' but rather as the ability of complex socio-ecological systems to prepare, change, adapt and transform in response to internal and external stresses.

It is the latter, more encompassing concept of resilience that seems most relevant in the current context where we can expect persistent, multi-dimensional stresses on communities.

A wide range of conceptual analyses have been proposed for the factors underpinning community resilience. An underlying pattern that emerges from these analyses is the fact that resilience hinges on two critical elements (Longstaff et al. 2010):

- The presence of critical **resources** (or assets) in communities supplemented by;
- The presence of **functions** (or capacities) to make productive use of these resources.

A resilient community can therefore be defined as follows: *A community that, on an ongoing basis, has robust essential community resources, embedded in a societal system based on democracy, social cohesion and equity and is able to identify and mobilise those resources to prepare, adapt and transform in response to external and internal disturbances and stresses, while maintaining essential functions and advancing its quality of life* (Longstaff et al. 2010).

Community **resources** can be categorised as economic, social-cultural, human, ecological, infrastructural and governance resources. Their robustness hinges on three characteristics: performance, diversity and redundancy (Longstaff et al. 2010). In other words, resources need to be of good quality, plentiful and diverse so as to be able to buffer external shocks.

The adaptiveness of the community rests in the presence of three crucial community functions (Longstaff et al. 2010):

- *Geographical place-based identity*: acknowledging the assets of diversity as a starting point for increasing social capital and social cohesion, leading to shared expectations as regards community's fate and future;

- *Innovative transformative learning*: the ability to experiment, learn, develop new practices and reconfigure resources in order to adapt to changing environmental demands;
- *Connectedness*: the ability to connect with others inside and outside the community in order to exchange information and experiences and to draw on resources beyond community borders.

This framework is proposed as a tool to assess how ICC contributes to community resilience. In the table below, the characteristics of ICC presented in Sect. 7.1 (rows) are mapped against the attributes of community resilience as discussed above (columns).

	Community resources						Community functions		
	Economic resources	Social-cultural resources	Human resources	Ecological resources	Infrastructural resources	Governance resources	Community identity	Innovative learning	Connectedness
Through the life course provision of care			•						
Focus on social determinants of health	•	•		•	•				
Co-development of services			•			•		•	
Investment in social cohesion		•	•				•	•	•
Greater integration between forms of care					•			•	•
Person goal-oriented			•						
Place-based governance	•	•	•	•	•		•		
Accountability for territorially defined population		•	•				•		
Enabling public services						•		•	
Focus on underserved groups		•	•						•
Whole system innovation			•			•		•	

Table: Mapping of features of ICC (as discussed in Sect. 7.1) against attributes of resilience-inducing community resources and functions. A dot denotes ‘contributes to'

The pattern that emerges from this assessment is the following:

- Features of ICC—particularly linked to its capacity to deliver health and care, to address determinants of health and its place-oriented character—contribute particularly to community resources.
- A complementary set of features—associated to the integrated, co-development, whole system character of the approach—strengthen community functions.
- A third group of ICC elements feeds into both as they are geared towards reinforcing social cohesion and supporting vulnerable and underserved groups in the community.

This confirms that there is a persuasive case to be made for Integrated Community Care as an important shaper of community resilience, an increasingly important requirement as our global society is faced with the urgent need to engage with multiple transitions—demographic, technological, biological, institutional and social—to find a new, sustainable equilibrium (Rayner and Lang 2012).

7.5 Conclusion

To strengthen communities and systems so that they are more resilient and better able to cope, respond and adapt to new challenges, a fundamental shift is required in the way we value and understand the role of people and communities as an integral part of the system.

ICC is about so much more than traditional ‘integrated health and care’ provision. At its heart, it is about the kind of society we want to create. It emphasises kindness, empathy, compassion and solidarity. It starts by listening and gaining a deep understanding of specific and local contexts, asking what a person’s and community’s strengths are, instead of focusing on what the problem is. ICC is a resilience-oriented approach that seeks to strengthen communities by tackling the determinants of health. It assumes accountability towards a territorially defined population, creating new cross-sectoral and interdisciplinary partnerships and taking a population health approach with a focus on prevention. In ICC, a new power dynamic and relationship is forged: people and communities co-design and co-produce health and care; the role of government is that of an equaliser (ensuring resources are allocated to those most in need) and investor in public services; and the traditional boundaries between informal and formal care are blurred.

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Path Dependence and Integrated Care

8

Carolin Auschra and Jörg Sydow

8.1 Introduction

Over the last decades, the integration of health care has become a political goal in many industrialized countries around the world (Amelung et al. 2017; Minkman 2017; World Health Organization 2015, 2016). For this chapter, we understand *integrated care* as being "the management and delivery of health services such that people receive … health promotion, disease prevention, diagnosis, treatment, disease-management, rehabilitation and palliative care services, through the different levels and sites of care within the health system, and according to their needs throughout the life course" (World Health Organization 2015, p. 7). In face of the interrelatedness of these services, integrated care not only requires a specific—integrative—practice of organizing health care, it also needs to become a fundamental design principle of entire health systems (Goodwin 2013). Because of the complexities involved, it comes as little surprise that the implementation of integrated care is often difficult (Raus et al. 2020), faces several barriers (Auschra 2018; Minkman 2017) and, in consequence, is slow or even failing to work (Amelung et al. 2012; Brandhorst et al. 2017).

The change of complex systems, even of important parts of such systems, is often difficult because such systems have become inert or persistent—technologically, institutionally and/or organizationally. One often overlooked but important reason for the slow or entirely lacking implementation of integrated care is the path dependence of surrounding structures, in particular the national health system with its more often than not highly institutionalized practices of healthcare provision.

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Path dependence is not only the hyper-stable state of a system, it is also a process property pointing to the mainly unintended consequences of intentional action and the working of at least one self-reinforcing mechanism based on positive feedback or, as economists would call it, "increasing returns" (Arthur 1994; David 1985; Pierson 2000; Sydow et al. 2009). What makes path dependence puzzling for practitioners is the fact that to some extent, for instance in the wake of positive coordination and complementarity effects, a system has to become path dependent to be efficient. But once it has reached this stable—efficient—state, it may already have lost its adaptive capacity, which makes change difficult if not impossible. The change towards integrated care is likely to represent such a case, though research that seriously made use of path dependence theory in this setting is rare. What is more, the practice of integrated care can, once implemented, become path dependent in itself. That is even likely, because such a practice is based on guidelines and routines that are well known to be a potential source of organizational path dependence. This aspect also needs to be considered.

In this chapter, we provide an overview of the theoretical concept of path dependence and apply it to the difficult but important transformation of health systems towards (more) integrated care. First, we introduce this concept and relate it to other sources of persistence and inertia. We then present different dimensions of path dependence that can affect organizations, interorganizational arrangements, institutions and technologies. We also illustrate self-reinforcing mechanisms that can cause path dependencies in health care. Subsequently, we review previous literature on path dependence in relation to integrated care. Finally, we reflect on possible ways of breaking path dependencies in order to facilitate the integration of care and discuss the dangers and advantages of manifested paths.

8.2 Understanding Path Dependence

Path dependence theory was originally developed to understand the adoption and diffusion of technologies that could be more efficient such as, most prominently, the QWERTY keyboard (Arthur 1994; David 1985). The theory of path dependence also helps to explain the persistence of institutions, e.g. in the case of transforming Eastern European countries into market economies (North 1990). More recently, the theory has been applied to the organizational sphere (Sydow et al. 2009). In all three domains—technology, institution and organization—the notion of a path has acquired theoretical meaning that goes beyond the simple statement that history matters. *Path dependence* is defined "as a rigidified, potentially inefficient action pattern built up by the unintended consequences of former decisions and positive feedback processes" (Sydow et al. 2009, p. 696). Positive feedback refers to accumulating effects that, although initially triggered by an action or event, govern a process that, at an increasing rate, runs out of the agents' control. Today, everybody uses a QWERTY keyboard, even on hand-held devices, for it represents a technological path that will probably be with us until the interfaces themselves have been replaced, for example, by voice recognition.

Path dependence theory is a process theory that distinguishes *three phases* (see Fig. 8.1): (I) a preformation phase in which actions and events unfold, influenced by present and—via imprinting (Marquis and Tilcsik 2013)—past contexts; (II) a formation phase that begins when one or more of these actions/events triggers at least one self-reinforcing mechanism; and (III) a lock-in phase in which the action pattern may still be economically efficient but becomes strategically inefficient because it proves to be a barrier to change when change may be needed. In Phase I, after a critical juncture, an action or event starts triggering off a self-reinforcing process characterized by positive feedback. In Phase II, this self-reinforcing process rigidifies the action pattern so that it becomes increasingly difficult to deviate from the developing path. In Phase III, the action pattern is finally locked in. In the institutional and organizational realm, the theory of path dependence allows for on-path change (see corridor in Fig. 8.1); it allows, for example, for changes in health reimbursement regulations while keeping up the separation of outpatient and inpatient care that is the characteristic of the German healthcare system. For practitioners, managers and policy-makers alike, path dependence creates a puzzling situation. First, in Phase I where choices are still possible, the question of how to break a path does not arise. Since path dependence dynamics are difficult to detect, it is likely that the question will be asked only when it has already become too late: when it becomes difficult, if not impossible, in Phase II and Phase III to escape the dynamics and finally the lock-in.

Path dependence shows properties that can be easily distinguished from other concepts indicating inertia or persistence of a technological, institutional or organizational system. Among these other concepts, structural inertia and institutional

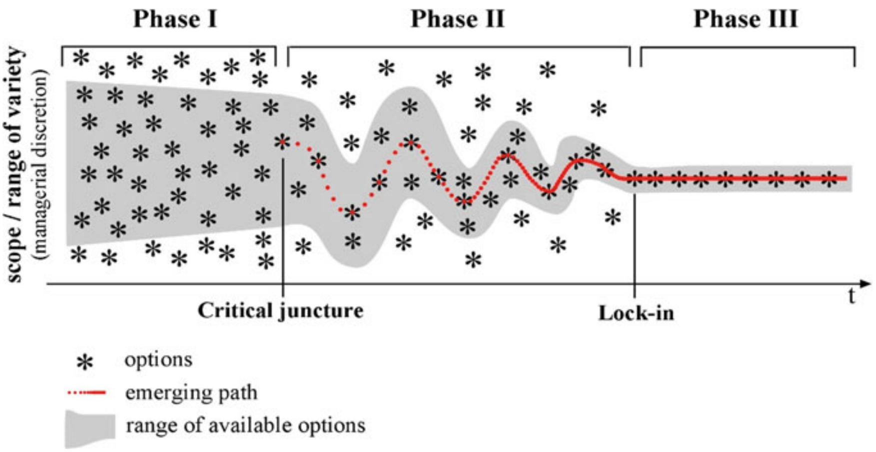

Fig. 8.1 Constitution of an organizational path (Sydow et al. 2009: 692; reproduced with the permission from the Academy of Management)

persistence appear to be the most prominent ones (cf. Sydow et al. 2009: 696–698). However, because of its dynamics, escalating commitment is another interesting concept to compare with path dependence. *Structural inertia*, not unlike path dependence, results from routinized actions. Like path dependencies, inertia is ambivalent. On the one hand, it is problematic as it makes organizational or institutional change difficult. On the other hand, inertia reflects routinization and efficiency and, thereby, contributes to the legitimacy of an organization or institution. In contrast to path dependence, however, this concept does not emphasize mechanisms that perpetuate or escalate a certain state. This aspect makes it similar with *institutional persistence,* although the latter concept stems from another (institutional, rather than evolutionary) stream of theorizing. *Escalating commitment*, by contrast, does not signal stability but a positive feedback process: the more managers have committed energy and resources to a certain strategy or practice, the more they are likely to spend, even if they realize the inadequacy of their action. In contrast to assumptions of mainstream economics, such sunk costs trigger prolong expenditures and matter in rational decision-making processes as they influence managers' emotions and adherence to social expectations. In sharp contrast to path dependence, however, escalating commitment departs from a decision considered suboptimal, while path dependence research can demonstrate that even initially promising developments only show their downsides in the course of time. In the latter case, neither process dynamics nor process outcomes are clear at the beginning.

Technologies, institutions and organizations can be subject not only to inertia, persistence and commitment but also to path dependence on different system levels of analysis: from a team as the smallest system unit to the macro-level of a whole society. Path dependence is a concept that provokes the analyst to take multiple levels of stability sources into consideration. While for integrated health care, the meso-levels of an organization, an interorganizational collaboration and the respective industry or field may be the most important ones, more micro and more macro-levels may well have to be considered to explain how path dependence came about, making the realization of more integrated health care difficult, if not impossible. In this chapter, we will focus on how path dependence arises on the meso-levels, which should be of major concern in studies of health care. Armed with respective insights, we will subsequently give advice on how to overcome technological, institutional and organizational path dependence in order to integrate care.

8.3 Self-Reinforcing Mechanisms Leading to Path Dependencies in Health Care

Healthcare systems are well known for being highly regulated. Nevertheless, it is naïve to believe that they can easily be changed via de- or re-regulation, i.e. via political policy. Many failed but seldom studied political initiatives to improve health systems in industrialized countries, not least in order to integrate care, demonstrate this effectively. From a path dependence perspective, this hyper-stability, if not lock-in, of most health systems is essentially caused by self-reinforcing mechanisms based on positive feedback. As in the field of technology (Arthur 1994), the most likely drivers of such positive feedbacks that amount to "vicious circles" (Masuch 1985) are (1) coordination effects, (2) complementarity effects, (3) learning effects and (4) adaptive expectation effects (cf. Sydow et al. 2009).

In health systems, *coordination effects* are likely to arise once rules and regulations have been implemented, i.e. are followed by actors. These actors, policy-makers as well as healthcare managers and health professionals alike are likely to benefit from following standards and routines that accompany those rules and regulations regarding, for instance, existing reimbursement systems. The more appropriate standards and suitable routines have been adopted, the more efficiently is the system coordinated. It is only when the context of coordination changes, e.g. if health insurers and/or clients require a better integration of health care that such coordination effects may become problematic as they keep the system on course. While major coordination effects are likely to develop on the meso-levels (organizational, interorganizational or field), more micro as well as more macro-sources of path dependence may add to these dynamics. Consider, for instance, coordination effects between teams in one organization.

A similar argument can be made with regard to *complementarity effects*. They arise from an optimal fit of the parts of a system. However, fit does not necessarily mean an optimal solution as shown by the QWERTY example. The more smoothly, for example, the collaboration between in and outpatient care (important sectoral boundaries in the German health system) functions and the better the actors with their distinct interests and capabilities fit together, the more readily a collaborative, boundary-crossing path will emerge. Once realized, changes required to break this collaborative path will become difficult. According to the theory of path dependence, after having set up a nicely fitted system that produces a lot of complementarity effects only on-path changes in this institutional or organizational realm would be likely.

Learning effects also stabilize a system. These effects arise in particular in the context of routinization. It becomes increasingly attractive to use routines, once they have been adopted and adapted for better coordination, and to stick to them in face of (single loop) learning. In health care, most policy implementations that draw on scientific evaluation aim at improving routines along existing paths instead of taking fundamental, i.e. path-breaking change into account. For instance, most reforms initiated in order to introduce integrated care into the German system focused on setting up projects within the existing system as well as on small adaptions of the existing budgetary system. However, they did not touch the existing divide between in and outpatient care in a fundamental way.

Finally, *adaptive expectations* arise once agents expect a standard to be widely adopted. In this case, however, it becomes increasingly difficult to deviate from this expected standard. So, while in processes of technological, institutional and organizational path dependence obviously the past—and its experiences—matters, the future—and its expectations—plays an important role as well. In healthcare settings, this refers, for instance, to the expectation that digitalization will not change dominant forms of organizing and expected accountabilities across professions, an expectation that may prove to be a hindrance to the integration of care.

Until now, research on the transformation of respective practice within established health systems of industrialized countries towards integrated care has not seriously been concerned with such self-reinforcing mechanisms, neither theoretically nor empirically. Even advocates of applying path dependence theory to health care (e.g. Trouvé et al. 2010; Wilsford 1994, 2010; in all cases with regard to path dependence of institutions) do not really investigate the working of these mechanisms, particularly on the decisive meso-level of analysis. Also, previous research has not been able to detect actions or events on this level which, at critical junctures, have triggered such difficulty to control dynamics. On the one hand, this is quite surprising as health systems are especially prone to technological, institutional and organizational path dependencies (Wilsford 1994, 2010). On the other hand, this is understandable, as such complex systems are not only idiosyncratic (and findings thus difficult to generalize) but particularly difficult to study. Hence, it comes as no surprise that, to the best of our knowledge and in sharp contrast to the field of management and organization (e.g. Brunninge and Melander 2016), not a single study of health systems has considered more than one level of analysis (e.g. health system and organization) when elaborating on path dependencies.

While pointing rightly to some theoretical weaknesses (e.g. the underspecified role of agency and temporality), some critiques of the theory of path dependence work with false assumptions such as linearity (i.e. neglecting potential feedback effects and tensions) or the complete neglect of the role of agents and their options for action (e.g. Brown 2010). The more important challenge, though, lies currently less in the theoretical advancement than in the proper application of this theory, which demands a lot from empirical researchers (Sydow et al. 2020). One example is the detection of a critical juncture that marks the transition from Phase I to Phase II. What this juncture is, is still debated; not only in the case of the emergence of the National Health System (NHS) in Britain (Ross 2007), but even in the classic case of QWERTY (e.g. Kay 2013).

Nevertheless, there are a few studies, mainly authored by political scientists, which make serious use of the path dependence theory. They provide some insights into why the still by and large state-financed, state-owned and state-managed unified NHS is so persistent, even though over time health care in the UK has in reality developed into a more hybrid system that balances hierarchy with network and market modes of governance. Such arguments are particularly true for Greener (2006), who tries to advance path dependence theory by anchoring it a realist (rather than constructivist) understanding of the world. He demonstrates the potential of this (theoretically enriched) conception by studying the path-dependent development of the NHS from its inception to the managerial and market-oriented reforms in the 2000s (see also Bevan and Robinson 2005). The same is true for Ross (2007) who, more specifically, even tries to show the effects of increasing returns in the development of the NHS. Nevertheless, this latter researcher critically concludes her study by stating that the changes of the system “cannot be discounted as non-significant, on-path adaptations” (p. 605) and deduces, with regard to the theoretical explanation, that “policy development is driven by a far more complex and endogenous set of forces than can be captured by a parsimonious model of returns” (p. 592). However, one may consider this conclusion to be premature and object that a focus on the “policy makers’ calculation of returns” (p. 601) is all too narrow to be able to explain rather complex structuration processes; processes in which “knowledgeable agents” (who nevertheless do not know everything) enact, reproduce and eventually transform structures in a recursive process in which an economic calculus may or may not matter, but in which agency and structure always interact in subtle ways (Giddens 1984).

Among the—admittedly so far few—studies, that take path dependence theory seriously and inquire into stability and change within health systems, are studies by Stache (2012), Reuter (2012) and Bach (2020). The first author investigates a (rather rare) case of path-breaking organizational change in acute lymphoblastic leukaemia (ALL) care in an otherwise strongly path-dependent Russian health system. Stache (2012) not only reconstructs the working of self-reinforcing mechanisms that make it so hard to change the health system, but also shows a successful alternative and its development over time in a subfield of the national health system. Here, the path of strongly centralized care was broken by new, cooperative forms of research and treatment. Reuter (2012) focuses on the change resistance of physicians to prescription practices in the field of diabetes treatment. Bach (2020) tries to understand whether and how the overall path-dependent development of the German health system can be broken by creating health networks that enable collaboration between previously siloed organizations. Finally, we see much promise in focusing on stability and change on a more micro, organizational level of analysis. An exemplary study in this respect is authored by Singh and colleagues (2015), who study micro-level (telehealth) innovations to understand better how public health organizations engage in the deliberate constitution of a path. In their empirical study, set in the state of Georgia, USA, these authors identify technological innovation paths and analyse episodes during with organizations respond to internal and external innovation triggers. They expect—and find—trajectories of technological innovation paths that are “shaped through reinforcing episodes that progressively reduce available innovation options and transforming episodes that make additional innovation options actionable” (p. 647). With their study of two decades of telehealth innovation in a rural area of the state, Singh and colleagues contribute to an understanding of path dependence that highlights the role of agents to achieve both stability and change, modifying the theorizing of path dependence without neglecting the systematic power of path-dependent processes (see also Garud et al. 2010).

In sum, beyond the general assumption that health systems are prone to technological, institutional and organizational path dependencies, we were able to identify only very few studies that seriously elaborate on path dependencies that hinder the integration of care. This, in turn, implies that there are many research opportunities enabling the exploration of critical junctures and self-reinforcing mechanisms that prevent the diffusion of integrated care. In addition, potential path dependencies of successfully implemented integrated care models also require future research.

8.4 Overcoming Path Dependencies in Order to Integrate Care

Practitioners, not least policy-makers and managers, in the field of health care, are typically less interested in understanding the emergence of technological, institutional and/or organizational path dependence than in the question of how to deviate from or even break the path. This is particularly true when it turns out that the path-dependent character of a health system hinders the implementation of a new practice such as integrated care. Nevertheless, it is important first to recognize the path dependence of a technology, institution or organization in order to understand better to what extent and why changing the direction of a path is so difficult, if not impossible. Only then can policy-makers, healthcare managers and health professionals start to think about how to overcome path dependencies in order to provide better integrated care to patients, even if the degree of integration may be less comprehensive than the definition cited in the introduction to this chapter suggests.

However, even just recognizing path dependencies can be difficult, as they overlap with other sources of resistance to change. The dilemma is that, in the preformation phase at the beginning of the process (see again Fig. 8.1), too many options seem possible. Once an action or event has triggered one or more self-reinforcing mechanisms at a critical juncture, it may still be difficult to recognize that a certain path manifests that may lead to a subsequent lock-in. When the path-dependent property of the process becomes more obvious, it may already be too late for health managers and health politicians to intervene effectively into the process. What is more, even if the process is monitored continuously, which calls for a particular organizational capability (cf. Schreyögg and Kliesch-Eberl 2007), path dependencies are difficult to detect because they provide advantages at the beginning of the path formation. Furthermore, it remains unclear when such advantages—in the form of increasing returns, e.g. or positive feedback more generally—turn into disadvantages.

Relevant questions leading to a better understanding of when and how technological, institutional and/or organizational paths can be broken still need to be answered by future research. In face of the societal importance of health care, on the one hand, and the difficulties to transform respective systems towards (improved) integration, on the other, it would be particularly important to remedy the situation in this field. The most pressing of such questions on the meso-level of analysis are as follows: How can the way one or more of these mechanisms works be undermined or even turned around? What kind of interventions may be promising in this regard? Early on, Schreyögg and colleagues (2003) proposed four possible approaches: (1) a discursive approach that aims at spreading insights, for instance to reach consensus for changing existing healthcare practices; (2) a behavioural approach that puts less emphasis on cognitions than on emotions, for instance to overplay personal short-term disadvantages; (3) a systemic approach that focuses more on the social structures than on the actor, for instance with the help of regulatory changes; and (4) a resource-based approach that reallocates resources and, thereby, power which in health care may also require legal action.

However, the following questions, too, regarding such potential avenues to break path dependencies are yet to be answered: What works best under which circumstances? Is it even necessary to combine these strategies of path breaking? How can an alternative path be created that, at least in the course of time, attracts more actors with more resources? What is the role of clarifying the (supposed) superiority of the alternative technology, institution or organization in this process? While only sceptics believe that technological, institutional and organizational paths can only be broken in the light of an external shock (Arthur 1994) such as COVID-19, we can learn from the few studies in the field of health care which make serious use of the theory of organizational path dependence (e.g. Bach 2020; Reuter 2012; Stache 2012) that well-organized collective agency may create at least an alternative path that competes with the established path if, and only when, it gains the necessary momentum.

In the light of this argument, many programmes that have failed to introduce better integrated care may be judged as having simply not been organized well enough to overcome existing path dependencies in a process of competing alternatives. However, we warn against attributing any failure to implement integrated care too readily to existing path dependencies and other external barriers. As Goodwin and colleagues (2017) state, the “reflection on how many integrated care programmes are immature, often ill-defined, and lacking in focus” (p. 21) can also help to support the spread of integrated care, despite the inert environment.

8.5 Conclusion

Using the theory of path dependence, this chapter has increased our understanding of the hyper-stability of certain practices in health care as well as of the whole health system. Technological, institutional and organizational path dependences are based on self-reinforcing mechanisms that create such stability, making deviations from existing paths extremely difficult. If coordination and complementarity or learning and adaptive expectation effects are at work, transformation towards more integrated care will be difficult, if not impossible. Policy-makers, health professionals and healthcare managers should be aware of these difficulties when aiming for technological, institutional or organizational change.

Much to our surprise, there is little in the way of research that makes serious use of this theory in healthcare contexts and aims to explore strategies for overcoming path dependence. Research focusing on the introduction of integrated care from a path dependence perspective, not to mention the study of path dependencies of any integrated care model, is almost completely lacking. While we encourage researchers to take both issues into account, we also need to acknowledge that empirical research on not only technological and institutional but also organizational path dependencies is highly demanding, as it requires not only longitudinal analysis (for instance, with the help of historical data) but also multi-level research approaches (see Sydow et al. 2012 for a very different context). The studies at hand that make serious use of the theory of organizational path dependence nevertheless show that such research is possible.

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9 Values and Culture for Integrated Care: Different Ways of Seeing, Being, Knowing and Doing

Robin Miller and Marisa de Andrade

9.1 Introduction

Culture and values are now recognised as an essential dynamic in the delivery of high-quality health and care services (e.g. Braithwaite et al. 2017; Mannion and Davis 2018). Culture, or 'the way we do things round here', has been connected to the quality and safety of such services both positively and negatively. An enabling and learning culture is seen to promote opportunities for identifying, reflecting and acting on any concerns in organisations, whilst a controlling and blaming culture is seen to stifle such concerns being raised and responded to appropriately (Willis et al. 2016), In turn values, both those expressed by an organisation within its mission and strategy and those which practically underpin the everyday decisions made by teams are a key component of institutional culture (Carroll and Quijada 2004). Personal values based on professional standards and individual beliefs further influence the choices and priorities of practitioners (Woodbridge and Fulford 2004; Mangan et al. 2015). Any organisation seeking to achieve effective change must take account of these multi-layered and multi-dimensional factors (Branson 2008). Integrated care initiatives, which commonly bring together professionals, practitioners and services from established silos, add yet more complexity. The clashes in values and culture which can emerge through their new arrangements can be a powerful obstacle as the parties involved are exposed to alternative ways of seeing and interpreting the world (Cameron 2011; Miller et al. 2016).

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These dynamics are commonly reflected in research regarding integration within health and care services (Box 1). This reflects study outside these sectors, where organisational culture and an alignment of personal and personal values have been recognised as key enablers of positive change management for many decades (e.g. Cummings and Worley 2014). 'Values alignment … could well be the bedrock, the foundation, upon which all truly successful organisational change depends' (Branson 2008, p. 392).

In this chapter, we will begin with a consideration of what is meant by 'culture' and 'values' and how they have been connected in relation to the field of integration. We will then focus on two key approaches to developing them positively—teamwork and inter-professional learning—whilst critically reflecting on some of the challenges. Creative-relational inquiry is then introduced as an alternative framework to exploring cultures and values. Finally, we conclude with a reflection on what this means for those leading and working in integrated settings.

Box 1: Examples of Culture and Values within Integrated Care Research

Petch (2014): Much of the achievement of integrated care and support is dependent on successful culture change. Both professions and organisations are likely to have developed particular cultures which help to shape their identity and foster allegiance (p. 8).

Cameron et al. (2012): By its very nature, joint working brings together professionals with different philosophies and values as well as divergent professional cultures. Not surprisingly, these differences can act as barriers to effective joint working (p. 13).

De Bruin et al. (2018): Differences in organisational cultures leading to different interests, priorities, interpretations, and lack of connection between organisations made it difficult to align the different organisations' ways of working (p. 49).

Miller and Stein (2020): Managing culture (and culture change) was unanimously considered a vital and separate skill, which many managers tend to ignore in the beginning of their [integrated care] endeavours, to often detrimental effect (p. 6).

9.2 What is Meant by Culture?

Despite organisational culture being a regular feature of health, social care and integrated care policy and practice guidance, there remains considerable debate about what is meant by this concept. The definition by Schneider and Barbera (2014) encapsulates many of the elements that are regularly associated with contemporary interpretations—'the values and beliefs that characterize organizations, as transmitted by socialization processes that newcomers have, the decisions made by management, and the stories and myths people tell and retell about their organizations' (p. 10). This reflects the view that staff members are inducted into the culture of the organisation through socialisation with others. And that culture is developed, conveyed and reinforced by influences as variable as the concrete actions taken by key players and the informal anecdotes and personal reflections of individuals and teams. Bissell (2012, p. 82) provides a simpler account—'deeply held beliefs about success'—which underlines the sense that culture is something that can be resistant to change through the strength of attachment, and that it can relate to what ends are aspired to (i.e. *why we do what we do*) as well as the processes through which these can be achieved (i.e. *the way we do things around here*).

One of the most commonly deployed models of organisational culture in current use is that of Schein (2010)—'a pattern of shared basic assumptions learned by a group as it solved its problems of external adaptation and internal integration' (p. 18). This again picks up on culture's deeply rooted nature. It provides the additional dimension of culture as being the process through which organisations respond to the challenges they face through collaboration between the individuals and functions within them. Schein proposes that culture can be seen to be operating in three domains—*values* (ideologies or charters), *artefacts* (physical manifestations such as dress code, company reports and environment) and *assumptions* (thought processes, feelings and behaviour). However, Meyerson and Martin (1987) contest the notion that organisations have a single culture, suggesting that it is more common for them to have *differentiation* (separate sub-cultures within departments that can be in a state of harmony, conflict or ambivalence and which combine to compose the organisation) or *fragmentation* (in which there are no whole organisation or fixed sub-cultures, but rather varying and fluid relationships between individuals and groups).

Sullivan and Williams (2012) highlight the importance of physical artefacts (or 'objects') to understanding the cultural dynamics within an integrated care initiative. They recall a comment made by one staff member in such an initiative on the symbolism of shared or separate refreshment arrangements between professional groups—with different kettles being seen to reflect a failure to achieve a common and shared identity. Gale et al. (2014) have developed a helpful framework which combines theoretical insights with the practice experience of those responsible for health and care redesign. This is suggests that the three domains identified by Schein can be considered as working on three levels—that of 'patients' (i.e. those accessing a service and their families and carers), 'people' (i.e. those working, managing and leading services), and 'place' (the physical environment and locality in which a service is based) (Table 9.1). Braithwaite et al. (2017) reviewed evidence of the extent to which organisational and workplace cultures are related to outcomes for individuals, and found that positive cultures result in better outcomes.

Table 9.1 Observable artefacts commonly encountered in integrated care initiatives across health and care (based on Miller et al. 2016)

Domain	Example of common artefacts within integrated care initiatives
Individuals and Families	*Terminology*: along with patients, service users, customers or clients are terms commonly used to denote those who are receiving support. Each of these terms highlights different interpretations of their relationship with the service provider *Documentation*: are assessments and care plans in a format that encourages service recipients to access and engage with this information? *Care co-ordination*: do processes expect decisions to be made with full participation of those receiving services and are adjustments made for those with alternative communication styles?
People engaged in delivering service	*Staff dress*: uniforms commonly worn by health staff which differentiate between them and non-health staff, and between different health disciplines *Terms and Conditions*: staff may be entitled to different holidays or opportunities for learning and development *Payment*: salary differentials lead to distinct variations in holidays, cars and housing
Place in which services are delivered	*Locations:* are people required to come to a discrete building or are they supported in their own homes? *Standard of building*: is the building in a good state of repair and/or specifically designed for the needs of the service in question? *Facilities for staff*: are there different expectations on office and desk arrangements, and facilities for refreshments between teams and professionals?

A good example of the impact of culture within an integrated organisation is that of ‘Care Trusts’. The option of developing a Care Trust as an integrated health and social care organisation in England was announced following long-standing concerns about the ability of the statutory bodies responsible for health and social care to work together. It was envisaged by central government that Care Trusts would become the norm for the planning and delivery of community services for older people, and they were also developed to deliver services for people with mental health problems and/or learning disabilities. Care Trusts were therefore primarily an example of structural integration, but (dependent on the individual trust) also sought to develop ‘linkage’, ‘coordination’, and ‘networks’ with other local health and social care organisations (see Miller et al. 2011 for overview of care trust policy and practices).

The initial policy intentions did not explicitly mention ‘culture’ as this was before the term’s rise to prominence. However, it is clear that developing a particular approach to the ‘way we do things around here’ and the subsequent impact on patients, service users and their families was at the forefront of policy-makers’ aspirations:

> They will enable staff to shape a new organisation around patient and user needs and provide a system that supports them in doing their jobs and rewards them for working together. For users, carers and patients, this will mean greater potential for tailored and integrated care, greater accessibility, and one stop shops for services that used to entail repeated conversations and a procession of different faces at times of illness, stress and vulnerability.' (DH 2002)

Evaluations of some Care Trusts did suggest that positive impacts had been achieved, although the extent to which these could be attributed to the development of an integrated organisation rather than other factors was not established (Thistlethwaite 2011). Senior managers in other Care Trusts suggested that using such a structural approach to achieving integration could cause as many problems as it solved and were less convinced that it provided an effective and efficient means to deliver the expected outcomes (Miller et al. 2011). In relation to cultural aspects in particular, it would appear that the ways of working, beliefs regarding the potential of partnerships and the likely response of key actors were central to their success even before the organisations were launched. In areas in which there was an existing inter-agency culture of joint working, care trusts appear to have had a positive impact as the next step in a shared journey. However, in areas where such a culture was not present and care trusts were being imposed as a means to force collaboration, there was considerable tension and mistrust which delayed or in some cases derailed success.

Once established, there were numerous reports of the importance of culture within these integrated care organisations acting as an enabler or as a barrier (Dickinson et al. 2007). Barriers included the 'clash' in cultures between health and social care staff, failure to address intransigent cultures within teams and professions and thereby facilitate innovations, and the culture within partner agencies viewing the new organisations as something separate. There were also examples of the opposite experience, such as development of a shared culture, new ways of working, and successful partnerships being achieved. Key factors that contributed to more positive engagement with culture were a transformational leadership style with consistency in vision over time; the development of shared artefacts through branding, mission statements and promotional materials emphasising a shared identity, incentive structures which rewarded collaborative practice and were supported by relevant development, and a focus not only on improving relationships between different professionals and practitioners but also with local patients, service users and communities (Miller et al. 2011). A common reflection of senior leaders within care trusts was that they should have had a greater focus on cultural issues and if repeating such an undertaking would put this at the forefront of the process.

9.3 What is Meant by Values?

Zonneveld et al. (2018) highlight the difference between 'value' and 'values' in the field of integrated care. They define 'values' as 'desirable goals that motivate action', and 'value' as the 'degree of success shown by a provider in meeting the needs of clients, relative to costs' (p. 2). Woodbridge and Fulford (2004) suggest that amongst healthcare professionals 'values are often synonymous with ethics' (p. 14). They highlight though that the term is also commonly applied to 'wishes, desires, needs' (i.e. quality of life) and 'self fulfilment'. In social care, the difference between values, ethics and practice principles has been defined as follows (BASW 2012):

Values	What people commonly believe is worthy or valuable in social care practice.
Ethical Principles	General statements about the attitudes, rights and duties that should underpin social care. For example, to promote inclusion in society, to co-produce solutions, to protect those who are vulnerable, etc.
Practice principles	General statements about how service users and their families can be supported to achieve the desired outcomes. For example, 'putting the person at the centre of any decisions', 'communicating clearly the options available', and 'treating people with respect'.

In this framing, 'values' can be summarised as 'what we see as important', with 'principles' providing guidance about how these values can be 'translated into practice'. Values are not always well defined, which means that people may not fully understand what they or others mean by them. This results in individuals, organisations, and policy-makers having different views about what the key values are, how they interpret these, and how they would implement the values in practice. For example, *independence* could be interpreted as someone not being dependent on public sector funding, living outside of an institutional setting and/or being able to make decisions over their own life without interference or control by someone else. *Empowerment* may mean being able to choose how to deploy the public service resources to which someone is entitled, being involved in the planning or management of services, or being enabled to be more assertive over one's overall rights. Through a critical lens, *empowerment* may be perceived as a slippery construct and evoke a sense of tokenism—a box-ticking exercise to meet organisational and political outcomes and targets (de Andrade 2016). Whilst some values and principles will be similar over the decades, others and/or their definitions will be added, omitted or amended as professional and societal values and insights change. Finally, there may be a clash between the values that underpin the different duties and responsibilities that professionals and practitioners are expected to undertake. For example, there may be a clash between responsibilities to 'control' peoples' behaviour in order to keep them safe versus the responsibility to promote autonomy and independence.

Different professions have their own 'ethical codes' which set out a 'framework of values' that individuals within this profession are expected to follow (Woodbridge and Fulford 2004). Whilst there are many areas of similarity (e.g. respect for individuals, do no harm), there is also the potential for differing emphasis which can lead to some tension within inter-professional settings. For example, Cameron et al. (2011) highlight that 'the emphasis placed on professional specific knowledge and socialisation shapes the values and identities of the different professions, ultimately causing separation' (p. 55). People receiving support will also bring their own values which can lead to very different interpretations of what is important in a situation than that of professionals. In conceptual terms, this is described as those concerned having different 'value hierarchies' (Schwartz 2012).

'Values-based practice (VBP)' has been suggested as means to enable effective collaboration and decision making in situations in which alternative (and hence potentially conflicting) values are in play (Woodbridge and Fulford 2004). Perry et al. (2013) describe VBP as seeking to put people accessing services at the head of any decisions. It requires professionals and practitioners to be respectful of each other and patients' values rather than trying to impose their own beliefs, and this may necessitate a new set of skills relating to negotiation and facilitation. Heginbotham (2012) suggests that VBP can also move from the realm of direct work with patients and services to the planning and purchasing of services. The core principles of VBP that are commonly promoted include *communication*, *person-centredness* and *partnership* (Woodbridge and Fulford 2004). These correlate with those seen as important to enable collaborative practice: 'respect, trust, shared decision making, and partnerships.' (CIHC 2010, p. 8).

A systematic literature review completed by Zonneveld et al. (2018) has defined the core set of values which underpin integrated care. They identified 23 values which were a mixture of those relevant to 'generic' delivery of health and social care, and those that were more specific delivery of integrated care. In relation to the latter, seven values were mentioned most frequently: 'collaborative', 'co-ordinated', 'transparent', 'empowering', 'comprehensive', 'co-produced', and 'shared responsibility and accountability'. They note that these values are relevant to multiple levels of a health and care system and within different contexts (Zonneveld et al. 2018). For example, at a macro-level values can guide principles of governance and setting of overall objectives, at a meso-level values can set how professionals will work together within multi-agency teams, and at a micro-level values can shape the expectation of people and families regarding their involvement in the planning of their care.

9.4 How Do We Positively Develop Values and Cultures?

Culture and values are deeply embedded within individuals, organisations and ways of working. Seeking to alter these is therefore unlikely to be simple or quick. Furthermore, there is a strong interconnection between these two elements of organisational life—our values influence our culture, and our culture in turn shapes our values. There is relatively little formal research evidence of successful and sustained culture change in relation to specific aspects of practice. As a consequence, details of what interventions will work best in which circumstance are not well established (Parmelli et al. 2011). However, there are insights based on practice and more applied research on the key elements of change programmes that can positively shape and build upon cultures and values (see, e.g., Drumm 2012). Mandated mechanisms from senior management may alter behaviour in the short term if the sanctions and rewards are strong enough, but are unlikely to result in fundamental and resilient improvements in cultures. This requires the engagement of key stakeholders and must demonstrate potential impact on outcomes that are seen to matter (Box 2). Willis et al. (2016) outline key principles of undertaking successful culture change programmes based on a realist review: align vision and action; make incremental changes within a comprehensive transformation strategy; foster distributed leadership; promote staff engagement; create collaborative relationships; and, continuously assess and learn from change.

Box 2: The Realities of Culture Change

'Culture cannot easily be mandated—it develops over time as a successful adaptation to conditions, bringing desired results and defining desired norms and values. It is tempting for senior managers just to announce new behaviours or new values, but if they do not clearly specify what is desired and how it connects to meaningful consequences … they will not give people a chance to learn that the new behaviours work better than current practices. This process is much more likely to succeed if key individuals are involved in helping to design new ways of doing things that solve real problems and thereby engage their internal motivation. Once enough people realise that things work better, the values that lay behind the mandated new behaviours become more accepted, and new assumptions arise to support how these behaviours are "the way we do things around here"' (Carroll and Quijada 2004, pii. 17).

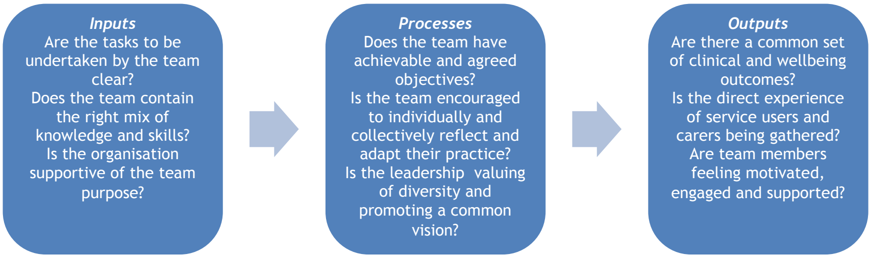
In this next section, we will turn to two interventions which can facilitate positive change in values and culture–*teamwork* and *inter-professional learning*. *Leadership*, which is covered in elsewhere in this compendium, is a third intervention central to such transformation of values and culture.

9.4.1 Teamwork

Teams are central to the delivery of most health and social care services, and there is increasing recognition of the importance of good teamwork to providing safe and quality services (see, e.g., Jelphs et al. 2016). This is also true for integrated services, with the strength of good inter-professional teamwork being evidenced in acute, primary and specialist settings. For example, Prades et al. (2015) report that cancer patients who receive care from a multidisciplinary team have increased survival rates and improved experience of receiving care. Franx et al. (2008) suggest that people with severe mental health problems have reduced rates of hospitalisation and better social wellbeing when supported by inter-professional community teams. It is important to remember that whilst individuals may have a core team to which they belong, they will often also be members of other teams, and that whilst some teams may be established on a long-term basis with a degree of continuity of staff and structure, others will be more short-term and transient in nature. This includes those that are formed around service users and their families and which may require collaboration between professionals and other practitioners that have never met or indeed worked together previously. Conversely, poor (or as it is sometimes described ‘pseudo’) teamwork can provide a difficult environment for people to perform their professional roles and can lead to poorer service user experience and outcomes (West and Lyubovnikova 2013).

Teams can also be highly influential in the shaping of ‘how things are done round here’ through the pressure that members can feel to conform to the norms and values that are adopted by a team. This can be a positive or negative influence on the quality of care that is provided, depending on the team culture that emerges. For example, it is common for inquiries of poor and abusive practice to highlight teams that had become very inward-looking and resistant to external challenge (Jelphs et al. 2016). It is therefore vital that teams are well run and focused on improving the lives of service users and carers and work in line with the expected values and vision. The Input-Process-Output model is based on the considerable evidence base regarding team working and depicts the core elements that need to be in place for a team to operate effectively (see Fig. 9.1).

Reeves et al. (2011) highlight that encouraging strong inter-professional team working requires both relational and processual elements to be addressed (Box 3). Relational interventions seek to promote trust and communication team members and include learning opportunities (see section below), opportunities to meet on a regular basis, and to spend time getting to know each other personally and



Inputs
Are the tasks to be undertaken by the team clear?
Does the team contain the right mix of knowledge and skills?
Is the organisation supportive of the team purpose?

Processes
Does the team have achievable and agreed objectives?
Is the team encouraged to individually and collectively reflect and adapt their practice?
Is the leadership valuing of diversity and promoting a common vision?

Outputs
Are there a common set of clinical and wellbeing outcomes?
Is the direct experience of service users and carers being gathered?
Are team members feeling motivated, engaged and supported?

Fig. 9.1 The input-process-output model of team effectiveness (based on West and Lyubovnikova 2013) professionally. Process intervention seek to better organise the work undertaken by a team and include care pathways detailing respective contributions, and ‘role-shifting’ to give greater flexibility in the tasks team members undertake. Jelphs et al. (2016) provide an overview of helpful tools and frameworks to support relational and process interventions. These include—the Belbin team inventory to facilitate reflection on team roles and behaviours; ‘de bono’s’ hat exercise to encourage creative thinking; the SBAR model of communication (*Situation: Background: Assessment: Recommendation*); and a ‘thinking environment’ approach to expressing the emotions that underlie team dynamics. Reflecting the IPO model, both Reeves et al. (2011) and Jelphs et al. (2016) highlight the importance of organisational context in the nurturing of teams. For those within integrated care, such context will be more complicated due to the involvement of multiple organisations and partnership governance arrangements.

Box 3: Enablers for Multi-disciplinary Team (MDT) Working (Miller 2018)

Clear purpose: MDTs need a defined role that requires team members to interact across professional and disciplinary boundaries.

Institutional support: The organisations which employ staff and (if in place) the partnership bodies overseeing this area of collaboration must provide support. This should include pubic endorsement (and so legitimacy), ensuring that the MDT has the necessary resources, and developing integrated performance systems.

Team leadership: Leaders should generally be facilitative in their approach to encourage different contributions, but be directional when necessary. An awareness of team dynamics and a willingness to challenge poor collaborative practice are important competences for a team leader.

Collaborative opportunities: Teams must have physical space and time for their members to engage across professions and disciplines. This enables them to improve communication and better understand each other’s roles and resources.

Person-centric: there is a danger that teams can become too inwardly focused on their own functioning. This can lead to people and their families feeling more, rather than less, excluded from discussions about their care.

Role diversity: There is no magic formula for MDTs. Rather, the mix of professions and practitioners must respond to the needs of the population concerned while still being small enough to allow members to know each other.

Evidence focused: Teams require timely and accurate evidence of their shared impact. Structured opportunities for teams to reflect on this evidence is one of the most impactful means to strengthen their work.

9.4.2 Inter-Professional Learning

Inter-professional learning occurs ‘when two or more professionals learn with, from and about each other to improve collaboration and the quality of care’ (CAIPE 2002). It can take place amongst under-graduate or post-graduate students, who are studying to become professionals (Gould et al. 2015) and within ongoing post-qualifying training and development (Reeves et al. 2013; Miller et al. 2019). Such learning involves interactive knowledge exchange between the professionals and can contribute to positively shifting organisational cultures and values through developing greater understanding of each other’s roles and responsibilities (Hammick et al. 2007; Thistlewaite 2012). This can help to then develop mutual respect over respective skills and knowledge which can help to overcome siloed ways of working (Frenk et al. 2010; Reeves et al. 2013; Thistlewaite 2012). Inter-professional learning could, for example, address the challenges posed by professional tribalism (Braithwaite et al. 2007) and encourage team working (Billingsley and Lang 2002). This reflects the theory of ‘intergroup contact hypothesis’ which suggests that contact between groups can counter prejudice (Allport 1954). For this to occur, within the learning process the groups must have equal status and have a shared visions of what should be achieved (Dovido et al. 2005; Pettigrew and Tropp 2011).

Inter-professional learning can also enhance a more comprehensive, holistic approach to care provision and understanding of the needs and abilities of individuals and their families (Billingsley and Lang 2002; Gould et al. 2015), and can therefore improve patient care and collaboration between professionals (McKimm and Brake 2010; Barwell et al. 2013; Reeves et al. 2013). Indeed, a variety of institutions including the World Health Organization, Canadian Inter-professional Health Collaborative and Inter-professional Education Collaborative Expert Panel advocate that inter-professional learning contributes to professionals working in a collaborative manner. This in turn contributes to improved patient care (WHO 2010; Reeves et al. 2013, IPEC 2016).

Inter-professional learning, conversely, may also be regarded as reductionist as it can be interpreted as devaluing the skills and knowledge of a certain profession (Billingsley and Lang 2002) thereby encouraging tribal behaviour as professionals strive to protect their own profession (Braithwaite et al. 2007). It could also be argued, however, that inter-professional learning takes into account the skills and knowledge specific to certain professions, whilst indicating the common ground of other skills and knowledge between professions (Billingsley and Lang 2002). The design and implementation process of the inter-professional learning is central to positive outcomes being achieved. Based on an evidence review and multi-agency workshops of practitioners, researchers and educators, Miller et al. (2019) outline seven enablers for successful inter-professional learning with qualifying and continuing professional development in primary care: involving those with lived experience patients in the design and delivery, providing a holistic focus, focussing on practical actions, deploying multi-modal learning formats and activities, including more than two professions, evaluating formative and summative aspects, and, encouraging team-based working.

Box 4: Example of Inter-Professional Learning in Practice (Miller et al. 2017)
As part of building future leadership capacity, NHS Education Scotland (NES) provided masterclasses on various topics varying from the Ladder of Inference (the thinking process that we go through, normally without realising it, to get from a fact to a decision or action) to wicked issues (complex problems that are challenging or impossible to resolve due to partial, contrary and changing conditions), and action learning sets. These masterclasses and action learning sets were multi-disciplinary and consisted of psychologists, doctors, allied health professionals managers, nurses and staff working in finance.

There was a focus on co-production—working with the assets that already exist within teams—to encourage mutual learning and create an understanding of the challenges people from different professions are facing through health and social care integration.

Participants found the experience invaluable as it gave them insight into the practical realities encountered by other professionals, but also helped them realise that people were experiencing similar challenges mainly related to dealing and communicating with others. The exchange cultivated respect and trust between staff and their respective professions.

The group also organised a collective community challenge at a secondary school, which involved preparing posters about various NHS jobs and corresponding study requirements and presenting these to schoolchildren. This helped raise awareness of career opportunities for schoolchildren while making NHS staff more aware of other roles within the organisation.

Digging a bit deeper, there is space to explore integrated care through an alternative lens that places the creative and relational at its heart. Whilst health policy and practice has been largely grounded in reductionist principles that privilege scientific evidence over lived experiences, there is now a shift towards acknowledging and integrating our different ways of seeing, being, knowing and doing. These are changeable aspects of the human experience that are intrinsically linked to culture and values within and between individuals, organisations, communities and nations. Through this framework, leaders and frontline staff working in integrated settings value creativity and their own (and others') 'situated, positioned, context-sensitive, personal, experience-near, and embodied' experiences'. They also connect these experiences to 'the political, the social, and the ethical' thereby problematising 'agency, autonomy, and representation'. This approach to understanding culture and values 'is dialogical and collaborative' and 'explicit and curious about the inquiry process itself. It could, for example, provide close-up explorations of the complex relationships in multi-disciplinary teams through the use of the arts and performance as a methodological approach (de Andrade et al. forthcoming) (Box 5).

Box 5: Example of Using A Creative-Relational, Arts-Informed Approach to Explore Culture and Health Inequalities

Multi-disciplinary professionals (including senior managers, health improvement managers, representatives from the voluntary sector and researchers) got together with marginalized community members to explore if/how they could co-produce a framework to evaluate the asset-based work they were doing in various settings. In one application of the Measuring Humanity framework, BME community members asked to engage through music as it was more culturally appropriate to collect 'data' in this way rather than completing a survey or questionnaire (there were language, literacy and trust barriers). We played instruments, sang, danced, laughed—all while learning about each other's differences and similarities. Through the process, we realised that trust needed to be rebuilt; we needed a greater understanding of cultural differences and more empathy; and more partnership working through creative community engagement. We also discovered how difficult it is to 'measure' aspects of the human experience linked to emotions, values and culture through positivist frameworks that exclude the creative-relational; and how much of what we experience at individual and organizational levels is linked to systemic issues (de Andrade and Angelova 2020).

9.5 Conclusion

Culture and values are deeply embedded within us all as individuals and as professionals, within our teams and networks, and within our organisations and partnerships. They are central to what we do and how we do it, and how we judge success. Culture and values directly influence our readiness to commit to new visions and practices. Where we see an alignment, then we are willing to accept uncertainty and disruption. If not, then we are likely to seek to maintain the status-quo through passive and active resistance. Engagement with culture and values is therefore not an optional activity for those seeking to achieve more integrated care. Teamwork can make a positive contribution through bringing together those from shared and different professional backgrounds to achieve a common aim and in doing so enhance individual and collective contributions to better care. Inter-professional learning can contribute through creating a mutual understanding of the other profession's values and ways of working as well as the competences of collaboration. Team and learning interventions are most impactful when introduced alongside each other, with the learning supporting inter-professional team working and teams providing a reflective environment to implement the new knowledge and skills developed through training and development. Together they can encourage the values and culture that will underpin the collaborative, holistic and potentially creative-relational approach and release the 'inner fire' central to achieving change and sustaining integrated care into the long term (Miller and Stein 2020).

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Part II
Management of Integrated Care

Positioning Integrated Care Governance: Key Issues and Core Components

10

Mirella Minkman, Nick Zonneveld, and Jay Shaw

10.1 Introduction

In the last decades, in integrated care practice and research, a lot of attention has been paid to implementation of improved care processes, alignment of tasks and roles, development of new professions and on the involvement and co-creation with users. All are important, but merely contribute to a piece of the puzzle of integrated care. Integrated care is in its end not about creating a multidisciplinary offer/supply of care, but it is about creating an integrative answer to the most important issues of people who are in need. Therefore, integrated care—or better integrated services that go beyond care—is not a set of interventions but a way of thinking, organizing, arranging and governing support for people with (often) multiple and complex needs.

In this chapter, we outline the importance and complexity of integrated care governance, by positioning it in the total spectrum of integrated care. In the field of policy and the organization and administration of health care, governance is a commonly used term and an important condition for delivering high-quality care and support. However, in integrated care settings, fundamental principles are present that ask for governance approaches that suit collaborative processes on mul-

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tiple scales around people with complex and diverse needs. Governance is not a separate dimension that 'also has to be fixed' in integrated care settings. It is not one-dimensional; it consists of multiple aspects; it is about leadership and accountability, but also about how decision making is supported and what guiding principles are underneath arrangements for steering and accountability. Integrated care governance also includes supervision both internal and external that tries to safeguard the intentions and fundamental principles of integrated care. Therefore, positioning integrated care governance and its core components first is important to understand the interrelatedness.

Dealing with these complexities is on the one hand daily practice in many countries; on the other hand, we do need more knowledge about what approaches work in what circumstances and why. Integrated care needs suitable governance to sustain and develop further in context. To support managers, policy makers and practitioners, we illustrate in this chapter possible approaches and action points, some examples which we like to share, and we raise new questions for future research and practice.

10.2 Positioning Integrated Care Governance

As also described by others like Goodwin (2019), integrated care partly is a black box. However, the state of knowledge has revealed parts of this box, by learning and researching integrated care approaches worldwide. Overall, four major key issues can be defined: (1) putting the person and their context at the center of a holistic approach; (2) organizing care and support around people; (3) re-arranging care and support systems on a suitable scale including digital solutions; (4) integrated care governance. This chapter is about the role of integrated care governance. Before elaborating more on governance in this context, it is important to see and understand the importance of the interrelatedness with the other three key issues, as illustrated in Fig. 10.1

10.2.1 Holistic Approach to Service Provision for People

The first key issue, 'putting the person at the center,' is a common starting point of integrated care as such. A holistic approach is essential that pays attention to all domains of life, to ask what matters to people and to know what is important for their health and wellbeing. This includes the social network around a person. This seems logical, but often is not really practiced. If we take the person and his/her needs as a starting point, this means a lot for how we organize our (health)care and welfare systems and for the needed connections with organizations and agencies that relate to other domains in life. For instance, if someone loses their spouse who always prepared the meals, a solution may not be 'meals on wheels' but a cooking

Fig. 10.1 Four key issues in positioning integrated care governance

clinic. A holistic approach also asks for effective collaboration between professionals, clients and organizations. Conceptual frameworks such as positive health (Huber et al. 2016) or quality of life (Schalock and Verdugo 2002) are useful, while they range from aspects like housing, wellbeing, social relations, work, safety and others.

Box 1. MacMillan Cancer Support
Macmillan Cancer Support has developed a collaborative model of integrated care which crosses secondary, primary, community care and utilizes community assets to provide holistic support to people living with cancer. It is a

social model of care including addressing wider social determinants of health such as housing. Anyone across sectors can refer including self-referrals. The Holistic Needs Assessment (HNA) covers also areas like emotional, spiritual/religious and lifestyle or information needs. An inventory among clients about what (ex)cancer patients worries most came to surprising findings: The three main areas of concern were money and housing, fatigue and tiredness, and mobility. Key to the success has been a joined-up approach between relevant organizations, the offer of support at the earliest opportunity, and the provision of a link worker giving help with holistic needs as a single point of contact (Smith 2018).

Action points:

- A holistic starting point for all who are involved is key. This does not mean that (medical) specialist care is not needed. At www.iph.nl, simple tools are available to assess needs from a holistic view. Always ask the person in need of care what matters the most and what he or she would like to change (Hofman et al. 2015).
- Professionals can be biased by their professional background in what they think patients/users find important, as well as the funding and organizational structures in which they operate. Always use strategies to ask patients/users themselves. Listen carefully to their views, experiences and preferences, and think beyond diagnostic, organizational and financial frameworks.

10.2.2 Organizing Support with and Around People

The second key issue related to governance is organizing support and care around the holistic needs of people. This can occur in different ways: by describing common care pathways and arranging collaboration between involved health- and social care professionals, by organizing a central/single point of contact or case management, by implementing local health and social services teams in the community, organizing personal care networks including informal care and many other ways. The Development Model for Integrated Care (DMIC) (Minkman 2012) describes a set of 89 activities that can attribute to realizing integrated care. The clusters ‘roles and tasks,’ ‘delivery system design’ and multidisciplinary working of the model illustrate these aspects well. Interconnectedness of services is the underlying principle which is important for governance approaches.

Box 2. Neighborhood Teams in The Netherlands

In the Netherlands, since 2015, 380 municipalities have increased responsibilities in arranging care and support for civilians in need. In the last years, the majority of municipalities worked on implementing local neighborhood teams composed of a mixture of professionals, depending on the characteristics of the neighborhoods. In 2017, 83% of the municipalities implemented those teams. Teams are the central point of entry for citizens, have multidisciplinary meetings and arrange connections with GPs and community nurses. Also, the neighborhood team connects with other professionals like the police, schools, working and housing agencies and organizations for residential living (Van de Schoot 2018).

Action points:

- Think beyond professional care structures. Next to the informal network with family, friends and neighbors' social associations, sports clubs, religious societies or even supermarkets could be a key part in people's daily lives.
- To gain a good overview of people and organizations active in the neighborhood, stakeholder analysis may be relevant. First, identify different roles/functions of involved (health) services and draw a picture/map displaying the relations and referral patterns. Assess what is missing and clarify local possibilities.

10.2.3 Re-arranging Care at Scale Supported by Digitalization

For leaders, managers and policy makers, an important question in integrated care development is how to deal with scale (Minkman 2020). Traditionally, scale is an important subject in geography. Robertson (2003) describes scales as '*graduated series, usually a nested hierarchy of bundled spaces of different sizes.*' Scales are often described in terms of a continuum, layers or a hierarchy—for instance micro, meso and macro; large, medium and small; or local, regional, national and global. Although this may imply that scales have a neat vertical structure, Taylor and Spicer (2007) emphasize, in line with insights from human geography, that there is no inherent and absolute hierarchical relationship between scales. Sometimes, 'lower' levels are much more important than 'higher' levels. It is essential to understand how different scales relate to each other and how they may become more or less important over time. This can have a significant impact on strategy and national policies (Postma 2015). It is important to realize that increasing scale is not the same as acting on 'a larger or on a national scale.'

Scale is an important issue for the organization of integrated services. Multiple players are involved, so what do we organize on what scale? Studies show that scale is not a neutral set of pre-given levels at which social processes take place. Instead, it is a subjective, contingent way of seeing and organizing. Postma (2015) underlines the concept of seeing scale as a social and political construct: the definition of scale, the scale at which healthcare is provided, and how this is achieved, is an outcome of the interplay between many different interests, i.e., the values and perceptions of people involved and the broader social and political processes. Healthcare professionals and organizations in integrated care are intertwined in multiple networks and collaborations at different scales. This means that there is no such thing as one scale or one optimal scale. There are always multiple scales to consider, multiple values that play a role and diverse perceptions of people (Postma 2015).

Scale is also related to ‘distance’ and to (digital) connections. With digital technology, a teleconsultation in Australia is no longer regarded as ‘far away’ from Europe, and experts from all over the world can be consulted for a second opinion. Assistive technologies for informal caregivers and professionals, such as lifestyle monitoring, can even make remote caregiving possible. Studies show that these technologies make a positive contribution to the caring abilities of informal caregivers living at a great distance from the person for whom they are providing care. The informal caregivers participating in a study on lifestyle monitoring noted that they felt more connected to the people for whom they are caring. They noted that they were able to talk with them about what they had seen in the system (Zwierenberg et al. 2018).

Box 3. Rethinking Scale

Scale is too easily taken for granted. However, scale should be an important subject of research in integrated care settings. Health reforms in countries all over the world often include changes in the scales services which are provided (for instances decentralizations). Scale choices are often related to the distribution of powers, financial budgets and/or autonomy. When for instance local scales like municipalities are responsible for purchasing support for civilians, this is aligned with decentral budgets to do so. Several countries puzzle what scale fits best for what purpose. Besides what the size should be of a certain scale, also what power or autonomy (policymakers) of a certain area at scale differs. In the Nordic countries like in Sweden, the municipality has a bigger say in local health and social care policy than the national government level (Nies et al. 2019). In Finland, it is interesting to note that although decentralization has been implemented, the current policies actually focus on partial re-centralization into 18 new counties instead of the initial municipalities (Koivisto 2018).

Action points:

- Don’t take scale for granted. Define what boundaries /borders do define the appropriate scale and why. Further explore if this scale fits the purpose of the collaborative network. Consider the five factors for suitable scales as ingredients for integrated care governance (Minkman 2020).

- Good use of assistive person-centered technologies can reduce physical distance between service users, their informal caregivers and professionals. Explore the technological possibilities that can help connect people with one another and their communities.

10.2.4 Integrated Care Governance

Governance can be defined as ‘the process of governing’ (Bevir 2012, p. 13). It refers to the process in which different efforts of involved parties within a certain organization, professional field, network, program or other entity are coordinated. It is important to be aware that these collective efforts are not always coordinated by a central party, such as the government. It stems from the actions of various parties which all have relationships with each other. The concept of governance therefore extends traditional unicentric hierarchy systems and also refers to the actions of various parties which are coordinated within networks or markets. Since integrated care is about collectively creating an integrated answer, it often involves multiple parties with different interests, views, constraints and objectives. Suitable governance is therefore highly important.

Based on the work of Provan and Kenis (2008), we can roughly categorize integrated care governance into three forms:

- First, organizations may choose to (partly) merge to integrate their services. Sometimes, a separate administrative entity or program will be set up by the collaborating parties to coordinate the collective activities.
- A second form is the establishment of contractual relationships within a program or network. In this form, the collective activities are often governed by a leading organization.
- The most frequently seen form is so-called shared governance. Whereas the healthcare organization as an entity was for decades the primary focus for optimization, the creation of valuable connections in network-like organizational models is increasing. Since there is no formal hierarchy in these networks, traditional top-down governance is often not appropriate. In this form, organizations therefore often jointly govern the network, focusing on their horizontal collaborative relationships.

Leadership, accountability, supervision and financial models have different characteristics in integrated care settings than in traditional unicentric models. In the following section, we elaborate on integrated care governance, by addressing these four key components.

10.3 Integrated Care Governance Components

10.3.1 Leadership

The increase of collaborative integrated care networks and programs, often jointly governed and focusing on horizontal relationships, has implications for integrated care leadership. With their professionals collaborating in networks and interdisciplinary teams, board members, managers and other leaders in integrated care also must look beyond their organizational boundaries. This type of leadership may be less hierarchical and demands different skills than before. Leaders must be more and more able to facilitate, cooperate, stimulate and negotiate. In an ever-changing context, leaders also must be adaptive and respond to changing situations. A sound analysis of a situation and the circumstances and, subsequently, adaptation of their behavior to that situation is relevant. An understanding of the interests of other stakeholders and their considerations related to the aim of the collaboration is necessary. Being able to cope with those different interests, to make them explicit and come to shared decisions is an important skill in integrated care leadership.

Furthermore, with integrated care being an increasingly cross-sectoral undertaking, leaders should also broaden their knowledge and be curious about what other domains have to offer. Lastly, the role of informal leaders in all layers of a network or organization should not be underestimated. Inspiring and motivated professionals, team leaders or directors can play a major role in the development of integrated care. Also, the role of 'civic entrepreneur' as more informal leaders (Ebbekink 2017) becomes increasingly important. Those are people with charisma who use other than traditional power sources like position and money tasks. They, for instance, use knowledge, relationships and persuasion to achieve their goals.

Box 4. Implementing Integrated Community-Based Primary Health Care in Canada

In Canada, health care is the responsibility of the provinces, and as such, each province has a unique healthcare system based on a set of overarching principles embedded in National Policy. In the Province of Ontario, the strategy to facilitate health system change is predominantly one of the providing incentives to encourage healthcare providers and organizations to re-organize their approaches to care delivery in more integrated and coordinated ways. Although the past decades have not seen substantial progress in this regard, there are certainly case examples where outstanding leadership has led to the development of high-performing integrated models of care.

In one case of collaboration in an area of urban Toronto, leadership enabled a group of organizations to establish a model of care that was integrated across hospital, primary care, and community-based settings despite many obstacles to achieving that goal. Leaders from the home care commissioning agency, at that time called the Community Care Access Centre, and the primary care agency, called a Family Health Team, established regular meetings to best determine how they could all better meet their clients' needs. Their leadership led to many innovations, driven by a determination to share resources and keep the patients and other community members as the primary focus in their work. The collaboration led to shared office space, joint access to medical records (a very rare phenomenon in Ontario) and collaborative applications for funding to do further integrated program development (Shaw et al. 2018).

These manifestations of successful efforts to integrate care were each governed by formal agreements based on a foundation of each party's commitment to collaboration. The shared office space was provided at no charge by the family health team as an expression of commitment to integrated care, and as a result, the community-based care coordinators were able to take a much larger role in the care of the family health team's patients. Supervision of these staff remained with their immediate supervisors in their home organization, the Community Care Access Centre. Although the care coordinators had access to the electronic medical records in the family health team, there was no integrated record. This meant that care coordinators were required to record their clinical notes in two different electronic records when working with patients who were also members of the family health team. Additional collaborative programs were developed on the premise of a shared commitment to integrated care. Although challenges were certainly encountered, the commitment to leadership in collaborating on care delivery meant that issues related to accountability and financing did not create substantial barriers to innovation.

Action points:

- When the needs of patients and community members were considered to be the primary motivation for creating more integrated models of care, the challenges posed by governance issues at the organizational level were viewed as secondary. This allowed organizational rules to be bent with the consent of the governing boards.
- Successful leaders for integrated care pay close attention to the quality of relationships. Relationships with leaders in other organizations are of course important, but so are relationships with the staff across any given organization who will bring an integrated model to life. Leadership for integrated care builds relationships and is the foundation of sustainable integrated services.

10.3.2 Accountability

Healthcare organizations must account for their efforts in delivering quality of care. Traditionally, accountability is a relationship between an actor and a forum, in which the actor has an obligation to explain and to justify his or her conduct. The forum can pose questions and pass judgement, and the actor may face consequences. Integrated care often takes place in collaborative programs or networks. The issue of being accountable, to whom and for what, is therefore an important question that many integrated health services networks and programs face. Traditionally, healthcare organizations are accountable to external institutions such as inspectorates, authorities and insurance companies. Often, this type of accountability focuses on controlling a single organization, for instance, by internal performance indicators. However, in integrated care networks and programs, organizations achieve results in collaboration with others. Furthermore, although the aim of these networks is to deliver good quality care for their service users, the interests of service users are often not considered (Minkman 2017). These observations demonstrate that integrated care networks and programs may benefit from collective accountability to their service users, collaboration partners and social goals. A shift from accountability within organizations to networks and service users has to be made. Accountability in integrated services in the end refers to being accountable to the society and public.

Box 5. The Delivery System Reform Incentive Payment (DSRIP) Program in New York State

Faced with a major budget shortfall, the Governor of New York State tasked a group of civil servants known as the Medicaid Redesign Team to reform New York State's healthcare services in 2015. In the USA, partial public funding for health care is available to certain groups (older adults, veterans, children and people with very low incomes). The program for people with low incomes is called Medicaid and provides partial reimbursement for services to a subset of the population in need. Drawing on a policy called a Section 1115 Medicaid Redesign Team (MRT) Demonstration Waiver Amendment, the State gained permission to use Medicaid funds from the federal government in unconventional ways to reform New York's health care. The initiative was represented in a project called the Delivery System Reform Incentive Payment (DSRIP) program.

One primary strategy in the new approach was to encourage groups of organizations to work more closely together in 'Performing Provider Systems' (PPS). PPS consist of independent healthcare organizations who create formal collaborations that are capable of accepting funds into a common budget that will fund services delivered by all participating organizations. These PPS would come together to strike collaboration agreements and then were eligible for additional funds to administer their services in more integrated and coordinated ways. Ultimately, the PPS were held accountable for achieving their goals as a group as opposed to as an organization individually. The DSRIP program has led to some very promising results, as documented in an interim evaluation report in 2019. This large-scale program illustrates the value of a shared accountability approach. However, the report documents the clear implementation challenges associated with making such an initiative successful.

More information:

https://www.health.ny.gov/health_care/medicaid/redesign/dsrip/2019/docs/interim_eval_rpt.pdf

Action points:

- Agreeing to be held accountable for goals that can be achieved only in collaboration with other organizations is a powerful strategy to encourage more collaborative, integrated care.
- Engaging in honest and transparent discussions about the incentives acting on each organization in a collaboration is an essential starting point to strike a balance between the goals of each individual organization and the collective as a whole.
- Starting with relationship building and small projects is a good way to build trust while working toward a more substantial agreement to share accountability.
- Large-scale policy programs have documented success using shared accountability strategies, but also illustrate the complexity of implementation.

10.3.3 Supervision

The growth of integrated care networks and programs has its implications for supervisory boards in healthcare organizations too. These boards supervise internal matters, such as performance, risks, integrity and efficiency, and external matters such as social effects, the position of an organization in society and compliance with laws and regulations. Now that integrated care networks and programs are increasingly organized across organizations and domains, the external and social issues may need more attention by supervisory boards. Supervisors have to be more and more connected to service users, professionals and the boards of the organization. They have to be informed about what really happens in practice and should be able to relate this to the societal context.

In addition to internal supervision, healthcare organizations are traditionally also supervised by external authorities with the task to control. Examples are parties such as inspectorates, review bodies, health insurance companies and governments, both local and national. Societal developments also have implications for these external supervisory bodies. In the old situation, care was often provided within nursing homes. Nowadays, however, people increasingly receive integrated care services in their home environments. As the example below illustrates, the Dutch Health and Youth Care Inspectorate (IGJ) has therefore developed new methods of inspection that suit to this transition (Health and Youth Care Inspectorate 2018; Buijze 2019).

Box 6. Inspecting Integrated Care in The Netherlands

As integrated care services are often provided by collaborative networks and programs, in which multiple organizations work together, new dilemmas for the Dutch Health and Youth Care Inspectorate (IGJ) arose. The Inspectorate has therefore been recalibrating its role, promoting cross-sectoral supervision and detecting bottlenecks and risks in care networks (Buijze 2019). Although the Inspectorate has no legal authority yet to supervise networks as a whole, they already supervise personal networks of frail people such as vulnerable older people, seriously ill children and people with severe mental health problems. When supervising these networks, the Inspectorate uses a recently developed framework for care networks (Health and Youth Care Inspectorate 2018), focusing on four main themes:

1. Person-centered care: Is care person-centered?
2. Informal care: Do professionals collaborate with informal caregivers?
3. Integrated care: Do professionals collaborate with one another to provide coordinated care?
4. Safety: Is care safe?

Action points:

- Creating awareness among internal supervisors and external supervisory bodies that services are increasingly delivered by collaborative networks and programs, organized across organizations, is important to be able to see the full picture.
- Connecting internal supervisors and external supervisory bodies to the key stakeholders, such as service users, informal caregivers professionals and the boards of the organization, could be a good way to keep the real, overarching objectives on the agenda.

10.3.4 Financial Models

Another crucial component of integrated care governance is the financial model that lies underneath the collaborative programs and networks. Insufficient funding and financial silos are often mentioned as hindering factors and explanations for not succeeding in integrated care (Lette et al. 2019; Stoop et al. 2019a, b). When collaborative programs and networks cause income reduction for the organizations and professionals involved, this may influence their intention to collaborate. Sometimes, coordination and multidisciplinary consultations are financed by funding parties, but often this is not the case. Integrated care therefore needs financial models that enable and stimulate integration of services. In practice, new financial models are developing, such as shared savings and population management (Drewes et al. 2014; Struijs et al. 2015), in order to achieve Berwick's Triple Aim: improving population health, improving quality and individual experience of care, and reducing per capita costs (Berwick et al. 2008). Although these models are promising, it is still too early to draw any conclusions. Chapter 21 elaborates more on integrated care financial models.

Box 7. Population Management in The Netherlands

In order to better respond to the needs of aging populations, population management has been implemented in many countries. In the Netherlands, the development of nine pioneer initiatives has been monitored (Drewes et al. 2014). The nine initiatives consist of primary care actors, a hospital and health insurers and focus on the needs of a specific population. The target population was specified based on geography (a certain area) or their health insurance. In the population management approach, people are seen as part of a larger group (population), instead of paying a fee per person or service (Struijs et al. 2015).

Action points:

- In order to successfully achieve integrated care, programs and networks should be underpinned by financial models that enable and stimulate integration of cross-sectoral services.
- An approach in which the ‘gains’ of the collaborative achievements partly can also be used for improvements and innovation is powerful, as illustrated by the Kinzigtal experiments (Hildebrandt et al. 2012, 2015).

10.4 Values Underpinning Integrated Care Governance

Although integrated services and care networks are organized and governed in a variety of ways, they are often underpinned by the same core values. These values form the core of many integrated care networks and programs. Zonneveld et al. (also see Chap. 4, this book) present a value framework of 18 underlying values of integrated care. The framework has been developed by carrying out a systematic review of literature (Zonneveld et al. 2018) and consultation of international experts by using Delphi methodology (Zonneveld et al. 2020). Values can be defined as meaningful beliefs, principles or standards of behavior, referring to desirable goals that motivate action. In lay terms: What we believe is important. Chapter 4 elaborates on these integrated care values.

10.5 To Conclude

If we want to achieve the 'next level' of integrated services, the alignment between all of the components of integrated care, a person-centered holistic vision, aligned organization and suiting governance are needed. If we do not manage to align these levels and free ourselves from thinking in isolating terms like primary care, secondary care and tertiary care or other professional and organizational silos, then we will end up with suboptimal results. Alignment of integrated care on all levels is the future direction to proceed. Also, integrated care governance in itself contains leadership, accountability and supervision. We include the attention to financial models, because financial incentives influence the behavior of people. Suitable integrated care governance is complex and not yet achieved, and countries remain in various stages of development due to competing priorities, interests and histories. Therefore, integrated care and integrated care governance will require continued long-term efforts.

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Perspectives on Governing Integrated Care Networks

11

Matthias Mitterlechner and Anna-Sophia Bilgeri

To increase the meaning of present experience is to add more conceptual sensors (Karl Weick).

11.1 Introduction

In many countries, increases in life expectancy entail a growing demand for long-term care and a rising number of patients with multiple chronic conditions. To meet these patients' needs, scholars and policy makers recommend that health- and social care providers coordinate activities in inter-organisational networks to enhance care experiences and outcomes for patients and their families (Glasby et al. 2011; Goodwin et al. 2014; Minkman 2017). Despite these considerations, network-based service integration remains challenging, and progress has been limited. As Goodwin (2019) notes, "we have yet to make any significant breakthrough to understand the implementation and sustainability of complex service innovations that so characterise the development of integrated care programs" (p. 1). One of the major challenges in forming and developing integrated care networks concerns the design and use of effective governance arrangements. Struijs et al. (2015) point out that, "In all initiatives, multiple actors are involved, with their own organisational interests, leading to varying governance arrangements. How to best arrange these new governance arrangements … is still widely discussed and yet to be resolved" (p. 1). Against this background, research has called for more

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innovative thinking about the governance of integrated care networks (Minkman 2017).

In this chapter, we contribute to this debate by synthesising knowledge on the governance of integrated care networks. To provide a more meaningful portrait of this growing field of scholarship, we draw together three perspectives. The first perspective, "*governance-as-structure*", addresses how the effectiveness of integrated care networks is determined by contingent network governance structures. The second perspective, "*governance-as-process*", explores how effective network governance results from individual actors' activities, skills and competencies. The third perspective, "*governance-as-practice*", combines the two previous perspectives and studies governance as a situated practice in the context of evolving network structures. For each perspective, we identify its theoretical origins, empirical focus, illustrative empirical findings, critical reflections and avenues for future research. Table 11.1 illustrates the key dimensions of the three perspectives that will be discussed in the following sections. Before going into depth, we define the key terms used in this chapter.

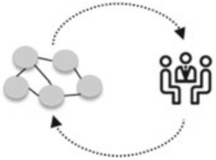
11.2 Conceptual Background

The three key terms used in this chapter—integrated care, inter-organisational network and network governance—are all "polymorphous" concepts that have been defined from various theoretical and disciplinary angles and with multiple objectives (Goodwin et al. 2017, p. 5). To establish common ground, this section defines the three terms and specifies the conceptual boundaries guiding this chapter.

The term "*integrated care*" has been defined in various ways and our understanding of what integrated care "is" and what it comprises still evolves (Goodwin 2016). For the purpose of this chapter, we follow Kodner and Spreeuwenberg, who define it as "a coherent set of methods and models on the funding, administrative, organisational, service delivery and clinical levels designed to create connectivity, alignment and collaboration within and between the cure and care sectors" (adapted from Kodner and Spreeuwenberg 2002, p. 3). Designing and using integrated care methods and models, actors aim to overcome inefficient care fragmentations and improve people's care experiences and outcomes through the coordination of their service activities (Goodwin 2016). Although the definition explicitely refers to multiple levels of analysis, this chapter focuses on the inter-organisational level, while agreeing that a multi-level perspective is required for understanding and dealing with the complexity of integrated care methods and models.

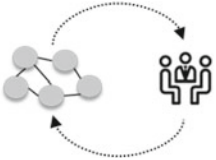
Similar to integrated care, research on *inter-organisational networks* is highly fragmented. Huxham (2003) notes that "even the most basic terminology is subject to varied interpretations and there seems to be little agreement over usage of terms such as 'partnership', 'alliance', 'collaboration', 'network', or 'inter-organizational relations'" (p. 402). This chapter draws on Müller-Seitz and Sydow (2012), who define a network as "a social system in which the activities of at least three formally

Table 11.1 Perspectives on the governance of integrated care networks

	 **Governance-as-structure**	 **Governance-as-process**	 **Governance-as-practice**
Theoretical origins	• Relational sociology • Social network analysis	• Methodological individualism	• Practice turn in the social sciences
Key empirical focus	• Explains social phenomena from patterns of relations linking actors like health and social care provider organisations	• Explains social phenomena as arising from individual actors' purposes, intentions, interests, competencies, skills and activities	• Focuses on practices rather than patterns of relations or individual actors to explain social phenomena. • Defines practices as social actions that recursively produce and reproduce the structures that constrain and enable social actions
Examples	• Provan and Milward (1995) • Provan and Kenis (2008) • Cristofoli and Markovic (2016)	• Vendetti et al. (2017) • Lyngso et al. (2016) • Williams (2002)	• Embuldeniya et al. (2018) • Mitterlechner (2018) • Martin et al. (2008)
Key contributions	• Directs attention to the systemic level • Offers precise representations of social structures and their consequences	• Draws attention to the important role of individual actors and their interventions and skills for effective network governance • Provides insights for designing individual training programmes	• Emphasises the recursive interplay between social structure and action • Focuses on social practices of network governance

(continued)

Table 11.1 (continued)

	 **Governance-as-structure**	 **Governance-as-process**	 **Governance-as-practice**
Limitations	• Lacks an explicit concept of human agency • Tends to be static, offering at best a succession of “snapshots” of static governance structures	• Downplays how human agency is not entirely free to act, but situated in evolving social structures • Unable to capture the temporal experience of governing an integrated care network	• Unable to provide statistical generalisations • Requires deep and time-consuming engagement in the field
Future research	• Provide temporal models of the formation, reproduction, and transformation of the governance of integrated care networks	• Look simultaneously at the properties of context and the detail of governance action to understand how results are achieved	• Study tensions and contradictions enabling and constraining change across levels of analysis

independent legal entities are coordinated in time–space, i.e. there is some reflexively agreed upon inter-firm division of labour and cooperation among the network members" (p. 108). This definition excludes dyadic relationships, recognising that third actors give such relationships a distinct social quality, e.g. one actor's option to play two or more others against each other for his or her own benefit (Simmel 1950; Sydow et al. 2016). Moreover, it is open to several types of integrated care networks, like cancer or diabetes networks, and includes multiple directions, i.e. vertical, horizontal, cross-sectoral or population networks (Goodwin et al. 2017).

Over the past three decades, a considerable literature has developed around the topic of *network governance*. A first research stream has discussed inter-organisational networks as a distinct mode of governance situated between markets and hierarchies (Powell 1990), analysing networks as a means to address complex ("wicked") public policy problems like migration, global warming or health care (Rittel and Webber 1973; Rhodes 1997; Emerson et al. 2012). In health care, governance has been understood as policy tools and processes needed to steer a system towards population health, which entail a move from hierarchical models of service delivery towards network-based collaboration among a range of independent organisations across different sectors (see the contribution of Mallinson and Suter in this book). A second research stream, which is the focus of this chapter, has studied the governance of inter-organisational networks per se, identifying structural and processual determinants of effective network governance. In this stream, network governance entails the design and use of structures and processes enabling actors to direct, coordinate and allocate resources for the network as a whole and to account for its activities (Vangen et al. 2015). This chapter sheds light on this second stream and synthesises current knowledge into three perspectives on the governance of integrated care networks.

11.3 Three Perspectives on Governing Integrated Care Networks

This section identifies three perspectives on the governance of integrated care networks. For each perspective, it describes its theoretical origins, empirical focus and selected findings. The findings are selected for illustrative purposes without any claim to a systematic review. What is more, the three perspectives are presented as ideal types, which researchers sometimes combine in their actual empirical or theoretical work. The subsequent section will discuss the contributions and limitations of each perspective and suggest avenues for future research (see Table 11.1 for an overview).

Governance-as-Structure

The governance-as-structure perspective explores how the effectiveness of integrated care networks depends on governance structures, which involve the member organisations of a network and the formal relations between them (Vangen et al. 2015). Rooted in relational sociology (Simmel 1950) and social network analysis (White 1963), this perspective explains social behaviour with reference to patterns of relationships among actors like organisations. It thereby constitutes a theoretical alternative to methodological individualism, which explains social behaviour in terms of the activities and properties of individual actors. This perspective has gained significant momentum from the 1980s, when networks among organisations were considered as a promising way of dealing with "wicked" policy problems and a globalising business environment (Powell 1990). Noting a surge of inter-organisational networks in the private and public sector, researchers began to explore how network-level outcomes depend on various governance structures under different contingencies.

In a pioneering study, Provan and Milward (1995) proposed a theory of network effectiveness, conducting a comparative case study in four US mental health delivery networks. They explain network effectiveness by various structural and contextual factors including network integration, external control, system stability and environmental resource munificence. Their findings indicate that networks are more effective if they are tightly integrated and led by a central core agency. Centralised network governance facilitates the coordination, monitoring and control of activities. With respect to other structural and contextual factors, the study suggests that network effectiveness is enhanced if networks are fiscally directly controlled by the state (rather than by regional agencies) and under conditions of general system stability and resource abundance.

Continuing this line of research, Provan and Kenis (2008) delineated three forms of network governance (shared governance, lead organisation governance and governance by a network administrative organisation/NAO) and developed propositions about the relationship between these forms and network effectiveness under various contingencies. For instance, shared network governance is most effective for advancing network-level outcomes when there are only few network members, trust and goal consensus are high, and the need for network-level competencies is low (Provan and Kenis 2008). By contrast, NAO governance is more effective when there are a moderate number of network members, trust and goal consensus which are moderately high, and the need for network-level competencies is high.

Further advancing this perspective, Cristofoli and Markovic (2016) examined how the effectiveness of twelve home and social care networks is determined by various combinations of resource munificience, formalised coordination mechanisms (e.g. formal agreements of defined procedures) and forms of network governance. They find that high network performance is influenced by different combinations of these factors, suggesting that there might be several paths to success. In addition, they highlight the role of individual actors' interventions, finding that in a resource-munificient context network, effectiveness depends not only on centralised network governance structures, but also the presence of managers promoting interaction, relieving tensions and supporting identification among network members. The observation of the importance of individual actors leads to the second perspective on governing integrated care networks, governance-as-process.

Governance-as-Process

This perspective examines how networks are governed through individual actors' skills and activities, which include ways of communicating, sharing responsibility and taking decisions (Vangen et al. 2015). It is grounded in methodological individualism, which assumes that the elementary unit of social life is the individual human action (Lukes 2006). To explain integrated care networks and their change, it shows how they result from the activities of individuals rather than structural patterns of relationships, explaining action by referring to individual purposes, intentions and skills.

An example is the study of Vendetti et al. (2017), who examined the barriers and facilitators associated with the formation of alcohol and other substance abuse networks in the USA. They find that the successful formation of these networks depends on committed charismatic individuals driving progress by delivering strong and consistent messages regarding programme importance, and by encouraging communication among key stakeholders. In addition to the activities of these higher-level strategic network "champions", network formation is supported by committed individuals at the operational level like nurses, who mobilise engagement for the network within different network member organisations.

These findings are corroborated by the work of Lyngso et al. (2016), who analysed the barriers and facilitators of network-based activity coordination for COPD patients in Denmark. They find that the effective coordination of activities among service provider organisations depends on managers who share a vision of integration with employees, acknowledge the tasks involved with inter-organisational activity coordination and allocate sufficient time to complete these tasks. In addition, managers support activity coordination by regularly arranging social events and informal network meetings to build up and strengthen personal relationships among involved health professionals.

Given the pivotal role of individual actors for building integrated care networks, research has addressed their required personal skills, abilities, competencies and experience. In a study including UK health promotion networks, Williams (2002) examined the skills and behaviours of "boundary spanners". He finds that effective individuals building inter-organisational relationships have strong abilities in communicating and listening, understanding and resolving conflict, managing through influencing and negotiating, managing complexity and interdependencies and managing roles, accountabilities and motivations. He concludes that an understanding of these skills is important to inform the training, development and education of current and future integrated care practitioners (Williams 2002).

Governance-as-Practice

The third perspective, governance-as-practice, studies situated governance practices in the context of evolving network structures. Inspired by the practice turn in the social sciences (Schatzki et al. 2001) and theorists like Bourdieu (2013) or Giddens (1984), it explains social order by referring to practices rather than structural relationships or actors' skills and purposeful activities (Reckwitz 2002). Explaining social order by practices means analysing *routinised activities* that are informed but not determined by structures and reproduce and change these structures over time (Schatzki 2005). Unlike the two previous perspectives, governance-as-practice studies the *recursive interplay* between social structure and action, suggesting that social action cannot be explained without considering the structural context in which it is embedded (Sydow et al. 2013). Vice versa, social structures have no "existence" independently of actors referring to them in their practices. In their practices, actors refer to previously established structures and thereby reproduce and modify them over time. Reproduce and modify means that actors do not simply reiterate practices of the past, but have a capacity to reflexively generate alternative trajectories in response to continuously emerging demands, tensions and contradictions in evolving situations (Emirbayer and Mische 1998).

A recent example illustrating this perspective is the study of Embuldeniya et al. (2018), who describe how care activities across organisational boundaries are coordinated by generating connectivity and consensus. The study finds that generating connectivity and consensus are not isolated individual activities, but social practices that are contextually embedded in histories of the existing cultures of clinician engagement and established partnerships. By showing how these practices are "contextually and temporally contingent, with the capacity to produce new contexts, which in turn generate new sets of mechanisms" (p. 783), it highlights a recursive relationship between social structure (cultures of clinician engagment, established partnership) and situated practice (generating connectivity and consensus). It thereby offers an analysis of how network-based activity coordination is enabled and constrained by the interplay of social structure and action in local contexts and histories.

In a related vein, the study of Mitterlechner (2018) explored how new trajectories of network governance evolve, analysing governance and activity coordination practices in a Swiss integrated care network over time. It finds that network governance and activity coordination evolve through repetitive sequences of collaborative inquiry, a practice through which involved network members jointly identify and address recurring contradictions in creative and experimental ways. It contributes to the governance-as-practice perspective by drawing attention to the pivotal role of meaning making, creativity and experimentation for understanding governance dynamics in integrated care networks.

A further example is the study of Martin et al. (2008), who showed how actors are not only enabled, but also constrained by evolving network structures as well as interfering market and hierarchical structures, observing the development of cancer networks in the UK. They examine the degree of convergence between the introduction of centrally mandated network structures and the possibilities of individual action for introducing structured cancer care pathways. In theory, they suggest that network structures, which are looser than hierarchical structures, should enable actors to implement change and coordinate service activities more effectively. In practice, however, they find that this is not always the case. While the structure of a network might indeed create an opportunity space for actors to coordinate activities, actors are simultaneously embedded in overlapping hierarchical (e.g. central performance management) and market structures (e.g. competition among network members), which constrain their ability to coordinate activities in the network without complimentary action at these two additional levels. The authors emphasise a recursive relationship between social structure and action, concluding that network structures have no causal force without embedded actors' agency.

11.4 Discussion

This section discusses key contributions and limitations of the three perspectives and outlines possible avenues for future research. The governance-as-structure perspective advances the field by conceptualising integrated care networks and their governance as social structures aiming at coordinating care activities across network member organisations. It thereby establishes a separate level of analysis that is different from the level of the participating network member organisations and the institutional field in which the network and its members are embedded. The creation of a separate level of analysis makes it possible to direct the view from individual actors and their categorical attributes to the systemic level and explain social phenomena by means of patterns of relationships among network members. This allows researchers to provide precise representations of the governance structures of integrated care networks and evaluate the impact of these structures on network outcomes under various contingencies. These phenomena and causalities are operationalised and measured using modern instruments from social network analysis. Not least thanks to rapid methodological progress in this area, the governance-as-structure perspective has become an important and valuable domain in integrated care research.

While the governance-as-structure perspective captures the systemic level, the governance-as-process perspective draws attention to individual actors' purposeful actions and competencies. It thereby responds to calls to bring individual actors back into the picture and avoid an overly structural view on integrated care networks and their governance. Williams (2002), for instance, notes that "comparatively little attention is accorded to the pivotal role of individual actors in the management of inter-organisational relationships" (p. 103). Similarly, Provan and Kenis (2008) demand that the role of network managers should be discussed in much more depth. The governance-as-process perspective redresses this imbalance, shedding light on crucial activities enabling the formation and development of integrated care networks. In addition, it draws attention to important personal competencies and thereby provides valuable insights for the training of current and future network managers advancing integrated care.

While both perspectives have enriched the debate, they are not without limitations. On one hand, the governance-as-structure perspective tends to lack an explicit concept of human agency, emphasising how actors are constrained by structure. Some authors in this tradition regard actors not as sources of action, but as vehicles for structurally induced action (e.g. Burt 1992), thereby downplaying how social structures and human agency presuppose each other. Parkhe et al. (2006) note that this perspective "risks understating the role of the very actors composing the network" (p. 561). On the other hand, the governance-as-process perspective tends to overestimate the possibilities of individual agency, ignoring how actors are situated in social structures simultaneously enabling and constraining (although not determining) their actions. In addition, the insights generated by both perspectives tend to be relatively static. Although the governance-as-structure perspective proposes optimal structures under various contingencies, it provides little explanation of how these structures change. Vice versa, reducing actors' interventions and their consequences to sets of interrelated variables, the governance-as-process perspective tends to be similarly limited in its capacity to grasp the temporal experience of acting in integrated care networks (Denis et al. 2010). This limitation is unfortunate because dynamism and instability have been shown to be a central characteristics of successful networks (Majchrzak et al. 2015). To deal with it, Provan and Kenis (2008) call for more research on the evolution of networks, research «focusing … on how the governance of public networks emerges … and how it changes over time» (p. 248).

The third perspective identified in this chapter, governance-as-practice, is able to cope with some of these limitations. It considers social structure and action not as a dualism, but as a duality. As Giddens (1984) writes, "The constitution of agents and structures are not two independently given sets of phenomena, a dualism, but represent a duality" (p. 25). This theoretical approach enables researchers to study the evolution of network governance over time. It implies that social phenomena are always "in the making"—network governance is an ongoing accomplishment reproduced and possibly adjusted in every instance of practice (Feldman and Orlikowski 2011). At the same time, the governance-as-practice perspective is not without problems, either. It requires deep engagement in the field to study the dynamics of network governance over long periods of time, often many years. In addition, practice-theoretical accounts are not designed for statistical generalisations, which may limit their acceptance in certain journals and research communities. Instead of universal variation, they produce theoretical generalisations and thick descriptions of situated dynamics that can be useful in understanding governance dynamics in other contexts (Feldman and Orlikowski 2011). However, to the extent that there is a need to open the "black box" of network governance and its underlying social practices (Goodwin 2019), this perspective can serve as a valuable complement to the other two perspectives. Future research adopting this perspective could explore the role of tensions and contractions as potential sources of change, connecting the network, organisational and industry level of analysis (Berends and Sydow 2019).

11.5 Conclusion

Countries around the world adjust the way they deliver health and social care services, responding to the changing needs of an ageing population and people living with one or more chronic conditions. In many cases, service provider organisations break new ground and start coordinating activities in inter-organisational networks. However, despite best intentions, progress has remained limited, not least due to the challenge of governing these networks. This chapter aimed at identifying three perspectives on the governance of integrated care networks, describing network governance as structure, process and practice. By doing so, it has hopefully added important "conceptual sensors" (Weick 2016, p. 339) to increase the meaning of our experience with this complex social phenomenon.

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Governance and Accountability

12

Sara Mallinson and Esther Suter

Governance may not be a top priority when debating healthcare transformation for the twenty-first century, but it is a critical instrument to strengthen public and institutional performance (Van Kersbergen and Van Waarden 2004; Chhotray and Stoker 2009). Governance matters, and never more so than in times of crisis. “For example, since 2008, in the UK approximately one in three NHS foundation trusts have been subject to formal regulatory action on at least one occasion, with poor governance a contributing factor in almost all the cases.” (Monitor et al. 2014, p. 4). The first two sections of this chapter cover theoretical aspects, including how governance and accountability are conceptualized and specific considerations of governance and accountability in integrated health systems. The latter two sections focus on the practical aspects of implementing governance and accountability into integrated health systems and the tools needed to support its implementation. We have tried to present a balanced view by drawing on a wide range of published literature; thus, while many of the innovative examples we discuss originate in the UK, we believe that they can easily be applied into types of health system.

12.1 What is Governance and Accountability?

In the following, governance is understood as the policy tools and processes needed to steer a system towards population health goals (Barbazza and Tello 2014; Task Team 2013). Governance is a multi-faceted concept that became an established part

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of the health system lexicon in the early 2000s. With the publication of the World Health Organization (WHO) landmark report ‘Health Systems: Improving Performance’ (WHO 2000), governance was adopted and adapted to health system contexts. Stewardship, leadership, strategic direction and regulation became important concepts to actualize health system priorities. The later 2000s saw the publication of a burgeoning literature on how to achieve large-scale change, including WHO’s 2007 ‘building blocks’ framework for health system strengthening (WHO 2007). This reflected governments’ ongoing struggle to manage health needs along with increasing health services expenditure.

The literature contains a number of different conceptualizations of health governance. They share some common features but none are universally accepted (Barbazza and Tello 2014; Mikkelsen-Lopez et al. 2011; Brinkerhoff and Bossert 2008):

- Governance must encompass all aspects of managing health services delivery to support health system goals, including financing, human resources, information and medicine and technology.
- A system perspective is required to understand the interdependencies between these domains and devise appropriate governance mechanisms.
- Governance mechanisms and processes must support achievement of overall health systems goals; this requires a number of conditions:
  - Clear accountability of key actors to beneficiaries,
  - Responsible leadership and a clear vision,
  - An equitable policy process that allows influencing of policymaking by all players equally,
  - Transparency,
  - Sufficient state capacity to manage healthcare policy and service delivery effectively and
  - Public engagement and participation.

There is agreement that ‘good’ governance leads to health improvement (Brinkerhoff and Bossert 2008; Mikkelsen-Lopez et al. 2011), but the lack of clarity in the nomenclature and in models and measures of governance has failed to produce clear evidence on the impact of governance models (Barbazza and Tello 2014; van Olmen et al. 2012). Developing appropriate governance processes that respond to the complexities of healthcare systems is important but so is understanding the situations in which governance is working and is delivering the outcomes desired by all stakeholders.

Most descriptions of governance highlight accountability as an important governance tool. Well-defined accountability structures, along with high-quality systems to monitor processes and outcomes towards agreed upon goals, are intertwined with successful governance (George 2003; Brinkerhoff 2004; Hammer et al. 2011; Lewis and Pettersson 2009; Barbazza and Tello 2014; Suter and Mallinson 2015; Baez-Camargo 2011).

Accountability discussions tend to focus on the relationships between different stakeholder groups on three levels (Fig. 12.1). Firstly, there is accountability at the level of the state, which may include various ministries (health, finance, social care, education). Secondly, there is accountability at the level of healthcare organizations, regulatory bodies and service providers. Thirdly, there is accountability to clients/citizens (individuals and families, communities and populations). Accountability mechanisms with the state have traditionally been vertical and unidirectional (Kickbusch and Behrendt 2013) with a focus on financial accountability and health system performance (Brinkerhoff 2003, 2004; Deber 2014). Service providers and healthcare organizations are accountable to state funders for the ethical use of resources and to clients for service delivery. Mechanisms focus on organizational performance and oversight and service delivery according to legal, ethical and professional standards (Brinkerhoff 2003, 2004; Deber 2014; Fooks and Maslove 2004). Failure to meet the goals and objectives needs to trigger real and enforceable actions. Lastly, accountability to clients/citizens has a number of potential functions: helping the public to hold the state and local healthcare organizations to account on electoral promises and services; supporting public engagement through increased transparency which, in turn, is a mechanism for checking that health systems represent the public's interest, values, needs and expectations (Brinkerhoff 2003). The interweaving of transparent public accountability mechanisms with improved public engagement can lead to better informed, accountable and legitimate decision-making (Abelson and Gauvin 2004; Kickbusch and Behrendt 2013).

12.2 Appropriate, Agile and Effective: New Directions for Governance and Accountability in Integrated Health Systems

In the second decade of the twenty-first century, the thinking around governance underwent a shift. Governments, organizations, communities and individuals began grappling with the changing global context in which influences on health and well-being transcend traditional boundaries in an increasingly globalized 'knowledge society' (Willke 2007; Kickbusch and Gleicher 2014). This has required a re-focusing on whole-system health, one which cuts across political, economic and social landscapes and demands an evolution in governance models (WHO 2013). This has in turn led to a distinction being drawn between health governance (i.e. structures, processes and mechanisms that govern health care) and governance for health. Governance for health is a much broader idea, tying in wider changes in globalization, knowledge, participation and co-production of health (Kickbusch and Gleicher 2012).

In parallel with calls to refocus on the broader idea of governance for health, there has been an evolution in health service integration. Integrated care systems, networks or models, often regarded as complex adaptive systems, are moving beyond horizontal integration between organizations at same level or delivering

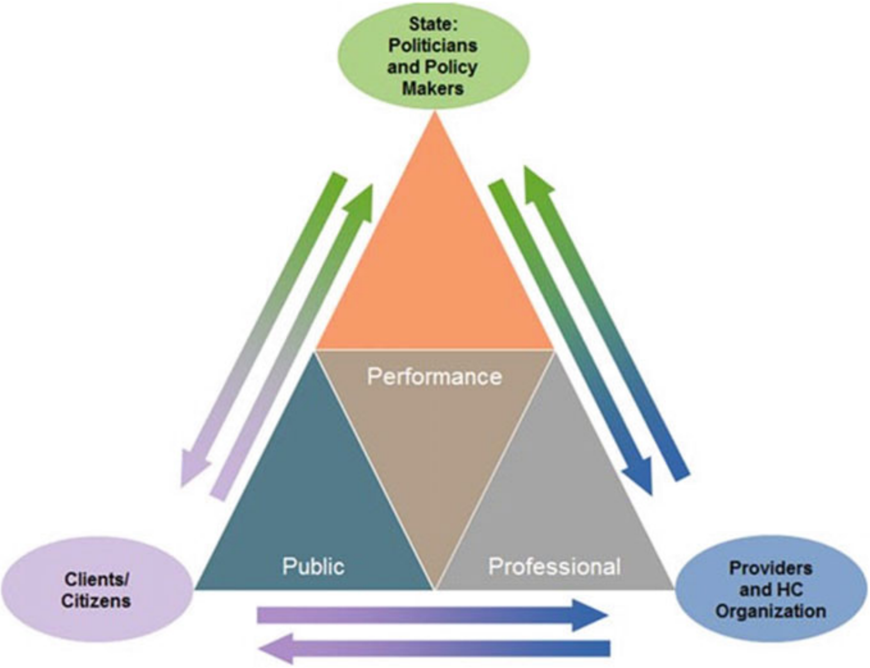

Fig. 12.1 Accountability relationships in integrated healthcare systems. Adapted from Brinkerhoff and Bossert (2008)

similar services. There are efforts to integrate more broadly across community-based services, including other sectors, and partnerships between communities, primary and acute care [i.e. vertical integration, Evans et al. (2013)]. The challenge is that many innovative cross-sectoral service arrangements require more flexibility and different accountability mechanisms to initiate and sustain change. They create new and ambiguous governance and accountability relationships (Brinkerhoff 2004; Deber 2014; Fooks and Maslove 2004; Kickbusch and Behrendt 2013; Maybin et al. 2011). In this context, the focus is increasingly on relationships and alliances, management of boundaries, shared information, best practice guidelines and establishing a common culture.

In addition, organizations have to respond to an increasingly informed public that demands better leadership in publically funded organizations and greater accountability for allocation and use of resources (WHO 2008). Some authors maintain that creating a strong public voice through appropriate governance and accountability is critical for the success of integrated health systems (Abelson and Gauvin 2004; CIHR 2012; Fooks and Maslove 2004). There is also a key role for people in monitoring system quality and performance, including reporting on people's experiences in the health system. These broader trends—global interdependence, a new understanding of the complexity of health, the changing roles of citizens in co-production of health and health care—are the impetus for new and smarter governance approaches (Kickbusch and Behrendt 2013). Governance and accountability processes have to keep pace with the diverse contexts within which they operate and be responsive to people in diverse roles and relationships. A recent high-level review of governance in UK health services (Grant-Thornton 2015) suggested that partnerships needed agile governance rather than the command and control styles of more traditional, siloed models of health service delivery. The review also noted the need for a mature risk management strategy and for genuine empowerment for governance boards, so their ‘risk appetite’ (Bullivant and Corbett-Nolan 2012) allows innovative arrangements to flourish. The problem for health system leaders is that these dimensions of new governance depend on a degree of culture change.

The idea of ‘soft governance’ to support collaborative care across multiple stakeholders is not new, but, as Fierlbeck (2014) argues, it has become particularly relevant as governments grapple with complex health problems across overlapping jurisdictions. She concludes that new ‘experimental’ governance models need to respond to limitations of hierarchical, vertical governance arrangements that do not allow a constellation of interests to negotiate alternative healthcare models. Kickbusch and Gleicher (2014) highlight global examples of whole-of-government (WOG) and whole-of-society (WOS) approaches to manage complex policy processes that govern health and might be fitting for integrated health systems. WOG indicates a commitment to health at all levels of government with joint working across sectors as a core premise. WOS goes beyond institutions and influences/mobilizes communities and other relevant policy sector, media and the private sector to co-create health. WOS approaches emphasize coordination through normative values and trust building among actors, which ultimately strengthens resiliency of communities. Their focus is on new forms of communication and collaboration in complex network settings, using social movements and negotiation to align diverse priorities, values and approaches.

Overall, this new vision points to the diffusion of governance from a state/health service-centred model to a collaborative model where a range of actors including state, private industry, the public, media and international organizations across levels co-produce governance by Kickbusch and Gleicher (2012).

12.3 Implementing Innovation: Next Steps for Governance and Accountability in Integrated Health Systems

Although many health systems in developed nations are experimenting with integrated healthcare systems, recent policy initiatives and implementation projects in the UK provide a timely and interesting example of the drive to move integration forward. Successive UK governments have explored ways to tackle health system pressures through integrated health systems. Substantive policy changes in the

Health and Social Care Act (Department of Health 2012) and increasing focus on the challenges of improving healthcare quality compel a new look at how services are organized, regulated, monitored and directed. In the following, we describe these new developments in more detail with special consideration of their impact on governance.

In *NHS Five Year Forward,* the National Health Service sets out a vision for an updated agenda View (NHS England et al. 2014) that reflects the significant changes in science and technology and the increasing complexity of health and social care delivery. Central to the vision is a renewed focus on prevention, public health and primary care through new partnerships that cut across traditional boundaries. A combined health and social care budget and capitated arrangements are some of the innovations outlined on the financial side. There are also a series of new care models in primary, emergency and specialist care, many of them focusing on multidisciplinary teams and networks. The challenge, as encapsulated in this plan, is the need for meaningful local flexibility in service delivery models, funding mechanisms and regulatory requirement to accommodate diverse contexts. These are vital to build new relationships with patients and the community that enhance patient empowerment and engagement in care decisions.

The new care models envisioned in the NHS Five Year Forward View will have implications on all domains of governance and accountability. Shared budgets and capitated arrangements will challenge how funds are distributed and managed between social and healthcare partners; local flexibility in service delivery models puts more onus on service providers and organizations to maintain quality standards; the focus on patient and communities demands more effective mechanisms for engagement and public reporting. Two commissioned reports have explored the governance challenges inherent in the new vision in more detail. The Dalton Review (Dalton 2014) explored the organizational forms needed to support the vision of the renewed NHS. The review strongly promotes the creation of different organizational models that are adaptable to local contexts. Organizational models comprise the structures of governance, accountability and management to achieve specific aims and objectives in delivering services. The report outlines a number of different models of service integration with different types of partnership and degrees of integration. They caution that embracing different models would require a shift in mindset of boards towards achieving what is best for patients and communities through joint ownership. Such collaborative arrangements require careful consideration of governance structures and processes that will likely have to deviate from the status quo.

Building on the Dalton Review, the NHS Governance Review (Grant-Thornton 2015) offers a comprehensive discussion of NHS governance challenges emerging from the Five Year Forward View vision. In a similar vein to Dalton (2014), the authors stress the need for '… NHS leaders to engender cultural change, support innovation and build a modern workforce—all will need to be underpinned by robust corporate and quality governance arrangements'. (p. 5). The report authors argue that cultural changes depend on transparent and robust performance monitoring across all major care pathways, especially where they are linked to payment mechanisms. However, their survey indicated ongoing uncertainty about accountability and delegation of authority between Care Commissioning Groups and NHS Trusts (p. 2). Collaboration and partnership governance with all health and well-being partners (including social enterprises, third sector, HealthWatch, and private sector) are essential, but the relationships and systems are still evolving.

12.3.1 Vanguard Integration Sites

The Five Year Forward View is using three waves of Vanguard sites to operationalize different integrated care models (NHS England 2014). All share the fundamental aims of improving patient experience and continuity of care while also dealing with the financial and resource pressures facing the NHS. This translates into four core values for the redesign: clinical engagement; patient engagement; local ownership; national support.

The Northumbria Healthcare NHS Foundation Trust, for example, is one of the eight Vanguard sites to spearhead the implementation of an integrated primary care–acute care model (https://www.northumbria.nhs.uk/about-us/vanguard). The trust already had a strong integration record and effective governance and accountability mechanisms in place to advance the integration agenda. An established Integration Committee had created a detailed integration plan (Freake 2013) and a dashboard to track progress against integration objectives, including patient experience.

As a Vanguard site, the focus is on the development of the primary care–acute care systems' integration with partners at Northumberland Care Commissioning Group and Northumberland County Council (https://www.northumbria.nhs.uk/sites/default/files/images/Vanguard_270815_LR.PDF). Specifically, Northumberland Vanguard will create a new Specialist Emergency Care Hospital that will act as an extension of primary care to create 'hubs' of primary care provision across the county. This new model will allow patients to access their primary care physician 7 days a week. Cutting across organizational boundaries, the model will enhance access to community nursing services and coordinated discharge through shared information technology. The ultimate goal is to provide care closer to home.

Although the launch of the first group of Vanguards in spring 2015 was reportedly met with lots of goodwill, they have a difficult balancing act to perform. They must embrace local context with innovative, experimental forms of service delivery while also setting the pace for system-wide transformation. Vanguards use a 'learn as we go' approach that emphasizes the importance of ongoing monitoring of outcomes for patients, staff and the wider population. Sharing of processes, metrics and learnings from high-performing integrated systems is also being encouraged, and all Vanguards who are implementing variations of a component will be asked to participate in 'action research' (NHS England 2015, p. 9).

This approach to healthcare reform may seem much riskier because it builds on demand-led rather than supply-led local service planning and extends well beyond traditional organizational boundaries. Collaborative leadership, commissioning and delivery of care will depend on agile governance supported boards that are open to risk. Clearly, this kind of innovation depends on leadership that advances system-wide cultural change, but there are concerns about whether organizations can overcome the inertia that has characterized the previous cycles of reform. Vanguards will have access to appropriate national, clinical and programme expertise to collaborate in the change process. As such, they will be able to share clinical pathways, outcome-based commissioning and improvement methodologies. Evidence-based, replicable models and frameworks built for scale are the driving forces for the implementation process. Joint leaders and supporting groups are responsible for developing processes to monitor impact for all stakeholders at national and local levels to support shared learning. Identifying appropriate tools to measuring patient-centred care is a particular area of interest. Initially, a suite of core metrics for each of the Vanguard models along with a standard dashboard showing its trajectory compared to its baseline and to other Vanguards is being proposed (NHS England 2015, p. 11–13).

12.4 Tools for Governance and Accountability

The Dalton Report (2014) and the NHS Governance Review (Grant-Thornton 2015) have both highlighted the formidable governance and accountability challenges facing integrated care networks. In the sections below, we highlight some of the growing number of frameworks and tools available to help governments, healthcare organizations and citizens grapple with governance and accountability in innovative integrated care models.

12.4.1 Frameworks

Well-led Framework for Governance Review

Monitor, the national regulator for health services in England, developed the well-led framework for governance reviews (Monitor et al. 2014). The framework aims to support the NHS Foundation trusts, in line with the Code of Governance, to complete an external review every 3 years. This tool allows boards to have robust oversight of quality, operations and finance in the face of uncertain future income and new care models. It also supports trusts in regular reviews of governance to ensure that they remain fit for purpose.

The four domains for governance reviews are:

1. Strategy and planning—how well is the board setting direction for the organization?
2. Capability and culture—is the board taking steps to ensure that it has the appropriate experience and ability, now and into the future, and can it positively shape the organization's culture to deliver care in a safe and sustainable way?

3. Process and structures—do reporting lines and accountabilities support the effective oversight of the organization?
4. Measurement—does the board receive appropriate, robust and timely information and does this support the leadership of the trust?

The framework is a 'core' reference document to shape the depth and focus of assurance processes. It also contains helpful guidance on how to conduct a governance review.

Good Governance Handbook

The Health Quality Improvement Partnership (HQIP) and the Good Governance Institute have released a new edition of the Good Governance Handbook (Corbett-Nolan et al. 2015). HQIP is an independent organization led by the Academy of Medical Royal Colleges, The Royal College of Nursing and National Voices in the UK (https://www.hqip.org.uk/). Established in 2008, HQPI promotes quality in health care by enhancing the impact of clinical audit. To that effect, HQIP commissions a series of clinical outcomes review programmes that complement the work of other agencies such as the Care Quality Council.

Structured around ten themes, the Good Governance Handbook includes self-assessment questions for good governance at the levels of the board, division and department.

Pathway to Accountability II

The Global Accountability Framework originated from the One World Trust (Blagescu et al. 2005) and incorporated self-check lists in the areas of transparency, participation, evaluation and complaint and response mechanisms. The Pathway to Accountability II (Hammer et al. 2011) is a revised version aimed to support capacity building and system development. The revised version still focuses on the four domains of transparency, participation, evaluation and complaints but acknowledges the interdependencies and hence the need for a crosscutting, inter-sectoral approach. It introduces a graded scoring system and a series of quality management indicators within each of these domains. It is being widely used in WHO initiatives to support global accountability assessments across health systems.

Results Based Accountability Framework

This framework was developed by the Fiscal Policy Studies Institute and Mark Friedman (Friedman 2015). It involves 'turn the curve' thinking—reverse-engineering solutions to problems by identifying desired outcomes and working back towards appropriate mechanisms and processes to achieve those ends, along with the data required to track performance. It focuses on three key questions: How much did we do? How well did we do it? Is anyone better off? It has been widely applied in social and community programs and is being adapted to health system applications. For an example, see work in New Zealand (New Zealand Ministry of Health 2015) or Washington (Washington County Mental Health Services 2015).

12.4.2 Tools

The frameworks described above help to assess the status quo of governance and accountability in integrated care networks and highlight gaps. Other tools target more specifically accountability domains of performance, financial and public accountability. For example, the *Health Data Navigator* (Hofmarcher and Smith 2013) is an interactive platform for researchers, policy makers and healthcare professionals to access health data from Austria, Estonia, Finland, France, Germany, Israel, Luxembourg and the UK. It contains information and links to support performance measurement of the health system including a list of international frameworks that can be adapted to national settings and methods for performance measurement. There is also a toolkit to promote generic standards for performance assessment and relevant data sources for comparative evaluations under the OECD healthcare quality indicator domains of quality, efficiency and access (Kelley and Hurst 2006).

Dashboards of health information have emerged to support public reporting on performance. One used by the Department of Health in Vermont, USA, allows the public to easily track the health status of Vermont residents through more than 100 goals in 21 focus areas (https://www.healthvermont.gov/hv2020/). This real-time dashboard presents measures, indicators and trends and helps to keep the Vermont government accountable in their health strategy. Similarly, the Canadian Institute for Health Information (CIHC) has developed an interactive website that allows the public to review performance data and health systems spending (https://www.cihi.ca/CIHI-ext-portal/internet/EN/Home/home/cihi000001).

Citizen/community score cards and surveys are a mechanism to promote civil engagement and demand-side accountability and empower individuals to express their views to government bodies. The surveys allow citizens to contribute to oversight and regulation and therefore aim to improve the quality and integrity of public services (Singh and Shah 2007). Different types of citizen report cards and community score cards can be found at the World Bank's participation and civic engagement webpage: https://www.worldbank.org/socialaccountability_sourcebook/Resources/pub4.html.

Identifying new governance and accountability mechanisms for financial management of resources and for engaging patients and the public will need to be a priority for the Vanguards and other innovation sites. People Powered Health was an innovative programme in the UK between 2011 and 2013 that focused on co-production of health for people and by people (Horne et al. 2013). They advocated bottom-up redesign of monitoring and outcome assessment as a mechanism to drive change. NESTA and the Innovation Unit bring together examples of collaborative action from across the UK in a *Co-production Catalogue* to illustrate what co-production looks like on the ground (Nesta 2013).

The catalogue outlines a number of different projects and models of co-production. It also lists a range of tools to assess impacts and outcomes from different perspectives when service innovations are rolled-out. For example, the NHS Five Year Forward View calls for new ways to distribute and manage funds, and an example of this is the personal health budgets introduced for specific populations receiving health- and social care services. A national evaluation of the pilot projects in over 60 primary care trusts showed favourable results with positive user feedback. The current work focuses on using a *personal outcomes evaluation tool* for annual, routine evaluation of user experience (Hatton and Waters 2015). It focuses on meaningful goals and capacity for people and communities. This includes a broad set of patient reported outcomes with focus on confidence and control over own health, behaviour change and lifestyle, measure of quality social networks and social support. Wider measures could look at satisfaction with equal and effective relationships, level of patient engagement using tools like the Patient Activation Measure and levels of participation.

These are just a few examples of the guidance and tools that are available to support service integration and build collaboration. For a more complete description of innovative governance and accountability tools, see Suter and Mallinson (2015).

12.5 Conclusions

We are at the advent of new relationships in integrated services. Large health systems are unpacking the challenges of whole-system approaches to health, and the best way to meet future challenges is through new organizational forms. There is a push for radical, bottom-up change with patients, clinicians and communities as co-creators in all aspects of health service design, delivery and governance. As the roles of patients, communities and other stakeholders as partners for health evolve, we need tools and processes that create clear and transparent accountability relationships.

The challenges for governing these new models are significant, and given their novelty, there is little evidence about what works in a given context. Commentators have noted that the monitoring of accountability is the least developed element of health system leadership and governance (Smith et al. 2012). Some have pushed for 'integrated governance', which focuses on partnerships between and within organizations (Delaney 2015; Jackson et al. 2008; Nicholson et al. 2014). Managing the interactions of governance structures associated with the different partnerships may be one of the biggest challenges (Delaney 2015). Jupp (2015) posits that we may be able to draw on experiences of other sectors that have undergone significant restructuring (such as education or the prison services in the UK).

Despite the uncertainty of what these new governance structures will look like or how they will operate, there is general agreement that governance will be an essential element of successful integrated care system reform (Brinkerhoff and Bossert 2008; Mikkelsen-Lopez et al. 2011). Some argue for a new or enhanced role of independent inspectorates to deliver on public accountability promises (Kickbusch and Behrendt 2013; Michels and Meijer 2008; World Bank 2013). Such agencies may also have a role in collecting and disseminating information on good practice and performance. One example is the Canada Health Council, implemented on the recommendation of an expert committee report on the state of the Canadian healthcare system. The agency had a vital role in monitoring progress on electoral promises and during its life span released a series of critical public reports (https://healthcouncilcanada.ca/reports.php). It also hosted a health innovation portal profiling best practice approaches across the continuum of care. Stacked with political appointees and representatives, the agency faced an up-hill battle to earn the trust and credibility it needed to make a difference and to satisfy citizens' demands for greater accountability (Flood and Archibald 2005). It disbanded in 2014.

Investing in good, smart systems to increase transparency across a wide variety of indicators of quality is likely to be central to improving accountability in a system with more autonomous providers (Jupp 2015). In addition, mechanisms for co-creation and patient empowerment will continue to play an important role. Power imbalances have been on the agenda for many years, but unravelling traditional relationships to respond to new partnerships and shared responsibility remains challenging. Strategic policy frameworks combined with effective coalition building and governance remain important tools to strengthen the coordination and integration of health services delivery (Goodwin 2002; Kickbusch and Behrendt 2013; Kickbusch and Gleicher 2012; Maslin-Prothero and Bennion 2010; Suter et al. 2009; Williams and Sullivan 2009; WHO 2013). In contrast to earlier governance approaches that focused on structures and organizational boundaries, newer approaches will need to pay increasing attention to the dispersion of power within integrated systems and accountability relationships across the four domains.

In summary, the multiple models of integrated care that are evolving globally raise the possibility of a period of experimentation and learning (Jupp 2015). Governance that is agile and can respond quickly to emerging changes is required to manage the complex interdependent partnerships in integrated care systems.

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Adaptive Approaches to Integrated Care Regulation, Assessment and Inspection

13

Patricia Sullivan-Taylor

13.1 Introduction

This chapter aims to provide foundational knowledge of how regulation, assessment and inspection are being designed and implemented across several countries in relation to integrated care. It begins with defining each term, the benefits of each and roles of various health and social system actors. A common theme throughout regulation, assessment and inspection is the focus on the client journey and how the client experiences and perceives care. Equally important is the value that stakeholders attribute to the regulation, assessment or inspection process. This forces governments, assessment bodies and inspectorates to be mindful to monitor outcomes that matter.

13.2 What is Meant by Regulation, Assessment and Inspection?

The definitions of regulation, assessment and inspection are consistent across the globe. However, what frequently varies is the scope of what is included in each. This section will address both the definition and practical application of each. Furthermore, we will explore the difference between legislated versus voluntary programs and what to expect from these levers.

Regulations are "rules made by a government or other authority in order to control the way something is done" (Collins Dictionary Online, 2020). Often, regulations are the legislative tool used by governments to establish the requirement

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for assessment or inspection. Regulations may include the standards and associated scope of services with which providers must comply and give powers to the assessor or inspector.

Assessment involves evaluating the quality of something, generally at a point in time or over an established period (Oxford Learners Dictionary Online, 2020). Assessment bodies may recommend improvements but have limited enforcement powers. Whereas, inspection is the act of looking at something to check that "rules are being obeyed and that standards are acceptable" (Oxford Learners Dictionary Online, 2020). Inspectors typically have the power to enforce change. Furthermore, inspection may be either scheduled or in response to a complaint. In the Netherlands, this includes "collecting information on the question of whether an action or an issue fulfils the relevant requirements, subsequently forming an opinion on the situation, and, if necessary, performing an intervention based on this opinion" (Leistikow 2018, p. 7).

The commonality in the three terms is that there is a requirement to be achieved by the recipient, either through regulation, guidance document or standards. Countries that inspect health and care systems and services do so through regulation, while countries that assess them may do so via voluntary measures (e.g. non-legislative guidance frameworks) or through regulation.

13.3 Benefits and the Importance of Integrated Care Regulation, Assessment and Inspection Now?

The act of integrated care assessment tends to be more heavily weighted on quality improvement, whereas the act of inspection has historically focused on quality assurance. However, there is emerging evidence that suggests inspection in several countries is moving to include elements of quality assurance and feedback that stimulates quality improvement (e.g. England, Scotland, Denmark, Sweden). Another prominent theme across the globe is assessment of integrated care from the client perspective. This will be further explored later in the section on approaches.

The public has attached increasing importance to governmental regulation of health and social care quality that protects society (patients) from the risk of harm (Frieden 2013; Legemaate 2013; Price 2020). The concept of integrated care regulation, assessment and inspection is important now due to people living longer with more complex health and social care problems. This usually requires intervention from multiple care providers across several organizations and sectors (Baxter et al. 2018; Sullivan-Taylor 2019). Furthermore, public expectations for equitable and coordinated care must be balanced with governments' need to demonstrate fiscal stewardship and quality oversight. These drivers demand more efficient and appropriate care that is client-centred and holistic; continuous from pre-conception and birth to end of life care *(note client is used to include patient).*

As a result, it is no longer acceptable for governments (regulators), assessors or inspectors to focus solely on quality assurance or quality improvement within the walls of a health care or social service organization. The needs of clients extend beyond the responsibility of one sector, organization or provider. Consequently, the regulation, assessment and inspection of this more integrated care across sectors, settings and providers must evolve as well. Assessments and inspections are moving to focus on systems, networks, partnerships and patient pathways rather than individual service or sector quality.

Doing nothing is not feasible in terms of both financial and stakeholder stewardship. One US study found that highly fragmented care was associated with $4542 USD higher healthcare spending ($10,396 USD in the highest quartile/most fragmented versus $5854 USD in the lowest quartile) (Frandsen et al. 2015; OECD 2017). "We must make collaboration across health and social care the default option. This means removing the barriers to collaboration and changing the way we measure performance, fund the system, build our workforce, and regulate services. Only by working across the health and social care system, recognising that health and social care services are often caring for the very same people, can we possibly hope to see the significant and sustainable change that is required" (Care Quality Commission 2018a, b, p. 7).

Ultimately, the perspectives of clients, providers, policy makers and the public determine the value of governmental regulation of health and social care quality. Providers and administrators have the most interaction with assessors and inspectorates and must demonstrate compliance with laws, rules and standards. Mutual respect and a good reputation between these parties allow for social and political debate on health and social care priorities (Danish Institute for Quality and Accreditation in Healthcare 2020).

The OECD report, *Patient Safety, The Way Forward Update* highlights the inter-dependent roles of macro, meso and micro-level levers. Specifically, the foundational levers must include policy and system-wide strategy enablers. This may include legislative changes, regulatory supports and funding models that incentivize and align integrated care rather than sectoral, silo-based care (OECD 2018). Historically, our care systems have been designed to diagnose and treat individuals once they are ill. Now, regulators understand the need to shift focus upstream on healthcare promotion, prevention and social determinants of health. Furthermore, publicly funded, universal systems that integrate primary health care with public health result in better outcomes and fewer inequities (Labonte et al. 2007). "Integrated social and medical services can be 10 times more effective than waiting for families to visit health services" (WHO 2020b, Areas of Work).

The UN's Sustainable Development Goal 3 mandates that we "achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all by 2030" (UN 2020). This will only be possible through the implementation of inter-dependent levers. The approaches section highlights examples of how integrated care assessment or inspection has been introduced to support system transformation and other structural changes in several countries. For example, there may be a reduction of acute care beds in order to shift care to home and community settings. This transformation may be combined with efforts to advance proactive team-based community care for people with complex needs. These system transformations can reduce avoidable acute care admissions and prolong a person's ability to stay safely in their home. Evaluation is therefore a key component given that "establishing integrated care is a multifaceted and long-term process" (WHO 2016, p. 19).

For clients, the benefit of integrated care assessment and inspection is a more seamless, coordinated experience with improved outcomes (Trankle et al 2019). There is evidence that integrated care may reduce hospital admission rates and lengths of hospital stay. However, the effectiveness of integrated care on patient-related outcomes in older adults requires further research (Liljas et al. 2019). Examples from Canada, England and Sweden show how people-centred care principles are influencing co-production of care and will be covered in the subsequent section.

For providers, improved integration and regulation may lead to more efficient care for patients. It has improved experience and collaboration with other care providers based on shared vision and clear accountabilities (Price et al 2020). In Australia, one integrated care model was seen to build capacity across providers (family physicians and specialists) while improving clients' access to care in the community and decreasing hospital and emergency department admissions (Trankle et al. 2019).

Regulatory colleges may benefit from clearer system-level accountabilities and advancing new models of care that improve outcomes for patients and providers. In Canada, the British Columbia Steering Committee on Modernization of Health Professional Regulation recently recommended moving from 20 regulatory colleges to six. The aim is to advance interdisciplinary teams of providers to better meet the healthcare needs of clients and families using consistent standards across professions (Steering Committee on Modernization of Health Professional Regulation 2020).

Always at the forefront, the regulator, assessor and inspector must determine what is critical in the creation of value. This will influence the focus and process of inspection as well as the interventions. Furthermore, evaluation must assess the consequences of regulation, assessment and/or inspection in contributing to the quality of care.

It is also essential to be learning and working collaboratively to bring other data sources and expertise to the assessment or inspection. Countries like Canada, England, Malta and Estonia are doing so through formal and informal channels (e.g. patient surveyors, coordinating with inspectorates across ministries, nation-wide information systems, etc.). Furthermore, many countries use client, staff and physician experience surveys to inform assessment and inspection decisions. "The art is in achieving the correct balance between effort and impact" (Leistikow 2018, p. 18).

13.4 What Role Can Regulators, Assessors and Inspectors Play?

Regulators may introduce health and social care quality policies that include legislation to establish new structures and introduce accreditation or inspection (WHO et al. 2018). This section provides two examples of this regulatory role to implement system-level strategies and create conditions for integrated care assessment or inspection. Some jurisdictions use standards, supported by assessment as an alternative instrument to regulation/legislation (World Trade Organization 2014).

Often assessment and inspectorate bodies have a great deal of experience monitoring quality within organizations and sectors. This, combined with their independence and objectivity, makes them well-positioned to evaluate collaboration between sectors and care providers. For example, in Quebec, Canada—the Ministry of Health and Social Services (Ministère de la Santé et des Services sociaux-MSSS) introduced legislation that "every institution must have the health services and social services it provides accredited by a recognized accreditation body" (Publications Quebec 2019, 107.1).

The value of assessment and inspection of integrated care is that results can inform regulatory and non-legislative efforts to promote new care models and opportunities to strengthen collaboration. It may also identify gaps that occur during points of care transitions—where accountability needs to be added to mitigate risk. Governments, providers, regulatory colleges, administrators and clients all benefit from effective assessment, inspection and reporting of integrated care.

Prior to 2018, the Care Quality Commission (CQC) focused on regulating and inspecting the quality of health and adult social care by assessing individual providers. In their report, *Beyond Barriers*, the CQC reinforced the need for a mandate that enables system-level reviews. "If we (CQC) are to encourage and recognise efforts to collaborate across the health and social care, then we also need regulation to look at the quality of care across whole systems. In reviewing systems, we are able to clearly understand what the journey through health and social care is like for people who use services, their families and carers and the safety and quality of this journey" (Care Quality Commission 2018b, p. 6).

In addition to the regulators role in setting policy for integrated care assessment or inspection, they have a significant role to introduce or decommission laws and policies that create barriers (OECD 2014). With respect to integrated care, these policies may relate to privacy, information sharing, funding, performance monitoring and reporting. The aim is to improve client and provider experience and as well as client and population outcomes.

Presently, in many countries, there is limited evidence of structural reform regulation to ensure integrated health and social services for people with complex needs. This is essential given that considerable evidence highlights that nearly 80% of outcomes for individuals and communities are related to social determinants of health (Magnan 2017). Governments may be able to make incremental progress on integrating health care at the functional, operational and professional level, but results will be limited without addressing the necessary connections to other determinants like income, housing, education and social networks (World Health Organization 2020a).

Historically, good care was about meeting a standard for a condition, organization or within a given sector. The concept of good care has now expanded to include the quality of collaboration across the care network and that services are tailored to the needs of the client and population served. As a result, new standards, assessment and inspection programs are evolving.

13.5 Overview of Approaches Used in Assessment and Inspection Programs

This section highlights mechanisms introduced by several countries to assess and inspect integrated care from the perspective of those receiving care. Clients and families benefit the most directly from health and social care quality, but often have limited visibility to assessment or inspection. To address this, many countries have increased the role of clients and are assessing or inspecting health and social care quality from the client perspective. Furthermore, there is evidence that countries are heeding the OECD advice, “where safety cannot be achieved without the end users being involved…governments should mobilise resources to raise knowledge and improve practices of consumers and citizens overall” (OECD 2014, p. 25).

13.5.1 Canada

Emerging trends in assessment and inspection of integrated care include a more system-level focus and one that follows the client journey. Health Standards Organization (HSO) embedded people-centred care criteria into its standards and accreditation expectations for all sectors and settings since 2015. These criteria require that providers, organizations and systems actively partner with clients, families, and the broader community. Furthermore, health and social care professionals are expected to collaborate with clients and families as equal members of direct care and organization or system (HSO 2019b). HSO’s affiliate partner, Accreditation Canada (AC) introduced the role of patient surveyors as members of the assessment team in 2017. AC surveyors are typically subject matter experts that may include physicians, nurses, pharmacists, social workers and senior administrators. Given the lived experience that patients offer, AC provided orientation and training to both the patient surveyors and the surveyor teams to fully co-design, implement and evaluate the model.

In Quebec, the ministry shifted the focus of accountability for quality from within organizations towards the system that clients and their families experience. Figure 13.1 provides the framework used in the client journey methodology, which is modified to accommodate each program being assessed.

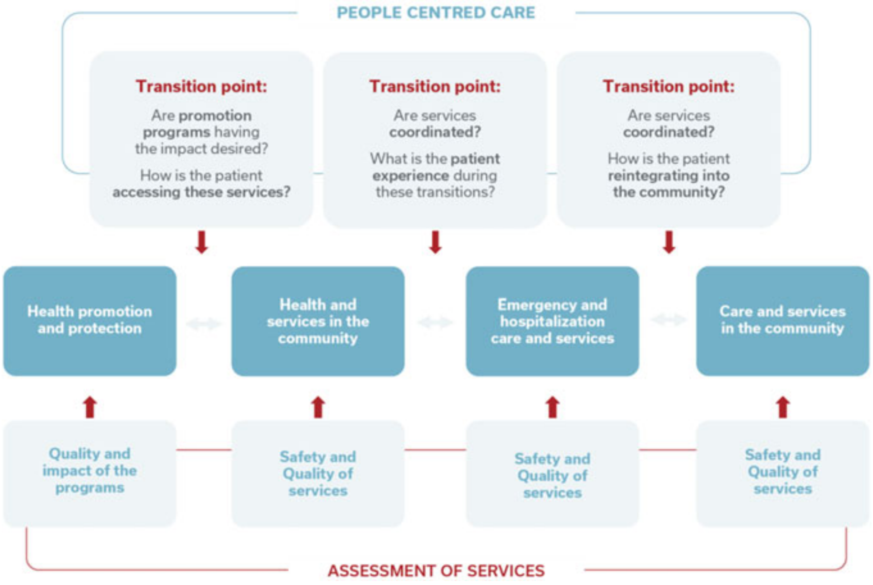

Fig. 13.1 HSO and Accreditation Canada's Client Pathway Assessment (Health Standards Organization 2019a)

In 2021, HSO will release the CAN/HSO:76000 Integrated People-Centred Health Systems Standard which has weaved people partnership throughout each section. It will support policy makers and health and social care system partners to implement and assess integrated care and services in accordance with international best practices. The standard is based on ten principles (Fig. 13.2) and is intended for application at the macro (policy) and meso (operational) levels (HSO 2020). To support local implementation, an additional HSO Pathways Design tool will be released in 2022 to support networks (micro-level) in designing and implementing pathways based on specific client population needs (e.g. child and youth mental health and addictions). To facilitate near-term monitoring, work is underway on an Integrated Care Assessment Tool aligned to the design principles and criteria and will be released in 2022.

13.5.2 England

The Health and Social Care Act 2008, Section 48 provided the necessary levers for inspection and public reporting on 23-local health authorities to address system-wide delayed hospital discharges. The aim was to assess safety, effectiveness, evidence of shared vision, governance and integrated care. The 2018–2019 inspection reviewed how each trust was resourced, accountabilities, their

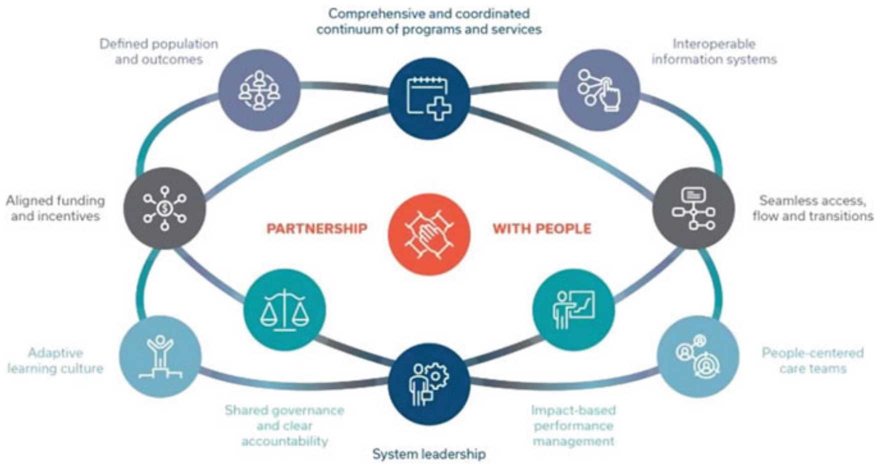

Fig. 13.2 CAN/HSO:76000 Integrated People-Centred Health Systems Standard—Design Principles (HSO 2020)

responsiveness to population and individual needs and involvement of the voluntary sector. It included use of a relational audit feedback tool to measure the health of relationships between people working within health and social care in the local authority areas (systems) (Care Quality Commission 2018a).

Notable findings from England's system-level assessment:

- Social care services may be paid for privately (based on means test), while healthcare services are covered through national insurance.
- Workforce capacity is stronger in professionally regulated roles. In social care, workers are paid less, resulting in a limited pool of unregulated workers willing to deliver services in community settings.
- There is limited coordination between professional regulators.
- There are limited system performance metrics that reflect client and family quality outcomes.
- Consider interpersonal aspects alongside structural changes (Care Quality Commission 2018b).

Figure 13.3 shows the inspection approach that focused on maintaining people's health and well-being at their usual place of residence, care and support during crisis and support to people when leaving hospital. *Making It Real* is a framework now used in England that describes what good looks like from an individual's perspective and what organizations should be doing to live up to those expectations (Coalition for Collaborative Care 2020).

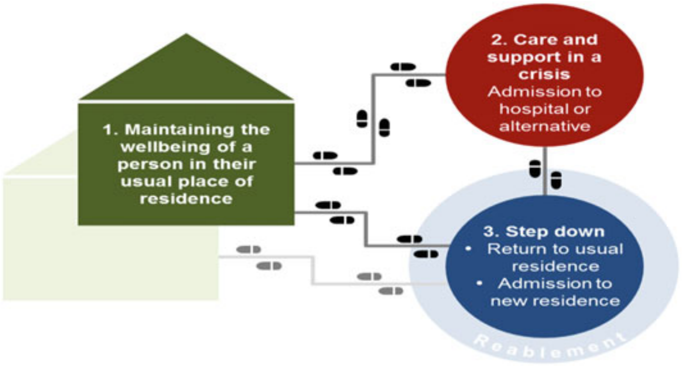

Fig. 13.3 Key areas of Care Quality Commission's system-level review in health and social care authority areas (Ortega 2019)

13.5.3 Netherlands

Since 2015, the Dutch Health and Youth Care Inspectorate has devised ways to involve clients' perceptions in regulation, through social media, deploying "Experts by Experience" and organizing "citizens" panels (Buijze 2019). The Inspectorate role in integrated care is to "identify, set the agenda and promote good collaboration in care networks" (Health and Youth Care Inspectorate 2018, p. 3). When clients receive both health and social care, the various Inspectorates collaborate (e.g. Security and Justice, Health and Youth Care, Education, Social Affairs and Employment).

The Dutch Healthcare and Youth Inspectorate has increased its focus on inspecting and public reporting transitions for populations with complex care needs. These inspections included: seriously ill children requiring specialist care at home, people with severe mental health conditions and vulnerable elderly people. With increased care complexity and less acute and long-term care beds, there was a need to ensure people can stay in their homes and communities safely while receiving the necessary care and services. Specifically, at the local and regional level, inspection is focused on the extent to which providers facilitate collaboration in care networks. At the client-level, inspection evaluates.

- Is care client-centred?
- Is care provided in collaboration with carers?
- Is care coordinated?
- Is care safe?

Inspection findings showed that although new networks were emerging, there was a reduction of beds faster than local networks were being established and consequently a lack of coordination between providers (Buijze 2019).

Achieving quality across care networks requires long-term commitment and joint effort of providers, administrators and governments (local, regional and system). This raises the issue of leadership, culture and skills needed in assessment and inspection bodies as well as the systems they are evaluating.

In their *Multi-Year Policy Plan 2020–2023,* the Inspectorate focus is on increasing trust and collaboration, including increased involvement of patient/client and citizen perspectives. This involves strengthening supervision of personal care, addressing provider availability, safe introduction of technologies and supervisory instruments and effective use of data in inspections (Health and Youth Care Inspectorate—Netherlands 2019).

13.5.4 Denmark

The Danish Healthcare Quality Programme (DDKM) is accountable for accreditation of hospitals. In their context, the purpose of accreditation (assessment) is to evaluate if the hospital meets the miminal requirements in the accreditation standards and to provide feedback in a way that inspires further quality improvement (Danish Institute for Quality and Accreditation in Healthcare 2019). Furthermore, evaluation of the quality is on the outcome rather than merely process or procedure. Assessors "look at the performance of the whole system from the perspective of the service user" (Danish Institute for Quality and Accreditation in Healthcare 2019, p. 11).

The Danish Patient Safety Authority was created in 2015 within the Danish Healthcare Act, Section 212A and 213. They support the Ministry of Health in management of patient safety and learning within the healthcare sector through supervision and reporting on acute care, nursing home care and integrated home care units. Social care is currently inspected separately though there is movement towards collaboration across the ministries. Evaluation on impact suggests that input from inspectors was useful and valued. Findings from integrated care inspections reported insufficient information upon discharge as well as lack of coordination and accountability between care providers and services. They are currently working to balance the use of various data sources (patients, providers and policy makers) (Haerslev and Dahlgaard 2019).

13.6 Value of Assessment and Inspection During System Transformation

13.6.1 Sweden

The Swedish health and social care system are highly decentralized and managed separately. Limited joint work had resulted in inadequate coordination between hospitals, primary care and social care services (Liljas et al. 2019). Over the past

30 years, Sweden halved the number of hospital beds and now has the lowest hospital bed rate per capita in the European Union. However, this reduction in beds did not see a corresponding increase in home help services. Consequently, the structural changes increased the pressure on municipal home help and primary health care and resulted in increased emergency department visits (Liljas et al. 2019). During this period, Sweden had the lowest performance on coordinated care of 11 OECD countries in the 2013 Commonwealth Survey, and this persisted in the 2016 results (Davis et al. 2014; Schneider et al. 2017). There have however been notable advancements in clients' ability to access their personal health information. In 2019, Sweden had the highest performance compared to its OECD peers when providing clients with online access to appointment scheduling, test results, prescription refills and visit summaries (Doty et al. 2019).

The recent Health and Social Care Inspectorate (IVO) work was prompted by the lack of care coordination. IVO focused on inspecting the care experience for people living with multiple sclerosis from the client perspective. Previous inspections included provider and administrator interviews; now, inspection involves talking with clients first. This was a substantive cultural shift and process change. Plans are underway to expand this model nationally to ensure the scope of the Health and Social Inspectorate mandate facilitates the inspection and necessary interventions.

IVO used client surveys, client interviews, reflection material and facilitated dialogue with care providers and organizations. The transcripts and videos of the surveys and interviews were summarized in reflections and used to support facilitated quality improvement dialogue with organizations, networks and interdisciplinary providers. Prior to this exercise, many had limited understanding of client user perceptions or overall operations. Inspection is focused on the level of co-creation, holistic care perspectives and adapting care to the individual. In 2020, the Inspectorate is developing a plan to deliver system-level inspection for primary and community care integration (Jonsson and Berneke 2019).

13.6.2 Malta

The Malta Social Care Standards Authority (SCSA) was created in 2018, with the aim of regulating social care through dialogue and collaboration. The SCSA establishes social regulation standards and employs these standards to inspect, monitor and licence social welfare service providers. They also take action where needed, to protect clients (Social Care Standards Authority 2020a). The SCSA also convenes quarterly collaborative platforms that bring together service providers to discuss challenges and best practices (Vella and Muscat-Camilleri 2019).

The SCSA standards and guidelines are legislated and client-oriented (not process-oriented). Performance indicators are built into the guidelines and used in the inspection visits for monitoring and licencing purposes (Social Care Standards Authority 2020b).

A unique feature in Malta is their use of augmented intelligence in planning and delivering social care services. They supplement inspections with data on service provision collected through social intelligence exercises. The results are presented back to service providers through reporting, presentations and dialogue (Vella and Muscat-Camilleri 2019).

In 2019, the SCSA collaborated with seven health authorities to conduct joint inspections of residential services for older persons using an integrated data system with results processed by the SCSA. Further collaboration may include training for carers, digital access to national health records for staff in residential settings and better handover between national health services and providers. The aim is to maximize human resources and interventions that improve care outcomes (Vella and Muscat-Camilleri 2019).

13.6.3 Norway

The Norwegian Board of Health Supervision supervises health, social and child welfare services. They have performed thematic inspections of care in two key areas: coordination between hospitals and primary care and integrated care for people with mental health and substance misuse. For these inspections, the inspectorate used a combination of data sources that included electronic health records, patient and provider surveys as well as interviews with patients, providers and system leaders (Hovlid 2019a). Findings from these inspections highlight.

- Lack of shared decision-making (both clients and primary care providers);
- Delays in information transfer during transitions and lack of coordination; and
- Lack of governance across services resulting in unclear responsibilities, despite having formal collaboration agreements in place (Hovlid 2019a).

The Norwegian Board of Health Supervision has worked extensively to strengthen the user perspective in inspections. They established a national users' council that provides input on how to incorporate the user perspective in all inspection activities. Moreover, they have introduced different ways of collecting and utilizing user data during inspections and incorporating users in planning and conducting inspections. Research funded by the Norwegian Board of Health Supervision is underway to better understand the impact of inspection activities and how resources can be optimized for impact (Hovlid 2019b). The first project in this research series focused on early diagnosis and treatment of sepsis and found lack of care coordination and delayed treatment (Husabø et al. 2020).

13.6.4 Scotland

The *Public Bodies Joint Working Act 2014* provides the legislative mandate for Integration Authorities. They are responsible for integrating health and social care services to improve outcomes for people against the national health and well-being outcomes framework. This legislation also required the Care Inspectorate and

Healthcare Improvement Scotland to inspect the planning, organization and coordination of the services (Mitchell et al. 2019).

Despite differing cultures, priorities and approaches, these two inspection bodies worked together to develop the Health and Social Care Standards and new methodology that was implemented in 2017. Since Integration Authorities were at an early stage of development, inspections assessed performance, strategic planning, commissioning and leadership in adult health and social care. Their inspection focused on quality assurance, improvement and innovation. Together, the Care Inspectorate and Healthcare Improvement Scotland jointly developed resources that included a shared electronic workspace to support data gathering and synthesis of inspection evidence. They also used learnings from inspections, after action reviews and feedback from the Integration Authorities to support enhancements of their integrated care inspections (Mitchell et al. 2019; Fidelma and Mark 2019).

In 2019, the Care Inspectorate and Healthcare Improvement Scotland developed a new inspection methodology focused on integrated service outcomes achieved. This reflects Scotland's national health and social care standards, which are person-centred and rights-based. These standards establish what people can expect when using the health and social services in Scotland. The new inspection methods will commence in 2020 and are accompanied with improvement projects and resources (Fidelma and Mark 2019; Care Inspectorate (Scotland) 2019).

13.7 Regulation as a Barrier or Facilitator to Integrated Care

There are many examples where regulatory practices have not created the necessary conditions for integrated care systems (Buch et al. 2018; World Health Organization 2016). For integrated care systems to sustain, they must include legislation, funding and administrative enablers. Each of these macro-level influences must be aligned to foster integrated care at the meso (organization) and micro-levels (direct care) (Auschra 2018). Countries that are more advanced in this regard ensure that legislation reinforces expectations; specifically, goals and outcomes of integration. A leading practice in regulation development is consultation with the various stakeholders that will be implementing or impacted by the regulation. In some cases, regulations are implemented in a voluntary manner (e.g. Ontario Health Teams, Canada (Ontario Ministry of Health 2020a), whereas other governments have mandated integration (e.g. NHS England). Regardless of method, governments must align the necessary funding and administrative levers so that all system actors including providers, administrators, patients and the public understand what is expected.

Denmark provides an example where providers did not perceive value. In January 2018, thousands of doctors signed a petition stating their lack of confidence in the Danish Patient Safety Board. Consequently, the mandatory accreditation of primary care physicians was discontinued in 2019 in favour of other strategies to promote quality improvement and coordination (Leistikow 2018; Rosenfeldt 2018).

Integrated care systems can enhance quality, improve system and provider efficiency, reduce costs, as well as improve access and patient satisfaction (Baxter et al. 2018; Goodwin and Smith 2011; Marino et al. 2018). While these benefits of integration have become clearer, it is less obvious what precise regulations and inspection models will reinforce the best outcomes in their respective contexts.

Emerging themes include evolving assessment and integration models to:

- Better support populations with complex care needs in their communities;
- System performance measurement that shifts from monitoring outputs to how organizations collectively improve outcomes for people and populations;
- Support system-level collaboration; and
- Assess, inspect and publicly report on the action of co-design and co-production.

Equally timely is whether the assessment and inspection are mandatory and how they are funded. When mandated through regulation, most governments currently use public funds to cover inspection and assessment costs. Though some would argue that where government regulates inspection through public funds, it must demonstrate the social added value of its supervision (Leistikow 2018).

Assessors and inspectorates are working to evolve methods to ensure they are fit for purpose. Some current challenges relate to appraisal of governance structures that advance integrated people-centred care (Minkman 2020). Furthermore, it can be difficult to determine who is accountable to address the gaps and shortcomings in care transitions. This necessitates the need for learning and sharing of regulatory and inspection practices as well as allocation of funds towards research and knowledge mobilization. It is essential that outcomes and experiences for clients and their caregivers are evaluated and improved upon. The “learnings from assessments and inspections inform refinement and support needed to scale broadly across system, organizational and care levels” (Sullivan-Taylor 2019, p. 1).

Regulation of integrated care must demonstrate value and ensure policies incentivize more people-centered health systems, reflecting both the needs of populations and individual patients (Goodwin 2018). This should include systematic measurement of patient-reported outcomes and experiences (World Health Organization et al. 2018). At present, there is limited collection of indicators sensitive to monitoring effectiveness of integrated care. That said, patient-reported measurement has expanded in ten OECD countries. Patient-reported experience and outcomes offers insights on how integrated care is performing and where gaps persist across care settings and providers (Fujisawa and Klazinga 2017). Standardized data collection and reporting across countries often requires regulatory intervention.

Another challenge is the need to clarify accountability between health and social service providers, particularly when these are often governed and regulated by different ministries or governments. This will improve transition gaps between care providers that impact client experience and outcomes (Haerslev and Dahlgaard 2019; Hovlid 2019a; Sullivan-Taylor 2019).

Some policies have introduced new models and/or settings of care. These have included alternative levels of care with interim step-down facilities for those unable to go home or awaiting long-term care placement. Additional regulation has increased the scope of services providers are able to deliver. Examples are the expanded scope of paramedics to provide palliative care at home, increased scope of prescribing by nurse practitioners and allowing pharmacist to administer immunizations (Ontario Ministry of Health and Long-Term Care 2020b). We have also witnessed incentives for various system actors to effectively work together helping people with complex care needs. NHS England introduced the Vanguard program to test models of integrated care, supported by resources including funding (Checkland et al. 2019). Canada, England, Sweden and several other countries have also introduced primary care reforms to advance integrated care (Aggarwal and Williams 2019; Doty et al. 2019; NHS England 2020).

There has been debate over the strength of top-down vs. bottom-up approaches in advancing integrated care systems and no doubt, both are necessary. The evidence would suggest that countries with "coherent, whole system approach…like Norway may be more effective" (Goodwin 2018).

It is important to understand the dynamic nature of regulation, assessment and inspection. As integrated care evolves, expectations among clients will likely increase. Governments must be diligent in their engagement tactics to validate outcomes that are most important to patients and citizens. Subsequently, as the outcomes are clarified, it becomes the role of regulators, assessors and inspectors to ensure the necessary levers are in place to achieve these outcomes. "A well-formulated enforcement strategy, providing correct incentives for regulated subjects can help reduce monitoring efforts and costs, while increasing the efficiency and achieving better regulatory goals" (OECD 2014).

A good example on the role of understanding diverse stakeholder expectations is from a study of eight countries. It looked at the importance of outcomes from the perspectives of patients, caregivers, providers, funders and policy makers. The findings showed that most stakeholders valued enjoyment of life as very important and cost as much less important. However, there was a two-fold difference between stakeholders in some outcome areas. For example, in the Netherlands, outcomes related to costs were considerably more important to policy makers than patients, whereas in Germany, patient centeredness was more important to providers than to patients or their partners. In three countries, patients included continuity of care in their top three most desired outcomes (Rutten-van Mölken 2018). This study reinforces the importance of engagement to understand the value of specific outcomes desired by stakeholders. These values must inform integrated care regulation, assessment and inspection.

It is imperative to keep a line of sight on the "overwhelming evidence of the 'softer' issues that will often influence whether integrated care models succeed or fail" (Goodwin 2019). The capabilities of coordinated governance, leadership and management, effective teams and networks and positive cultures and behaviours are less easily regulated, but may ultimately determine whether the desired outcomes are to be realized (Kershaw 2018).

The necessary capacity, skills and training for the health and social service systems as well as those that assess and inspect them will need to evolve. No longer will hierarchical leadership models suffice to ensure quality. Leaders will need to be collaborative facilitators that work well across boundaries and bring clarity of purpose to empower others. Interdisciplinary teams will include professional, unregulated and voluntary sectors that will need to work seamlessly to support the needs of people and populations with complex needs.

Countries like Norway, New Zealand, Sweden, Netherlands and the UK have implemented regulation that enables robust information systems. These improve care coordination and patient safety across providers through sharing of labs, diagnostics, medication and client summaries (Doty et al. 2019). System-wide data repositories may also facilitate more seamless integrated care assessment and inspection. We are learning that having a system-level assessment or inspection program enables iterative monitoring of changes that may foster responsive action by regulators, providers, administrators and citizens.

13.8 Post-COVID-19 Implications

The COVID-19 pandemic has touched every facet of health and social care systems globally and required significant near-term changes to regulation, assessment and inspection. In many parts of the world, onsite visits were put on hold, and risk assessments were undertaken to focus support and/or oversight on parts of the health and social care system where it was most warranted. Much of the focus during the response and recovery stages has included providing just-in-time resources and assessments for specific sectors/settings and in some cases for specific population types (e.g. dementia care, long-term residential care, childcare centres).

Furthermore, the pandemic has led to a public call for improved regulation, assessment and inspection in areas hit hard, including long-term care homes. It also reinforced the need for additional scrutiny in emergency disaster preparedness and management and infection prevention and control.

An emerging trend resulting from the pandemic has been a shift towards virtual assessments and inspections. During the period with strict travel and contact restrictions, some countries implemented virtual assessments enabled by information communication technologies. The model has limited or no on-site staff (inspectorate or assessor) with team members linked virtually. This shift enabled continuity, improved efficiency and consistency across organizations, as well as public and provider confidence. Longer-term this may advance accreditation into new areas (Qudah 2020; Vehring 2020).

Virtual assessments and inspections require additional training for assessors and staff in the organizations and systems being assessed. ISO standards exist for remote assessment and reinforce that all parties are aware of their role in the process, inputs, expected outputs, risks and opportunities to achieve the program objectives (Castro Alves 2020). There are limitations to virtual assessment such as the inability to assess culture, communication between patients and providers and complex organizational or system activity (Vehring 2020).

13.9 Summary

Effective regulation, assessment and inspection of integrated care offer benefits that are shared among governments, providers, regulatory colleges, administrators and clients. However, these levers must be tightly woven to direct the necessary system changes and monitor the effects of regulation on the people that use health and social care services.

The emerging practice across countries is that of embedding the experience of the client, assessing or inspecting from the client perspective. Additionally, there is a movement to monitor the quality of integration across services rather than from within a single organization, setting or sector. This necessitates a shift in the data collected and used to measure how organizations work collectively to improve outcomes for people and populations.

Consequently, collaboration is essential across various Ministries, assessment bodies and inspectorates. This need for collaboration must be balanced with independence so that the assessor or inspectorate is neutral and able to publicly report findings. Though we need to monitor and improve quality within organizations and sectors, the purpose of integrated care regulation, assessment and inspection is on how well systems deliver the services people and populations require for health and well-being.

While this chapter focused on integrated care regulation and the use of assessment and inspection levers, governments also enable integrated care through regulation of care providers. This will continue to evolve in order to increase interdisciplinary teams' accountability for improving client and population outcomes.

Furthermore, more information is needed on what exactly drives improved performance within integrated systems. Experience across many countries acknowledges that it is not simply a matter of copying and adopting models. Local context is extremely important when introducing methods from one system into another. More insights are also needed on the impact of integrated care on client experience and outcomes, as well as better indicators to monitor progress towards integrated people-centred care systems.

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Leadership in Integrated Care

14

Volker Amelung, Daniela Chase, and Anika Kreutzberg

14.1 The Neglected Topics in Designing Integrated Care

Leadership is certainly one of the neglected topics in integrated care. This is surprising, as the leadership challenge is greater in networks for integrated care than in typical organizations (Sydow et al. 2011). This is due to, on the one hand, network structures that require leadership of and within networks, and on the other hand, a higher level of complexity in the healthcare sector (see Fig. 14.2).

Structures in health care seem to be very complex due to numerous reasons:

- Services are usually provided by more than one person which brings in complexity as communication about various services and coordination of these need to take place.
- Care providers act within a specific setting and its respective management.

The figure clearly demonstrates the need for a more complex leadership approach than in traditional hierarchical organizations.

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14.2 No Coincidence: What Management Literature Tells Us About Leadership

In common management literature, there is a discussion about whether management or leadership approaches are appropriate to successfully lead modern companies (Mintzberg 2013). Whether an organization is "*overmanaged and underled*" or "*overled and undermanaged*" is difficult to assess from the outside. Clearly, management and leadership need to be synthesized and well-balanced in an organization since they depend on each other (Mintzberg 2013; The King's Fund 2011). Thus, it is the leader's task to communicate the organization's goal and align management and administration to take aim at these goals (The King's Fund 2011).

14.2.1 Manager Versus Leader

> Management is doing things right; leadership is doing the right things. (Peter F. Drucker)

In this chapter, the focus is to provide an overview of leadership and management. For this reason, we give a rather broad definition of leadership and management although there is a plethora of definitions for both.

> Leadership is a process whereby an individual influences a group of individuals to achieve a common goal. (Northouse 2013).

Management necessarily takes place in every organization and functions as the interface for people, information, and action (Mintzberg 2013). Interestingly enough, the word "to manage" originates from the Latin expression "*manus agere*" which basically means to lead from the hand and reportedly was used in the context of leading or taming horses (Mintzberg 2010).

In Kotter's (2001) paper on the differences between managers and leaders, the main characteristics and tasks of each are outlined (see Table 14.1).

Table 14.1 Differences between leadership and management

Leadership	Management
Preparing a system for change	*Coping with complexity*
Example: The leader knows the conditions of a market which oftentimes lead to change (e.g., new competitors) and prepares the system for change	*Example*: The manager oversees structures and tasks in a system in order to prevent chaos, specifically in large organizations
• Setting the direction • Aligning people • Motivating and inspiring	• Planning and budgeting • Organizing and staffing • Controlling and problem solving

Source Kotter (2001)

14.2.2 Types and Styles of Leadership

The general discussion on leadership takes place on the continuum between more and less abstract theories and practical principles. Literature on leadership contains many approaches and entails quite a history. Many sources have roots in the field of psychology and human resources research. Thus, this overview makes no claim to completeness. Newer literature focuses on key qualifications of leaders, which we will outline toward the end of this chapter. In the following paragraph, we introduce a selection of theories and concepts (overview, see Table 14.2).

In the first part of this overview, we will elaborate on four historical leadership eras.

14.2.2.1 Theories

Throughout the vast literature on leadership theories, Den Hartog and Koopman (2011) demarcate four leadership eras throughout the twentieth century. Elaborating on each of the theories' leadership styles would go beyond the scope of this overview. According to Den Hartog and Koopman (2011), leadership developed from "*who leaders are*" (trait) to "*what leaders do*" (behavior). Over the course of the century other important topics emerged: "*how leaders act in certain situations*" (contingency) and finally "*how leaders engage followers for common goals*" (new leadership) (Table 14.3).

14.2.2.2 Learning from the Big Bosses' Experience

Religious role models like Mahatma Gandhi, entrepreneurs like Jack Welch or Steve Jobs, politicians like Ronald Reagan or military leaders like Colin Powell: they all were great leaders. Over time, they gained invaluable experience leading people and are entitled to pass on their lessons learned on this topic. Two big leaders of modern times, Jack Welch from competitive industry and Colin Powell from the

U.S. Army where hierarchies are part of the system, were selected to highlight their leadership credo in this summary. We chose two out of many examples to illustrate the line of argumentation in these approaches.

Table 14.2 Types and styles of leadership

Theories	Principles	
Leadership theories	*Individual leadership styles*	
• Den Hartog and Koopman (2011) • Blessin and Wick (2014)	Individual examples of "role models"	Examples based on empirical research
	• J. Welch • Powell (2013)	• Kouzes and Posner (2009) • Schoemaker et al. (2013) • Battilana et al. (2010)

Table 14.3 Overview of four leadership eras throughout the course of the twentieth century

Leadership theory	Explanation/leadership style
Trait approach (search for "the great man") **!** Up to late 1940s	*Focus on innate characteristics of the leader and his influence on the success/change achieved*
Style approach **!** Late 1940s–late 1960s	*The leader's behavior is pivotal to success/change achieved. Leadership behavior can be learned* **!** e.g., authoritarian, democratic, laissez-faire
Contingency approaches **!** Late 1960s–early 1980s	The leader's behavior needs to be congruent with aspects of the situation; the effectiveness of leadership is contingent on the situation. Thus, there is not only a single leadership style appropriate for the situation but many. The leader must be capable of distinguishing between and carefully applying these
New leadership **!** Since early 1980s	E.g.: Transformational, charismatic, inspirational, visionary leadership New leaders attain extraordinary levels of followers' motivation and engagement to accomplish the organization's goals

Source Adapted from Blessin and Wick (2014), Den Hartog and Koopman (2011)

Jack Welch: Former CEO of General Electric

Over the course of 20 years (1981–2001), Jack Welch was CEO of General Electric. In order to sustain success, he needed to reorganize one of the world's largest companies several times to achieve his goal of being among the best companies. This entails understanding and forming the skill- and mind-set of 290,000 employees by overcommunicating new strategic and organizational goals (Bartlett and Wozny 1999; Krames 2005).

Jack Welch himself spent a vast majority of his time on people's issues, by training and developing them. He aimed to create so-called *A Players with four E's* (see Table 14.4).

The vision of excellence in every competitive market is only one of many possible ways to lead people. Different branches afford different ways of leadership. Next, Colin Powell's leadership style will be shortly illustrated.

Table 14.4 Jack Welch's "Four E's" of his best players as prerequisites for leadership

Energy	*Energize*
Fascinated by ideas and eager to open new doors even though this might involve risks	Sharing this enthusiasm with others in order to have a common vision
Edge	*Execution*
Being a strong competitor and not hesitating to make tough calls (e.g., firing someone) for the good of the company	Always eager to perform and deliver results. Leaders can turn vision into results

Source Bartlett and Wozny (1999), Krames (2005)

Colin Powell: Former U.S. Secretary of State

Serving for the U.S. Army as four-star general as well as in the George W. Bush administration from 2001 to 2005 as Secretary of State, Colin Powell was confronted with the topic of leadership for a long time and published his *Leadership Secrets* in 2002. A summary of his leadership principles is provided in Table 14.5. Even these two leadership approaches are from very different settings, they add significant value for the discussion about leadership in health care. Both focus on principles and values.

14.2.3 Leadership Learnings from Empirical Data

Separate from situational theories of leadership, there are different standpoints regarding whether one needs to be a born leader or one can learn to be a leader.

14.2.3.1 Fundamental Practices by Kouzes and Posner (2009)

In their book, Kouzes and Posner (2009) discuss pivotal prerequisites to be a leader based on their empirical research since 1983. By interviewing leaders and their followers, the authors could identify five fundamental principles for leadership which are summarized in Table 14.6.

Table 14.5 Colin Powell's principles to excel in leadership

Topic	Examples of principles
Being a provocateur	*Always being diplomatic and polite will not bring forward ideas of change*. Change needs to be a top priority in the organization and has to be communicated clearly
Promoting discourse	*Promote an open dialogue* with all levels of staff by establishing an open-door policy. Everyone can participate in communication and information flows diverse opinions are more than welcome *Leaders must avoid the ego trap* by accepting new facts and change. Do not be too focused on your own path if it is not aligned with the organization's vision *When instituting change* keeps authority and their GO in mind, yet in some cases, it is fundamental to go forward with alternatives
Overwhelming strength	*Define your own strategic interests* by stating your mission clearly but only if you are capable of implementing it. Implement change only in certain parts of an organization while being open for alternatives in other parts
People over plans	*Choose people on your team* who are loyal, integer, and energetic and let them perform by decentralizing your organization's structure. Leadership can take place on all levels and does not need to rely on job position or seniority. The organization should be balanced out and a fun working environment for others. This means that individuals need to be balanced as well by spending time on home and family life
Detail diligent	Leaders are aware of details in their own organization, i.e., know all the information flowing to prevent mistakes. Details open doors for extraordinary opportunities

Source Harari (2002), Powell (2013)

Table 14.6 Summary of fundamental leadership practices (A–E) and derived leadership commitments (1–10)

Fundamental practice	Short explanation
A. Set an example	Leaders are always willing to go first and set an example as they have a detailed operational plan
1. Strengthen others, give away power, assign critical tasks, and offer support	
2. Make your behavior consistent with shared values. Achieve small wins that promote consistent progress and build commitment	
3. Achieve small wins that promote consistent progress and build commitment	
B. Inspire a shared vision	At the beginning of every successful business is a vision of the ideal future state of the organization
4. Experiment, take risks and learn from your mistakes	
5. Envision a future that is more uplifting and ennobling	
C. Challenge the process	Leaders are pioneers who are open to new grounds and the unknown
6. Seek challenging opportunities to grow, change, innovate, and improve	
D. Enable others to act	Enforcing your team for action, building trust and solid relationships and competencies are key for collaboration and a sense for responsibility
7. Appeal to others people's values, dreams, and hopes to share your common vision	
8. Foster collaboration by promoting cooperative goals and building trust	
E. Encouraging the heart	Build a culture where values and success are appreciated and celebrated
9. Recognize individual contributions that lead to the success of each project	
10. Celebrate team achievement, not just individual ones.	

Source Adapted from Kouzes and Posner (2009)

14.3 Leadership in Networks

Leadership in networks (or ecosystems) differentiates itself fundamentally from that in traditional hierarchies. There are five crucial aspects of leading networks:

1. Network structures resemble new hierarchies that have to be embedded in well-established structures;
2. Networks render it possible that individuals can lead other individuals, likewise organizations can lead other organizations (Sydow et al. 2011);
3. Fundamentally, network structures are parallel structures with little power and are predominantly free of hierarchy. Specifically, rules and resources create power;
4. Negotiations are more important than "Command and Control" and are therefore a matter of more complex and invisible structures (Sydow et al. 2011);
5. The leadership complexity is considerably greater than in traditional structures, as stakeholders represent various sectors and professional cultures.

Sydow et al. (2011) have developed a regulatory framework in order to describe the type of leadership applied in the respective network. In its basic form, it can be transferred to any system, e.g., healthcare systems. Its fundamental purpose is the classification of leadership style rather than evaluating it.

In Fig. 14.1, four different networks, e.g., leadership in healthcare networks such as integrated care systems, are illustrated, embedded within three axes:

- Organization of the network: emergent—formal
- Nature of leadership: centralized—distributed
- Leadership attribution: individual person—organization.

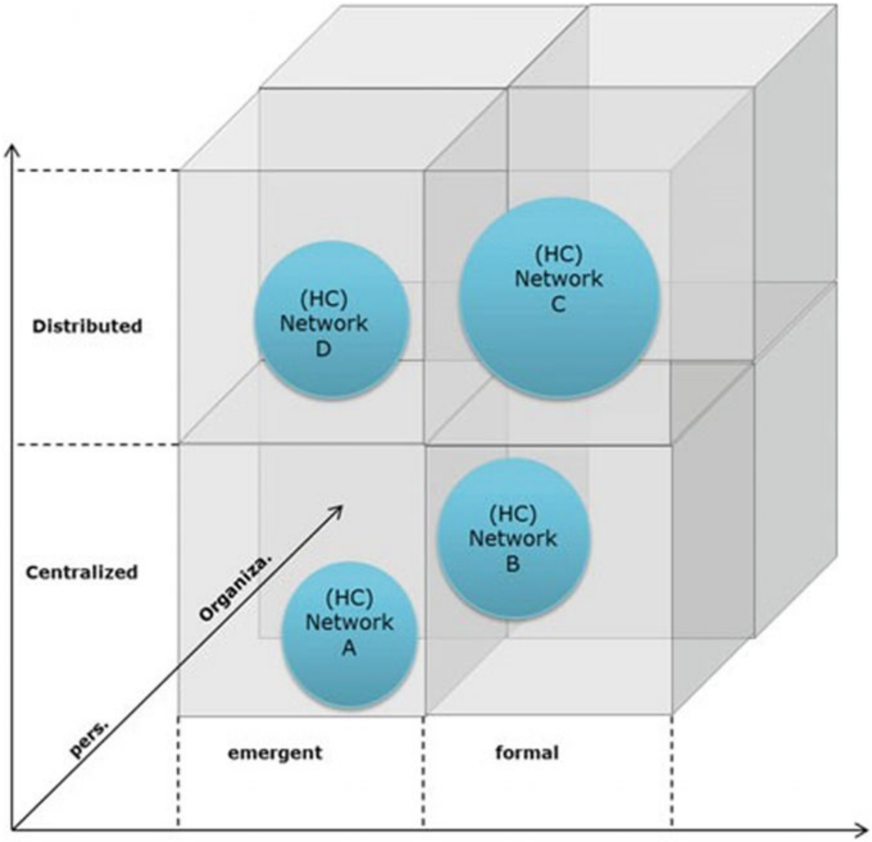

Fig. 14.1 Example of healthcare (HC) networks localized within dimensions of organizational structure. Size and location of a network within the dimensions do not relate to quality of organization and leadership. *Source* Adapted from Sydow et al. (2011)

All three dimensions pertain to both leading a network and leading within a network.

The first dimension refers to the structure and style of organization. It reaches from emergent/ad hoc/informal organizations to formally organized structures. Within the network structures, one can detect both forms in parallel, meaning in different areas of the network various forms of structures might apply.

The second dimension differentiates the nature of leadership according to the degree of centralization. Within network structures, one can distinguish between very centralized and decentralized/distributed structures.

The third dimension considers the question of whether leadership refers to persons or organizations.

A completely new question is the role of leadership in ecosystems. Ecosystems from an economic angle describe a group of interacting firms that depend on each other's activities as a new way to depict the increasingly competitive environment (Jacobides et al. 2018). They can be connected more loosely by shared knowledge, by using the same platform (e.g., Amazon market place, App store) or by contributing to the same value-added chain. As ecosystems differ widely, there is no principal answer to how these business networks can best be led. Platforms such as Amazon require most probably a very tight leadership, as reputation and acceptance of the platform heavily depend on the performance of the partners. Ecosystems in the healthcare sector start to emerge as well. At the moment, there is little evidence on this topic, but its relevance will increase in the near future.

14.4 Leadership in Health Care: Learning from Best Practice

Not surprisingly, there is evidence that leadership matters in health care, too (The King's Fund 2011). Engaged leadership can achieve an increase in healthcare quality and a reduction of patient harm (Swensen et al. 2013). Regulators, payers, communities, and informed patients increase the pressure for leaders of healthcare delivery systems to achieve better performance. Efforts that have been tried so far focused most times on micro- or project-level. Achieving improvements on an organizational level appears to be much harder (Reinertsen et al. 2008).

To a certain extent, general leadership theories and principles can be applied in the healthcare sector as well. Particularly nowadays, with increasingly competitive structures in most countries, healthcare organizations have evolved to be more business-oriented units that need to be led appropriately. Therefore, leaders of healthcare organizations often are facing challenges similar to leaders in other industries. However, the healthcare sector also has some unique characteristics which need to be addressed.

14.4.1 What Is Different in Health Care: The Logic of Healthcare Delivery

Healthcare organizations can be described as complex adaptive systems which are difficult to manage and organize in detail (Reinertsen et al. 2008). Delivery processes can be compared to value chains with structurally fragmented activities (Amelung 2019). Each medical intervention is delivered in small disconnected applications, yet they interfere with each other (Glouberman and Mintzberg 2001). Furthermore, healthcare interventions always take place for persons and communities. Den Hertog et al. (2005) illustrate how different sectors in health care (walls; sectors and interdisciplinarity) and system levels (ceilings; policy-makers, managers, and professionals) create a hard to manage and innovation-hampering system (see Fig. 14.2). These walls and ceilings are embedded in a patient-centered and community-based environment in which leadership needs to design and implement change.

Berwick et al. (2008) introduced the idea of the triple aim. This idea requires the simultaneous pursuit of three aims in order to improve a healthcare system:

- Improvement of the individual experience of care
- Improvement of population health
- Reduction of costs of care.

These goals need to be treated interdependently as changes made to achieve one of the goals can affect the other two, often negatively. That means the aim lies in balancing the triple aim (Berwick et al. 2008). To achieve triple aim results, high-impact leadership is needed (Swensen et al. 2013), bearing in mind two critical enablers for all of the abovementioned, that is staff health and staff satisfaction.

Triple aim results represent a shift from volume to value (Swensen et al. 2013). All too often quality in healthcare organizations is seen as an expense or regulatory requirement, but leaders need to develop a fundamental understanding of quality as

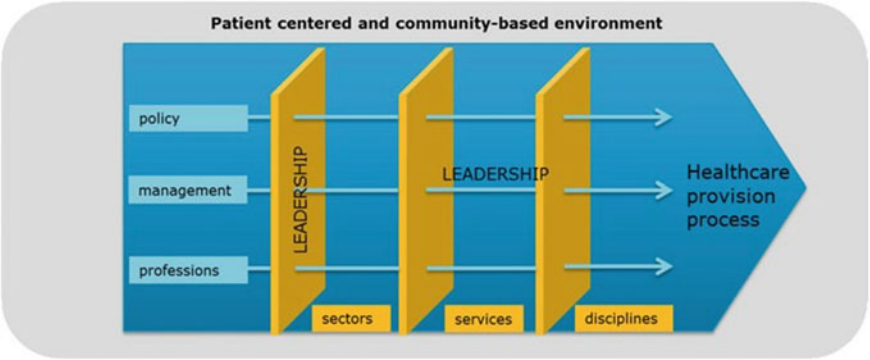

Fig. 14.2 Walls and ceilings within healthcare systems. *Source* Adapted from Den Hertog et al. (2005)

a business strategy and part of their core work. As quality improvement is rarely part of the medical school curriculum, leadership must be familiar with the science and potential of such methods (Swensen et al. 2009).

New invasive interventions often carry significant risks and costs. Leadership in health care needs to understand when interventions are beneficial and evidence based. This stresses the importance of data in this sector. Health care is dominated by data, e.g., from clinical trials or healthcare services delivery data which build the basis for guidelines. Guidelines are the summary of best evidence and foster the triple aim. They can be an effective tool to develop a core standard work based on best practice where deviations from the rule are expected only for patient-centered reasons, not because the physician "*likes to practice this way.*" Standardization is important to create a culture of safety in healthcare delivery (Swensen et al. 2009). But standardization in medicine always causes an inherent tension between excellence and physician autonomy which leads us to the next section about the role of professional cultures in health care.

14.4.2 Professional Cultures in Health Care

Delivering high-quality health care requires the creation of a collective mind characterized by optimal teamwork, communication skills, and an attitude of transparency and psychological safety, that is a professional culture. For the establishment of this professional culture, physicians have played a major role as leading persons. In many countries, healthcare systems only have scarce resources for big challenges, e.g., increase of chronic diseases or age of the population. For this reason, there is a demand for more, respectively, different, leadership and management in the healthcare sector than what traditionally was provided by physicians. For effective leadership and management, difficult and controversial decisions are required to be made which may infringe on the autonomy of healthcare providers. Doctors strongly believe that physician autonomy is crucial to quality in health care. The challenge in health care is that even with increasing leadership and management efforts physicians do not feel a loss of control or want to reject new forms of leadership and management (Schmitz and Berchtold 2009).

Glouberman and Mintzberg (2001) characterize healthcare organizations by four main subsystems: Cure, Care, Control, and Community (see Fig. 14.3). All are highly differentiated. Physicians, representing subsystem Cure, as well as the nursing staff, subsystem Care, work in the operative core business of patient care. But, they are divided by completely different roles. Physicians work *in* the hospital but not *for* it. They intervene with the patients in short visits and control treatment decisions before they depart, leaving most of the care to the nursing staff. They distinguish themselves by their medical discipline. In some countries such as Germany, the nursing staff can hardly specialize within their profession. They are tightly committed to the institution and provide care on a rather continuous basis seeking to coordinate complex workflows.

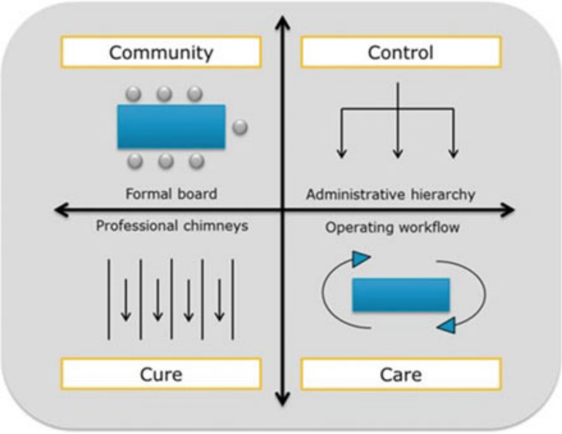

Fig. 14.3 Differentiated subsystems in health care. *Source* Glouberman and Mintzberg (2001)

Control—representing the organization's management—is responsible for the system at large and controls the resources. As administrators, they exercise formal authority trying to control a patchwork of more or less autonomous staff groups. Community represents the societal level, i.e., elected politicians, advocacy, and various advisory groups seeking to exercise influence. They supervise the organization's management and build the formal connection to the outside world.

Professional cultures are pronounced and powerful. Leadership needs to address those subsystems and their professional identities in order to be successful (Schmitz and Berchtold 2009). Therefore, clinicians—particularly, but not only doctors—need to be engaged in management and leadership. But, healthcare providers—similar to the situation in other industries and sectors—must recognize that the type of leadership is changing. The old model of "heroic" leadership by individuals will be replaced by models of shared leadership both within organizations and across organizations (The King's Fund 2011).

The "post-heroic" model of leadership described by Turnbull (2011) involves multiple actors with leadership roles working together collaboratively across organizational or professional boundaries. Thus, leadership represents practices and organizational interventions, rather than just personal behavioral style or competencies. But as mentioned, this does not apply only to health care, but also for other sectors.

14.4.3 Leading a Healthcare Organization: Personal Skills and Institutional Habits

Often leaders are struggling with how to focus their efforts. There is abundant literature on what personal skills or behavior leaders should bring with them in order to be successful. All approaches are helpful in different ways. Just to take one example, Swensen et al. (2013) defined five critical behaviors that are inherent in

Table 14.7 Behavior of leaders in healthcare organizations

Person-centeredness	Frequent interaction with patients and families in daily routines (e.g., participation in rounds, discussing results in terms of patients)
Front-line engagement	Establish an understanding of the work at the front lines of care—being visible and building trust (e.g., asking questions, sharing concerns, engaging in problem solving)
Relentless focus	Creating focus and urgency on high-priority efforts by framing the vision and strategy
Transparency	Forcing transparency in, e.g., results, progress, aims, and defects as a catalyst to create understanding for change and thus functions
Boundarilessness	Establish a culture open for change and innovation (e.g., deliver health services across the continuum and person centered)

Source Swensen et al. (2013)

most of these theories (Table 14.7). The list is intended to be open ended. Adopting these behaviors can be a starting point to move the organization from volume to value, i.e., driving to better performance.

Another area of the literature does not focus on the leader as a person but on the organization and its success factors. Though there seems to be no dominant delivery model so far, there may be certain activities, behaviors, and ways of thinking that high-performance organizations do share. Bohmer (2011), for example, identified four so-called *habits* that high-value healthcare organizations typically do have in common (see Table 14.8).

The expression of these habits may be unique for each organization depending on the individual regulatory and reimbursement environment. However, successful approaches to care management are based on the same habits.

14.5 Lessons to Be Learned for Leadership in Integrated Care

As already noted, leadership structures in networks differ from those in typical hierarchies. Network structures "*provide a unique context for leadership that is characterized by ambiguity, diversity, dynamism, and complexity; the genuine failure of hierarchical fiat; and the importance of networks or relationships*" (Sydow et al. 2011, p. 341). In integrated care concepts, seven aspects could be identified as particularly deviating from structures in other sectors and could be considered as potential pitfalls (see Fig. 14.4).

14.5.1 System-Related Pitfalls

First of all, governance structures and service delivery processes are important. Integrated care needs to adjust governance structures in order to steer patients

Table 14.8 Four habits of high-value healthcare organizations

Specification and planning
• criteria-based decision making for both, patient flows as well as clinical decisions; manifested, e.g., in treatment algorithms, discharge planner, pre-procedure checklists, standardized patient assessments
• advanced planning to specify choices, transitions, subgroups, and patient pathways
! shift from expensive resources to problems which they are designed for to solve
Infrastructure design
• designing microsystems to match defined subpopulations and pathways including staff, IT, physical space, business processes, policies, and procedures
! shift from single platform, general services organization designs to patient group-specific approaches maximizing use of scarce resources
Measurement and oversight
• internal process control and performance management by collecting more measurements than those required for external reporting
! shift to measurement as an integral part of accountability and performance management
Self-study
• examination of positive and negative deviance in care and outcomes

Source Bohmer (2011)

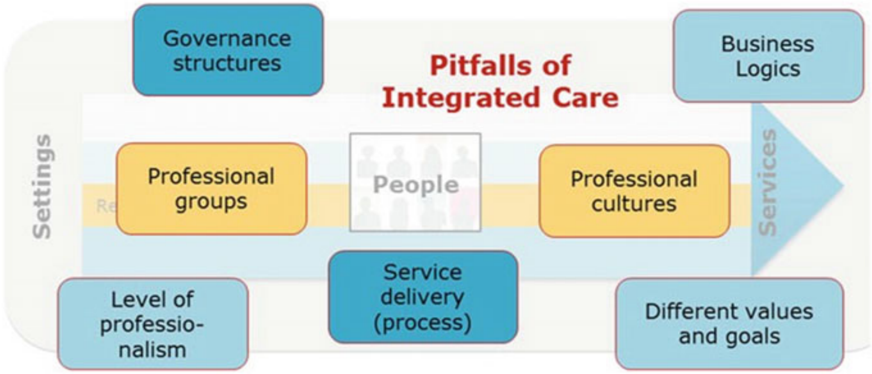

Fig. 14.4 Pitfalls of integrated care hamper successful implementation: system-related (dark blue boxes), people-related (yellow boxes), organization-related (light blue boxes). *Source* Own illustration typical sectors, other areas such as nursing services, pharmacists, medical engineering, service providers, and various others are involved

through the system. Governance structures are healthcare policy at a macro-level, the process of healthcare provision at the meso-level, and the individual patient at the micro-level. As mentioned above, the complexity for leadership in health care emerges because of the importance of patients (and communities) as well as the highly complex legislative structure. Health policy usually entails fragments of other fields of expertise, such as the judicial or social authorities.

The service delivery (process) takes place in three (simplified) sectors, primarily outpatient care, inpatient care, and rehabilitation. Yet, care delivery is much more complex in practice as it takes place in a whole system of stakeholders. Next to the

14.5.2 People-Related Pitfalls

The second area comprises the dimensions of professional groups and cultures. Integrated care needs to encompass various occupational groups that distinguish themselves through strong professional cultures that have grown over years (e.g., nurses and physicians). The medical profession has distinctive inner differentiations (medical specialists vs. general practitioners, outpatient vs. inpatient physicians). Leadership in integrated care needs to work toward acceptance of these professions and cultures. Yet, it is clear that leadership should not become "*one more burden that comes with the job*" for professionals. Rather people need to be trained in leadership and be paid appropriately for leading. A well-balanced approach is needed: The King's Fund Commission on Leadership and Management in the NHS elaborates on how much systems invest in professional management. Whereas the primary care trusts in England spent approximately 1–2% of their budgets on management, there are American organizations which invest around 12.5% of their budget for professional management and leadership (The King's Fund 2011). We postulate that a well-balanced investment is indispensable to sustain professional leadership in health care.

14.5.3 Organization-Related Pitfalls

The third area is more complex and comprises the dimensions of different target systems and business mind-sets as well as the degree of professionalization.

Integrated care often engages public–private partnership approaches, meaning that fundamentally different target systems need to be harmonized. On the one hand, there are stakeholders interested in common welfare (e.g., municipalities), and on the other hand, there are non-profit organizations, such as religious hospitals and private institutions like pharmaceutical companies. For leadership, it is necessary to understand these divergent mind-sets in order to make them to cooperate.

Furthermore, the degree of professionalization as well as the structure of organization differs among various stakeholders. In integrated care, governmental and other public organizations that act according to public law might need to interact with private business models of all sizes. These organizations are all in need of leadership but with different demands to it. Leadership in health care does not mean regulation or imposed change. It means that there are people who—next to their medical profession—understand the necessity of a strategic line of approach toward higher quality. They understand that better care, i.e., integrated care, will not *"just happen*" but needs conceptual input from different perspectives. Most certainly, appropriate resources (e.g., generated through participation fees of the individual stakeholders or governmental subsidies) are required for the implementation of integrated care concepts.

14.6 Conclusion

Leadership in integrated care does not differ fundamentally from leadership challenges in other network structures and needs to be addressed adequately. Besides the general underestimation of the importance of leadership in health care, several aspects have to be considered specifically. The following general recommendations highlight the importance of the topic for integrated care:

1. Integrated care concepts are strategic assets

   Integrated care concepts have to be recognized as strategic assets by the relevant institutions. Independent of their actual importance for the business model, integrated care concepts need strategic tailwind. This tailwind can be fostered by leadership.
2. Leadership in integrated care is necessary
   Leadership structures should be implemented separately from already well-established structures; meaning, the implementation should not be carried out solely by physicians or other service providers along the way but has to be organized separately and professionally, ideally within a management company.
3. Leadership in integrated care requires investment
   The expenditures for leadership need to be budgeted. Leadership is an integral field of activity and has to be remunerated separately. Expenditures on proper leadership and management skills as part of the budget assignment document an appreciation for it.
4. Leadership in integrated care must build a culture of shared values
   Expert knowledge and professional authority are indispensable for the leadership of integrated care concepts. Leadership should be embedded in existing structures—nearly invisible—and occur indirectly through pointing out direction and growing a culture of shared values. Otherwise, resistance will build up.
5. Leadership in integrated care needs time
   Leadership needs to motivate all parties involved in integrated care. The longer structures have been in place, the longer it needs to force them open.
6. Leadership in integrated care needs to be focused
   Leadership needs to focus on the components and occupational groups that are most difficult to integrate. Generally, this is the medical profession. But leadership should also initiate local activities (e.g., regional conferences, workshops, quality circles, groups of regulars) in order to strengthen and document the solidarity within and between the groups and the involvement of the broader community.
7. Leadership in integrated care needs to be data-based

> Medical care is strongly influenced by data. Therefore, in order to lead successfully, a comprehensive data warehouse is crucial. Healthcare professionals will be mainly convinced by strong evidence of the suggested pathway. But, data needs to be transparently accessible for all partners and should not be a source of power.

Leadership is still a highly underdeveloped and underestimated topic in healthcare management. But besides several important differences in health care, the main challenges are very similar to those in general management. Therefore, the main focus should be on adapting general management approaches in the healthcare setting.

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Co-leadership—A Facilitator of Health- and Social Care Integration

15

Charlotte Klinga

15.1 The Interpretation of Leadership Over Time

A search of scholar.google.se 25 February 2020 returned 424,000 hits for the phrase "leadership". Even though the variation in the matches is wide, it says something about the vast arrays of studies. The definition of leadership is still polysemous. Stogdill (1974) concluded after an extensive review of literature that "*there are almost as many definitions of leadership as it is persons who have attempted to define the concept*". Moreover, there are differences between the definition of leadership and management, as discussed by, e.g. Bolman and Deal (2017), as well as between leader and leadership development (Day 2000). In this chapter, the words managers and leaders are used interchangeably with reference to the circumstance that exertion of leadership is often one part of the management role together with the formal management responsibilities and obligations. In addition, the empirical findings (Sects. 15.3, 15.4, and 15.5) are statements from managers who exert leadership in integrated services in Sweden.

Historically, the importance and the role of leadership has been studied from different perspectives and focuses. The original leadership studies focused on the leader's personality and were later to be known as the *great man theories*. This era was followed by leadership research using many different approaches. Tyssen et al. (2013) have in their review of leadership theories divided the theories into three categories, person-oriented approaches, situation-oriented leadership, and

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interaction-oriented leadership theories. Yukl (2013) offers another way to describe leadership in organizations by dividing the concept into person, role, and process. One example of a more modern view on leadership is *the relational leadership* that views leadership as a process of social construction (Crevani et al. 2010). Another example of leadership that differs from the view of leadership as a solo activity is, *the collective leadership*. This concept can be found in the literature as early as the 1950s [Gibb 1954 cited in Gronn (2002]. It has existed in practice for a long time. However, the perception of leadership as a solo activity, continues to be predominant in practice as well as in research (Gronn 2002).

15.1.1 The Conceptualization of Co-leadership

The collective leadership approach rejects the distinction between leaders and followers since leadership is seen as a function or an activity that several persons in an organization can possess and share at the same time (Jackson and Parry 2008). Cullen et al. (2012) argue that collective leadership development is complex and contains several challenges, such as requiring new perspectives, methods, and interventions.

One of the concepts of collective leadership, referred to as co-leadership, was introduced by Heenan and Bennis over 20 year ago (1999). The authors defined co-leadership as two leaders equally positioned, sharing the responsibilities of leadership. This conceptualization will serve as a working definition in this chapter. However, as described before, a variety of concepts can be found in the literature (Bolden 2011).

There are only a few empirical studies on co-leadership and its influence on the function of an organization (Yammarino et al. 2012; Ulhøi and Müller 2014). Some studies can be found from sectors such as sports, fire brigades, telecom, schools (Döös 2015), and the arts (Järvinen et al. 2012). In general, existing studies on co-leadership emerge from the health care or the social services sector, yet rarely from integrated health- and social care services (Currie and Lockett 2011; Konu and Viitanen 2008; Rosengren and Bondas 2010).

15.1.2 *Co-leadership in Integrated Service*—Opportunities and Obstacles

In order to successfully manage integrated services, it has been suggested that leaders should be brought together to establish a situation of co-leadership (Ham 2013). Furthermore, the World Health Organisation has proposed that distributed leadership between multiple actors who work together across professional and organizational boundaries is key to achieving people-centred and integrated health services (World Health Organization 2015). Integrated services, however, increases the organizational complexity and thereby the managerial challenges. Inefficient interactions continue to persist due to inherent differences between health and social services (Ahgren 2010; Chong et al. 2012; Hultberg et al. 2005; Kodner and

Spreeuwenberg 2002; Leutz 2005; Rämgård et al. 2015). Such differences include the lack of economic incentives, separate funding streams, different information, and communication systems, and poorly harmonized legal frameworks (Leutz 1999). Beyond the organizational complexity, differences in perceptions of responsibilities, management, and leadership role, as well as organizational culture and resource availability, have been identified to act as further obstacles to cross-boundary interaction and collaboration (Cameron et al. 2014; Ling et al. 2012; Robertson 2011).

Perhaps the challenges that today's managers working in the complex area of health- and social care integration are facing could be handled more efficiently by two managers working together than by a single manager acting alone? Perhaps co-leadership could be a piece of the puzzle to enforce more patient orientation, efficiency, and quality in care delivery? There is some evidence showing that co-leadership has several benefits on the organizational and managerial level, including broader competence and more well-founded decisions (Miles and Watkins 2007), personal development and learning, (Wilhelmson 2006), and more efficient use of expertise (Friedrich et al. 2009). In addition, there are good reasons to consider the benefits of co-leadership from the service user perspective. When services are integrated and managed by co-leaders, different competencies, missions, and responsibilities are gathered in one place (Klinga et al. 2018). This, in turn, makes co-leaders better equipped to see the broader picture and to ensure that the services users' needs are considered when planning for coherent care and support. All this sounds beneficial, but how do we get there? How can well-functioning co-leadership be achieved? I argue, based on research performed by others and by myself, that some crucial prerequisites, relating to contextual and personal and interpersonal factors need to be in place. This will be discussed in the following sections. In case other sources than my thesis are cited, the references will be given.

15.2 What Prerequisites Are Needed to Exercise Co-leadership in Integrated Services?

15.2.1 Contextual Prerequisites

To be successful in exerting co-leadership, some essential contextual prerequisites need to be in place.

Firstly, there must be a will to engage and invest in joint efforts to build up the integrated services. This is based on an understanding of the value of managing care jointly.

Secondly, having one clear common mission and understanding of the objectives and vision of the services can facilitate cross-boundary integration (Cameron et al. 2014; Rämgård et al. 2015). In addition, it can give guidance in the daily work by focusing on the creation of shared mental models consisting of integration tasks, system roles, and belief in integration (Evans and Ross Baker 2012). Although, it is also of importance to encourage the organizational identity that reflects self-similarity and variation (Schneider and Somers 2006).

Thirdly, the idea of co-leadership as a management solution needs to be strongly anchored in the overall organization. The whole organization-wide model of cross-boundary cooperation needs to recognize co-leadership as a managerial solution implying that adequate organizational support; i.e. policy strategies enabling co-leadership as a management solution throughout the organization need to be in place (Copland 2003; Dunér et al. 2011). Thus, the exertion of co-leadership in organizations characterized by a less supportive overall policy and administrative structure might be challenging.

Fourthly, the exertion of co-leadership on all managerial levels plays a crucial role as the superior managers are perceived as role models and bearers of the culture. Being a role model includes continuous promotion of the idea of integrated health and social care in order to maintain collaboration and cooperation. Co-leaders are opinion leaders and cultural carriers with a strong symbolic value, and by their own close cooperation in their co-leadership, they illustrate how co-leadership can be exercised in practice. Continuous encouragement and promotion of co-leadership and of leaders who act as internal coaches in operational management has been found to support co-leadership as an embedded part of organizational culture (Ulhøi and Müller 2014).

Fifthly, a facilitating factor for jointly leading integrated services is the creation of one culture, i.e. a common professional culture, consisting of shared values that unifies all employees (Lindqvist et al. 2011). One way to do this is by putting effort in creating a consistent terminology and adopting common job titles—regardless of profession—for those employees that have similar functions, as for example, the coordinators.

Finally, the last essential contextual precondition for achieving co-leadership in integrated health and social care service is co-location. This is not only an enabling precondition for the management of the integrated health and social care services, but it enables teamwork and has proven to be beneficial for the service users. Co-location enables informal discussions, sharing of knowledge and experience as well as smooth transfer of information (Gibb et al. 2002; Kharicha et al. 2005; Robertson 2011). Further, co-location has been regarded as a facilitating factor when it comes to offer the services jointly and to exercise inter-professional teamwork. Research has found that co-location promotes more formal and informal team time, which in turn makes the teams work in a more integrated manner (Cameron 2016; Duner 2013).

15.2.2 Personal and Interpersonal Prerequisites

In addition to contextual prerequisites, some personal- and interpersonal prerequisites need to be in place in order to succeed with co-leadership. Perceiving the management role as a collective activity and having a common understanding of the purpose of integrated services is essential. This is of the utmost importance as barriers to co-leadership addressed in the literature origin in personal disbelief in the model of sharing leadership (Toole et al. 2002). In contact with employees and service users, it is of importance to be clear about the fact that the management team consists of two equal leaders managing one common service.

Furthermore, to understand and manage the big picture, it is crucial to be interested in and willing to invest time in collaboration and in learning about each other's responsibilities and sector-specific activities. This approach is based on an understanding of the value of learning, and development and an explicit strategy is needed to prioritize continuous exchange of competencies and experiences. The transformation to integrated care has been conceptualized as a process and as an organizational learning experience that requires learning on different levels among cross-disciplinary teams (Nuño-Solinís 2017). As a co-leader, having the ability to demonstrate new and innovative ways of developing and managing practices with the aim to promote health and social care integration is beneficial in many ways.

Getting along with one's leader colleague is a key precondition for working together, side by side in a fruitful collaboration. Some characteristics such as responsiveness, lack of prestige, and self-confidence will enable close collaboration as well as openness, fruitful interaction, and transparency. Other prerequisites on the relational level that are crucial are the ability to rely on one´s leader colleague, allowing one-self to be influenced by him or her as well as being able to compromise. Moreover, the readiness to take a step back, thereby allowing your colleague to take the foreground, is crucial. In addition, openness and constant communication including, e.g. sharing information and striving to achieve consensus, is underlined as essential for a successful co-leadership. The creation of a trustful and loyal relationship is indispensable, as is also the confidence that emerges from trust and loyalty. This in turn provides a space for mistakes to be made without jeopardizing the relationship. Several studies emphasize the importance of establishing trust and personal relationships between managers exerting co-leadership (Döös 2015; Friedrich et al. 2009; Ling et al. 2012; Miles and Watkins 2007; Wilhelmson 2006) and between professionals in joint working (Halliday and Asthana 2004; Kuluski et al. 2017).

15.3 How Can Co-leadership Be Operationalized in Practice?

15.3.1 Management Tasks

Co-leadership as a management model in integrated services is about clarifying the organizations' equal status, specific duties, and cost responsibilities and sometimes harmonizing the two organizations' economic steering mechanisms. Furthermore, it can be about keeping the resources together requiring that both leaders are willing to "give and take" and occasionally even "step back".

Involving all team members in a problem-solving process can be a way of finding cross-effective solutions irrespective of where in the integrated services the problem emanates. By doing so as a co-leader, a consensus-oriented decision-making process is facilitated and at the same time, conditions for a feeling of solidarity with the services are created. This approach is not uniquely related to co-leadership; however, it is demonstrated in the co-leaders' daily practice. Thus, co-leaders act as role models for all team members.

Where providers work in a larger system consisting of several smaller units, the co-leaders for those units need to work out a common co-leadership approach towards all employees. This enables provision of equal health and social care services, irrespective of unit. One way to achieve this is by holding joint meetings for all managers exercising co-leadership and their superiors which provides a forum for exchange of experience, reflection, and learning.

15.3.2 Daily Operation

A common challenge for most managers within health and social care services is to keep up to date with everything that may have an impact on the services. The possibility for keeping abreast of what is happening in the workplace is facilitated by co-leaders sharing office. Furthermore, it enables natural updates on the service situation as well as involvement in matters concerning both sectors. By allowing time for informal conversations on daily basis, the formal meetings can be more focused and time efficient.

Another advantage by being two leaders working in a team is that a better presence of leadership can be offered since the leaders can cover for each other in case of illness or interfering external meetings as well as vacations.

The exercise of co-leadership has its own inherent problems; for instance, employees may try to drive a wedge between two leaders and try to separate them. Therefore, it is of the utmost importance for the co-leaders always to present themselves as a united team. In front of the employees, they should always emphasize the teamwork being done by acting as role models themselves in their own co-leadership team. Another difficulty related to being part of a leadership team is the requirement for decisions founded on consensus. To achieve this, the decision-making process must be based on dialogue and negotiation. Research has shown that this is a more time consuming process than decision-making single handed (Miles and Watkins 2007). However, this negotiation and pursuit for consensus results in better founded and more long-lasting decisions.

One important advantage of being two managers with different knowledge backgrounds and responsibilities is that they can complement each other's areas of expertise (Crevani et al. 2007; Kocolowski 2010; Miles and Watkins 2007; Rice 2006). As a result of the broader competence achieved by combining different areas of expertise, they can feel better equipped to manage a cross-boundary service.

Co-leadership enables a more holistic approach through the combination of different competencies, missions, and responsibilities of the managers benefitting all the work related to the service users. Faster decisions about health- and social care interventions can be made enabling faster access to care and support from both the health- and social care services for the service user. Co-leadership exerted in an integrated and co-located service allows managers to deal with service users' needs and problems in a more holistic and efficient way.

15.3.3 Leadership Development

Joint decision-making can be challenging, especially if one´s previous experience is to be a single manager. However, the difficulties related to acting as part of a co-leadership team are outweighed by the advantages, in terms of self-development and the sense of confidence which derives from never being alone. This continuous cooperation creates an environment for learning and support. Co-leadership provides the advantage of immediate guidance and mentoring from one's leader colleague. The support co-leaders give one another can result in more robust management.

15.4 What is the Contribution of Co-leadership for Integrated Health and Social Care?

Given the literature in the scientific fields of integrated care and co-leadership and the empirical findings in my own research, I argue that co-leadership (among many other components) can contribute to a sustainable integration of health and social care:

- Co-leadership is about sharing responsibility for integrated services; thus, the managers can work more long-term oriented. This way of working in managerial teams creates greater possibilities for finding cross-organizational solutions. In addition, through discussions and negotiations, various perspectives will more likely be considered before reaching consensus in decision-making. Thus, the decisions can be better founded and thought-out.
- Co-leadership entails broader competence. By combining different expert areas and by having different mandates the co-leaders can together have a more holistic approach, i.e. considering service users' collective needs. Furthermore, the possibility to make faster decisions which is beneficial for the service users is enabled when co-leaders are sharing office and/or meet service users together. In addition, it is likely that co-leaders are better equipped to see the broader pattern of events concerning organizational matters.
- Co-leadership can enable continuous learning and support. This might result in managers feeling better equipped to manage cross-boundary services and less vulnerable in their leadership. This is directly transferable to employees in the teams. By enabling trans-disciplinary knowledge exchange across teams the

members can use this knowledge to solve problems related to special cases, by referring to a larger body of practice and experience, and by specifying each member's role and duties inside and outside the organization (Gibb et al. 2002)

15.5 Summing Up

Co-leadership may be challenging in many ways; even so, it can be argued that it does facilitate health- and social care integration. Many arguments exist for this claim from the organization, service user, and the leadership perspective. However, it should be noted that certain prerequisites need to be addressed to optimize the achievement of well-functioning co-leadership. Attention needs to be given to several contextual factors aiming to create a supportive environment which enables exertion of co-leadership. In addition, we need to be aware of some personal prerequisites such as the perception of the management role as a collective activity and the maintenance of equality in co-leadership, to mention a few. In addition, interpersonal factors such as getting along with one's leader colleague and trustful and loyal relationship together with characteristics such as openness, lack of prestige, and transparency are other important prerequisites to successful co-leadership. In the end, integrating care is all about building bridges and breaking barriers. Co-leadership can be a successful contribution to this endeavour.

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Change Management

16

Nicholas Goodwin

16.1 Introduction

> The experience of organisations that have made the transition from fragmentation to integration demonstrates that the work is long and arduous. [Managers responsible for achieving change] need to plan over an appropriate timescale (at least five years and often longer) and to base their actions on a coherent strategy (Ham and Walsh 2013, p. 7).

Enabling health systems to become more coordinated and integrated in how they function in the delivery of care to people is a long-term and complex task. The process of change towards integrated care requires decision-makers to take action at a number of different levels to not only ensure that the key building blocks for integrated care are in place but that they function well together to promote continuity of care and coherence in the way care is organised and delivered. There is a need for *simultaneous* action to be taken at a number of levels to support the range of changes that are necessary—for example, in supporting shared decision-making between patients and providers; in building inter-disciplinary teams of care professions; in creating effective networks between partners in care; and in engaging and promoting action to support changes that help to embed integrated care as an accepted and legitimate approach to care delivery.

However, despite recognition that the complexity of integrated care requires pro-active management support and action, there has been little guidance produced that might help to understand the various processes that are necessary to support change to happen (WHO Regional Office for Europe 2015). This chapter seeks to articulate the components of a change management strategy for taking forward integrated care policies in practice at a local and regional level.

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16.2 A Conceptual Understanding of Change Management

Any successful strategy for change depends on its mission, the resources and competencies it has at its disposal, and the environment in which it is operating. The strategic direction to be chosen for change must analyse these elements and identify what needs to be done to ensure the ‘strategic fit’ of the various organisations and stakeholders involved. It should be recognised from the beginning that in no health and social care system, given the history in the way care provision has been established, does integrated care emerge naturally as a solution. In order to achieve change towards integrated care, there is strong evidence to demonstrate that systems must be effectively led, managed and nurtured (Ham and Walsh 2013).

In health and social care, leaders and managers must seek to empower people at all levels to take responsibility for an appropriate level of decision-making. This is particularly important for integrated care where evidence and experience point to the need to grow integrated care strategies from the ‘bottom-up’ where professionals and local communities work together with a degree of operational autonomy to lead the change process. This is why building communities of practice to support change, and investing in their ability to collaborate with each other effectively, should be seen as a core area for action within the ‘change’ domain. In other words, the change management process is seeking to support three core things (Goodwin 2015):

- Alignment—to support organisations to take on integrated care as part of their core business;
- Agility—to develop systems and processes that enable integration to happen;
- Attitudes—through changing behaviours of key stakeholders by addressing cultural issues through good management practice.

It is likely that significant variation will exist in the way integrated care is implemented, but a key lesson from policy reviews is that long-term commitment to change is necessary to enable reforms and changes to health systems to embed over time. To make change successful, a balance needs to be struck between ‘top-down’ management of change, with the necessary space for innovation, and emergent strategies to be created at a more local level by creating the right environment for innovation (Bengoa 2013; Montenegro et al. 2012). Hence, participation and support across all stakeholders in health and other sectors (including policy-makers, managers, professionals, community groups and patients) is a key to success (World Health Organisation 2015). The managerial challenge is to create a step-wise process through which this can be achieved.

16.3 The Evidence Base

There is a lack of research evidence on the change management process when designing, piloting, implementing, assessing and scaling-up innovations that support integrated care (Engineer et al. 2014). Indeed, as Chap. 1 outlined, most frameworks describe the process as highly 'complex' given the range of stakeholders that must necessarily be involved in working together in devising new approaches to integrate care (Edgren and Barnard 2009; Goodwin 2013a; Minkman 2012). Hence, pro-active change management is needed. Yet, there is a lack of appreciation and understanding of the complexity of this process and of the tools that can help support change (Cash-Gibson and Rosenmuller 2014; Goodwin 2013b; Valentijn et al. 2013).

A planned change management strategy represents a reasoned and deliberate set of actions for managers of the system that requires a need to identify and explore new ways of working as well as to challenge established practice (Goodwin et al. 2006; Iles and Sutherland 2001). Change management, therefore, represents the 'how' of integrated care implementation through setting out the various operational tasks that need to be undertaken to enable change to happen. The approach requires 'whole systems thinking' since it is necessary for managers to understand and capitalise on interrelationships rather than linear cause and effect chains.

Evidence from experience and research has contributed much to our understanding of the building blocks for the effective deployment of integrated care, yet the field of integrated care remains weak in terms of the implementation science to support policy-makers and managers to make effective decisions. Indeed, there is a lack of appreciation of the necessary change management processes and skills needed (Goodwin 2013b). In part, this lack of understanding is because achieving success through integrated care appears highly complex since it involves change at the nano-scale (e.g. with patients) micro-scale (e.g. with multi-disciplinary teams) meso-scale (e.g. through organisations of physician networks) and macro-scale (e.g. by alignment of government policies) (Plsek and Wilson 2001; Curry and Ham 2010; Valentijn et al. 2015a). Hence, efforts to reform complex systems like integrated care need to look at 'whole system' change with a priority in influencing the high-level behaviour of key decision-makers, the performance of individual sub-systems and—crucially—the interdependencies between different stakeholders and how these impact on outcomes.

A number of relevant frameworks to integrated care have been developed to explain these interdependencies as a means to understanding how change might be achieved—for example: the normalisation process model that focuses on the importance of building relationships and skills in collaboration (May et al. 2009); the continuity of care model that tracks how chronic care to populations may be achieved through adopting different strategies at different points across the life-course (Sunol et al. 1999); and the multi-level framework that sought to understand how care coordination between provider organisations and care professionals operates in practice (McDonald et al. 2007). None of these, however, has really articulated the management strategies necessary to achieve change.

Perhaps the most famous approach to change management adopted in healthcare settings has been lean thinking (Womack and Jones 2003) and related improvement methodologies in health care that have sought to improve quality and safety in health care (Institute of Medicine 2001). By focusing on the effectiveness of teams and the promotion of evidence-based and cost-effective care pathways, the manager has been provided with a new suite of tools through which to transform care. The lean approach in health care has been strongly developed with many tool-kits and support agencies advocating its use. Whilst lean is highly relevant to the management of integrated care, the biggest criticism labelled against it is that it focuses on 'doing right things' (i.e. eliminating waste through efficiencies) rather than 'doing the right thing' (i.e. focusing on quality of outcomes and effectiveness). Lean also tends to work best for specific diseases or for predictable care processes but is perhaps less relevant for people with variable care trajectories (Allen et al. 2004). In the field of integrated care, the most coherent approach to date that seeks to explain how the management of integrated care may be taken forward is the Development Model for Integrated Care (DMIC) (Minkman 2012). Unlike other work, the DMIC was specifically designed to help managers and leaders reflect on whether the essential elements for integrated care were in place and, in particular, established a four-phase programme for change: design, experimentation, expansion and monitoring and then consolidation.

The DMIC is a complex evidence-based model since it includes 89 unique elements for action grouped into nine clusters. These clusters provide a basis for a model for the 'comprehensive quality management' of integrated care. In particular, in terms of change management, the model highlights the conditions necessary for effective collaboration such as commitment, clear roles and tasks and entrepreneurship. The model can be used for self-assessment and evaluation and provide inspiration and insights for further improvement. The DMIC is an important resource since it also shows that certain attributes of integrated care are more important at different phases of implementation. For example, in younger collaborations, it stresses how the management of change should focus on building inter-professional teamwork and defining roles and tasks. The DMIC can also enable a situational analysis to be undertaken to examine any deficiencies in the competencies needed to achieve integrated care in practice (e.g. the lack of attention on quality of care and performance management).

The DMIC was developed in the context of the policy innovation in the Dutch context of Care Groups that encouraged primary care providers to utilise new financial incentives (bundled payments) to support chronic illness care to people with specific diseases such as diabetes. Whilst the DMIC approach has been applied with some success in other settings, for example in the context of stroke care in Canada (Minkman et al. 2011), there remain some caveats to how the model might be adapted to the needs of populations with physical and mental health co-morbidities and complex healthcare and social care needs (Fig. 16.1).

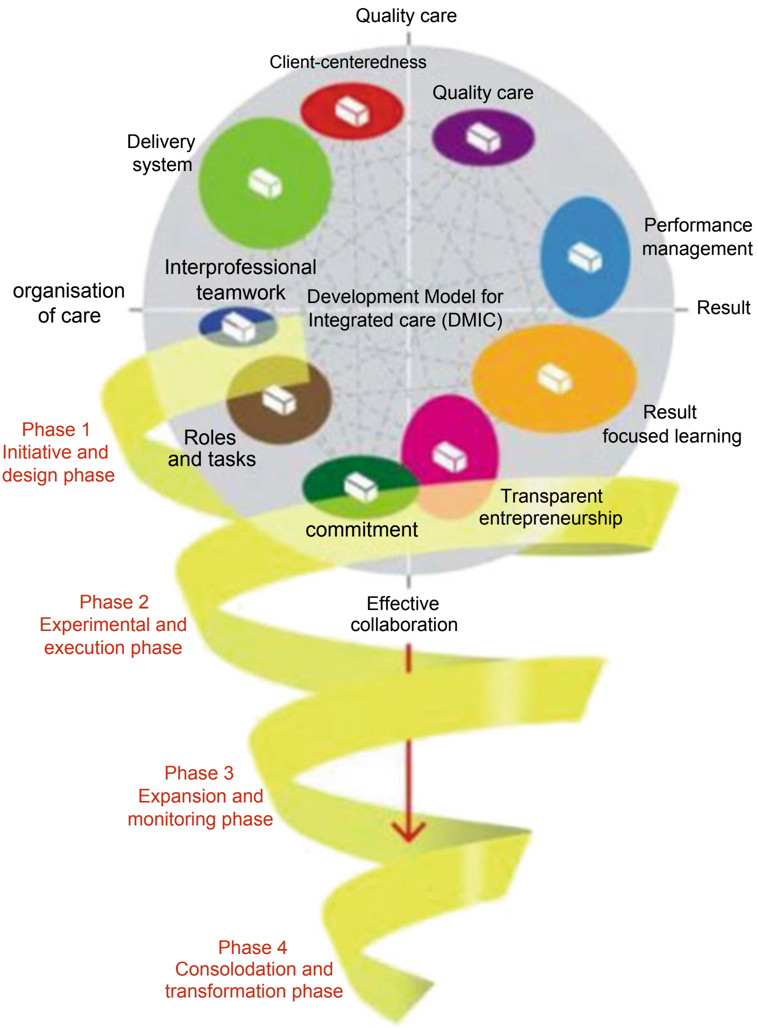

Fig. 16.1 Development model for integrated care (Minkman 2012)

16.4 Lessons from Practical Experience

The development of the evidence base to support the uptake of integrated care remains in an early stage of development yet much can be learned from the experiences of key leaders and managers who have been at the forefront of implementing integrated care strategies at a national and regional scale. Though captured through relatively few documents and presentations, a summary of the evidence would suggest that there are a number of key managerial lessons to be learned (see Box 1).

Box 1 Key Lessons for Change Towards Integrated Care from Practical Experience

- Finding common cause with partners;
- Developing a bold shared narrative to explain why integrated care matters, written in a way that is tailored to meet local circumstances and conditions;
- Creating a compelling and persuasive vision for change that sets out an urgent case for why 'business as usual' will not work and describes what integrated care can achieve, especially to the potential benefits of patients;
- Identifying services and user groups where the potential benefits of integrated care are the greatest;
- Understanding that there is no 'one model' of integrated care and supporting a process of discovery rather than design;
- Building integrated care from the bottom-up that has support from the top-down whilst avoiding structural solutions that over-emphasise cost containment;
- Aligning financial incentives, or removing financial disincentives, for example through pooling resources to enable planners and purchasers to use resources flexibly;
- Innovating in the use of contracting and payment mechanisms;
- Supporting and empowering patients to take control over their health and well-being;
- Sharing information about patients with the support of appropriate information governance;
- Using the workforce effectively and to be open to innovations in skill mix and staff substitution;
- Restructuring care delivery assets, for example through less hospital-based care and more primary and community-based care;
- Setting specific objectives and measures to stimulate integrated care delivery, enable the evaluation of progress, and supported by a performance and quality management system;
- Establishing a strategic communications plan that enables a clearly defined message to be provided and understood across all stakeholders;
- Being realistic about the costs of integrated care;
- Integrated care is a long-term agenda and represents an ongoing system-wide transformation; and
- Acting on all these lessons together as part of a coherent strategy

Sources WHO Regional Office for Europe (2015), Bengoa (2013), Goodwin and Shapiro (2001), Bengoa (2014), Kizer (2012, 2014), Timmins and Ham (2013), Meates (2014), Øvretveit et al. (2010)

The list of key factors in Box 1 is based on the lived experience of those that have led the management of strategies to support integrated care. What they reveal is a striking resemblance to Kotter's 'eight steps' model for leading change derived from an analysis on the key strategies taken by managers in making a success of transformational change (Kotter 1996). These eight steps are:

1. Create a sense of urgency
2. Form a guiding coalition
3. Create a vision
4. Communicate the vision
5. Empower others to act on the vision
6. Plan for quick wins
7. Build on the change
8. Institutionalise the change.

A key observation from this work is that care systems often need to have *external* change management support to help manage the various viewpoints of different stakeholders within the various contexts for change in which integrated care will be implemented. Furthermore, since the needs for developing integrated care require an appreciation of the complexity of the task, there is a need to find a balance between emergent strategies (one that adapts over time) versus approaches that seek to systematise processes. Flexibility in the management of change is therefore needed and learning networks and communities of practice need to be built to support adoption and build capabilities.

16.5 The Components of a Change Management Process Towards Integrated Care

This section examines nine core components in the management of change that, taken sequentially, sets out a sequence of actions that managers should consider when addressing the need to introduce or develop programmes that support integrated care (see Table 16.1). The nine steps represent a range of actions from the

Table 16.1 Nine core components of a change management plan

1. Needs assessment
2. Situational analysis
3. Value case
4. Vision and mission statement
5. Strategic plan
6. Ensuring mutual gain
7. Communications strategy
8. Implementation and institutionalisation
9. Monitoring and evaluation: developing systems for continuous quality improvement

planning stages that define the priorities for action, to issues related to strategic planning, implementation and evaluation. This section draws upon work previously undertaken by the author for the WHO Regional Office for Europe and the CAREWELL project funded by the EU CIP Framework Program 2007-13 (see Lewis and Goodwin 2017; Goodwin 2015).

16.5.1 Needs Assessment

Integrated care represents a strategy that recognises the fundamental seriousness of the challenges faced by health and care systems to meet current and future demands (WHO Regional Office for Europe 2013; Stein et al. 2013). Yet, at a local and regional level, it can often be difficult to find 'common cause' amongst local stakeholders on the priorities for action that need to be taken in local communities to overcome system fragmentations through new approaches to care integration (Goodwin and Shapiro 2001). One of the core issues in the change management process is that organisations will be asked to work together and, as a result, share their sovereignty in pursuit of the greater good of the population they serve—and this is not always easy (WHO Regional Office for Europe 2015).

A first step, therefore, is for the different key stakeholders to develop an objective understanding of population health needs to support the underlying rationale for integration and to promote priority setting. This might be achieved, for example, through the development of a Joint Strategic Needs Assessment (JSNA) that looks at the wider determinants of health and needs of a local community. Though the process varies in different countries across Europe, it usually involves local health authorities with a responsibility for population health to work alongside public health departments, municipal authorities (social care), housing and other sectors to examine the current and future health needs of a local population. Such JSNAs might typically focus on a specific patient cohort (e.g. people with chronic illness or older people with frailty) and enable priority setting by mapping the flow of financial resources spent on key priorities and/or examining gaps in care provision (NHS Confederation 2011).

16.5.2 Situational Analysis

Understanding change management towards integrated care faces a series of problems related to implementation including issues such as the legacy of existing service provision; changing environmental pressures; changing technologies; varying degrees of complexity of organisational systems; the many competing views of stakeholders; and the potentially adverse impact of unforeseen events or unintended consequences of different strategies. Managers therefore face the challenge in adopting the right tools and strategies for the circumstances they face.

The literature on change management commonly shows how achieving change rests on actions at a number of levels, for example: the *political* system where formal and informal configurations of power influence decision-making; the *technical* system of existing human, technical and financial resources available to produce more integrated service delivery; and the *cultural* system that encompasses organisational values and behaviours of those influenced by changes (Tichy 1985). In other words, managers need to recognise that change towards building the technical competencies of integrated care will be significantly influenced by economic, political and cultural forces that may be beyond their control.

One of the key methodologies to enable the change management process is the use of diagnostic tools to assess the current situation in relation to what is trying to be achieved. These situational analyses attempt to yield insights on the 'strategic fit' of new approaches like integrated care amongst key stakeholders and are often used to justify change management programmes and/or to prioritise the focus of change.

16.5.3 Value Case Development

One of the most pressing concerns in the process of developing integrated care strategies is how to convince key stakeholders, and particularly health insurance organisations or those holding the financial power, of the 'value case' for investment. A 'value case,' however, looks at more than just the potential financial returns from the development of integrated care, but looks at the benefits to patients and whole communities of the approach (e.g. from the perspective of living healthier lives through to the development of stronger local economies).

The focus on value cases is important since it helps to develop the shared vision and set of common goals across different providers or teams. Hence, value cases do not just articulate the aims and objectives of integrated care based on the needs of local populations, but they also represent a pro-active process through which to engage partners in care and build social capital. Hence, in the design phase of an integrated care initiative, there needs to be inclusion of all relevant stakeholders in preparing the case for change and, in so doing, establishing a shared understanding, a shared vision for change, a degree of mutual respect on each other's roles in the integrated care enterprise, and the development or election of respected professional and managerial leaders whom people trust to take initiatives forward.

There are many examples internationally about how this approach has been used to create a convincing argument for change. For example, in Canterbury, New Zealand, the creation of the 'value case' and subsequent mission was supported between different provider agencies through a mantra of 'one system, one budget' (Timmins and Ham 2013). In other words, an argument was constructed in favour of an integrated health and social care system as a means to improving patient care as well as balancing the financial budget. To support this, more than 1500 managers and professionals completed learning courses—named *Xceler8* and *Collabor8*—in which staff themselves were tasked with coming up with projects for change with help from planners, funders and business developers. Rather than a full 'business case' with a cost/benefit analysis, the underlying questions discussed were of the value for improving patient and staff experiences.

16.5.4 Vision and Mission Statement

Change management theory argues that it is important to articulate a vision of the future with a compelling case for change. Evidence from experience suggests that is especially true for progress on the journey towards integrated care that would otherwise be slow unless it is possible to describe an alternative and better future that motivates and inspires care providers to work differently (WHO Regional Office for Europe 2015; Goodwin 2015). This includes developing a clear understanding of what integrated care means for all those involved, including those delivering services but also for those living in the community. Important in this process is to create a sense of urgency (that business as usual will not work) but also to centre the narrative based on improvements in care and outcomes to people and for quality improvement in bold but reachable terms. The vision and mission also needs to be co-produced with key stakeholders, including patients (and perhaps even led by service users).

A common strategy has been to develop a shared narrative of the future to explain why integrated care matters to both care providers and to patients. In England, the national strategy for integrated care has been underpinned by 'the narrative' developed by National Voices, a non-profit organisation representing the views of patients and patient groups (National Voices; National Collaboration for Integrated Care and Support 2013). The purpose of the narrative has been to articulate a national vision for person-centred coordinated care, and it has proven hugely influential in establishing the overarching purpose of national strategies.

16.5.5 Strategic Plan

A strategic plan is the document that is used to communicate within and between the organisations involved in the planning and delivery of integrated care the core actions and critical partnership elements necessary to achieve shared goals and outcomes. The development of a strategic plan has the advantage of committing a range of organisations involved in funding and delivering care to a collective set of objectives and actions to guide what needs to be done, by when and why. An effective strategic plan, therefore, helps to tie together networks of care professionals and otherwise separate organisations into a collective agreement, sets the terms of engagement between the different parties, their key roles and responsibilities, and the range of outcomes and performance indicators that may be used to judge whether integrated care strategies have been successful.

16.5.6 Ensuring Mutual Gain

One of the most important issues at stake in the development of effective partnership working within programmes that support integrated care is not just related to the development of a 'shared vision' that enables key stakeholders to recognise the ‘interdependencies’ that each have in working together to achieve a better outcome for patients and communities. What appears to be just as important is the ability to ensure that all partners in care fully understand and accept their roles and responsibilities to the extent that a high degree of trust and respect exists built on the knowledge that each partner is contributing fully and as expected. The building of trust, therefore, requires all partners to recognise and value the level of commitment and reciprocity of actions of others. In other words, each partner recognises the ‘mutual gain’ that can be made through collaborative actions. Hence, it is essential that any partnership which focuses on integration recognises from the outset that a ‘win-win’ scenario needs to be supported otherwise there is a risk in undermining the degree to which partners in care are willing to cooperate with each other.

However, one of the core problems with integrated care is that it is usually not the case that the benefits of involvement are equally shared compared to the effort or workforce that is needed to make it happen (6 et al. 2006; Leutz 2005). As a result, it can be difficult to bring partners to the table to discuss integrated care where it is perceived that some partners might gain, yet others lose. Moreover, the issue is not simply related to budgetary or financial concerns but also involves issues related to perceptions of authority, to social and professional status, to workload and effort, to intellectual property and, often, to the competitive advantage different care providers might gain in terms of gaining clients (patients) at the expense of others.

> Collaborative partnerships and networks are necessary to achieve integrated care, yet the evidence demonstrates that these can be time-consuming, resource-intensive and unstable leading to the observation that there is a high failure rate in such innovations. (Goodwin 2013a; Roussos and Fawcett 2000; Weiner and Alexander 1998)

The recognition of the need to articulate ‘mutual gains’ and build ‘tie-ins’ is important since it establishes the ‘baseline’ that underpins the nature and expectations of the collaboration that recognises their underlying interests. A useful conceptual framework by Bell et al. (2013) can help to evaluate the strength of the collaborative process across five key themes:

1. The degree of shared ambition (the shared commitment of the involved partners)
2. Mutual gains (understanding the various interests of the involved partners)
3. Relationship dynamics (the relationships and degree of trust displayed between each partner)
4. Organisational dynamics (governance arrangements across the partners)
5. Process management (the skill with which managers help negotiate relationships between partners over time) (Bell et al. 2013).

A good example of this is recent research that looked at the comparative effectiveness of 69 Dutch Care Groups enrolled in a Ministry of Health initiative to create integrated care primary care programmes to support the management of chronic diseases such as diabetes or COPD (Valentijn et al. 2015b). The research found that difference in the perceived success of the different programmes was *not* related to issues related to shared ambition. Rather, they relied heavily on the explicit voicing of interests of the partners in determining the ‘mutual gain’ to be made, primarily by setting out the preconditions for what a successful partnership would look like and ensuring that managers and decision-makers ‘steered’ the process of integration to ensure that these partnership preconditions were maintained. Relationship dynamics between partners in care, therefore, are a key to the successful functioning of professional and organisational partnerships that in turn are reliant on the continued brokering of the ‘contract’ between them and the ‘gains’ that each expect.

16.5.7 Communications Strategy

Often missed, but important in the literature, is the need to create an effective communications strategy and plan that delivers clear and consistent messages to all key stakeholders, but specifically to organisations and professionals tasked with delivering change at the clinical and service level (e.g. doctors, nurses and patients). Lessons from managerial experience suggest that effective communication of the vision requires multiple channels as a means to develop relationships (e.g. the Internet and social media) and therefore needs to be achieved using consistent and simple language.

As many of the proposed changes for care integration are likely to be complex and have a direct impact on vested interests as well as patients, it has been suggested that an experienced communications manager or team is likely to be essential to engaging and aligning teams and organisations. The nature of communication management might include: ensuring that all senior managers are aware of, and own, the narrative for integrated care; developing a communications and engagement strategy; establishing and managing a wide range of communication channels at a local, regional and national level (where required); and developing media releases to provide updates and briefings on progress, good news stories and case examples of best practice, and dealing with enquiries to build relationships (The Better Care Fund, p. 11)

16.5.8 Implementing and Institutionalising the Change

The next key element in the management of change involves the implementation of the change in practice, both in terms of ‘system’ (e.g. joint financing, governance and accountability) and ‘services’ (e.g. joint delivery through the development of teams). Often, the change process requires the initial piloting of options with the intention of ‘institutionalising’ or rolling-out the lessons learned for wider adoption afterwards. Moving from small-scale programs is important in order to deliver benefits on the scale needed to make a significant and transformational impact on the way care is delivered (Ham 2011). There are, however, very few examples of tool-kits which have sought to address the issue of scaling-up of pilots, though one is the DMIC model cited earlier in which ‘phase 4’ of the model supports strategies for consolidating change (Minkman 2012).

16.5.9 Monitoring and Evaluation: Developing Systems for Continuous Quality Improvement

A common weakness in approaches to integrated care is that not enough time and effort has been placed to agree the specific objectives for integrated care and how to measure and evaluate outcomes objectively. In particular, it is common that the lack of evidence for cost and impact can lead to significant problems (and programme failures) when seeking to embed programmes within wider health system funding streams (Valentijn et al. 2015b). In practice, therefore, managing change requires the ability to measure and monitor outcomes in a number of areas including: user experience, service utilisation, staff experience and the costs of delivering care. Progress towards these goals must be measured frequently to support learning and inform implementation (Table 16.2).

For healthcare systems, it is important to adopt and use a set of measures that align with the main elements of a national, regional or local strategy for integrated care. However, the complexity and the necessary variety in how integrated care strategies need to be developed means that outcomes and measures need to be chosen to suit local and national priorities. Many countries and regions have sought to establish a set of key measures and indicators for people-centred and integrated health services as a means to monitor and manage performance (e.g. Raleigh et al. 2014; IPIF 2013) and the range of measures that have been used has been usefully summarised through work supporting WHO’s Global Framework on People-Centred and Integrated Health Services (World Health Organisation 2015). An important aspect of developing a monitoring and evaluation framework is that it can be used to bring relevant stakeholders together to define the outcomes through which integrated care strategies should be judged and, as a result, promote joint

Table 16.2 Examples of indicators of maturity to integrated care change management

Examples dimension	Objective	Maturity indicator
Readiness for change	Compelling vision, sense of urgency, stakeholder support	Public consultations, clear strategic goals and milestones, stakeholder engagement
Structure and governance	Sustains and delivers new systems of integrated care, presence of effective change management	Funded programmes, effective communication, governance and accountability in place
Capacity building	Investment in training, skills and technologies of the workforce, including systems for continuous quality improvement	Developing of funding and availability of courses to support bottom-up innovation and workforce development

ownership and collective responsibility to achieving key goals. Including key stakeholders in how care systems will be held to account supports the inclusive process of developing a vision and driving change forwards.

A final key element of a change strategy is to utilise data and information from the monitoring and evaluation process to build in a process for continuous quality improvement, for example to identify ‘high impact’ changes that would most benefit patients or reduce variation in standards between provider teams. In essence, an ‘improvement process’ is needed to help clarify or re-frame objectives, redesign processes, address capabilities, integrate risks, develop performance measures, learning from performance measures and, crucially, create a feedback loop for improvement over time. Two key aspects for this include: first, the need for managers to properly engage service providers, communities and service users; and, second, the need to build in ‘rapid cycles’ of building and re-building strategies for change following their implementation and assessment of progress.

16.6 Building an Enabling Environment

The change process towards integrated care can take considerable time and effort to achieve but enabling the environment within which the management of change is to be taken forward is a necessary process and catalyst for change (Kotter 1996). This includes three core tasks:

- the building of *a guiding coalition* of leaders and key stakeholders to drive change forward from the top-down;
- the building of *support for change* from the ‘bottom-up’ within and between key professional groups and the communities of practice where integrated care is to be deployed is a core requirement for success, including the development of a shared set of norms, beliefs, values and assumptions that help to enable change to happen; and
- the development of *collaborative capacity* at a local level that enables and supports professional groups to work together effectively in multi-disciplinary or multi-agency teams that new approaches to coordinated and integrated health service delivery will require.

16.6.1 Developing a Guiding Coalition

There is a significant amount of literature that describes the importance of developing a ‘guiding coalition’ of partners at a political and senior level in order to agree on the collective aims and mission of integrated care and so provide the mandate to people working within different parts of the healthcare sector to cooperate with each other and co-ordinate activities. For example, reflections on the process of development of strategies to support chronic care management in the Basque Country emphasised the importance of taking the integrated care agenda to a 'policy level'. As a result, bottom-up approaches to innovation were supported by a regional research institute which monitored progress, whilst at a national level, there were regular meetings convened by the Ministry of Health which included public administration, professional associations and patient representatives to discuss the burning issues and how they may be addressed on the national and regional levels.

Pulling together a 'guiding team' of key people and organisations is also highly relevant at a local and regional level to champion integrated care and to lead change amongst key professional and patient groups. The effectiveness of such an approach is often cited as a key step in change management strategies (King et al. 2008). To make such as approach effective, key issues include choosing key managers with the position power, credibility and ability to drive the change process; and developing an inclusive and multi-disciplinary guiding team with the management skills to control the process (6 et al. 2006). Developing such front-line commitments requires the removal of barriers to integration by policy-makers, supporting the observation that creating an enabling environment for change requires both top-down and bottom-up initiatives (Ham and Walsh 2013; Bengoa 2013).

16.6.2 Building Support for Change

Evidence suggests that building support for change across networks of health and social care providers and other local stakeholders (such as patient representative groups) is complex and adaptive in nature (Goodwin 2015). A key reason for this is that each stakeholder usually will have a different perspective on the purpose of integration. Hence, politicians, managers, clinicians and patients are likely to have different priorities and different levels of understanding—integrated care will mean different things to different people. Moreover, attitudes to change are reliant on relationship-driven behaviours and inter-personal connections. Building support for integrated care between key stakeholders is thus a socio-cultural task akin to 'nation-building' through developing notions of community and citizenship.

The building of such support, then, requires being 'inclusive' at the design stage with those who would benefit or be influenced by the networks created as a result of care integration. Even so, a number of key managerial tensions will remain when building support for change including:

- Achieving a centralised position through which to wield managerial authority; yet to ensure the right balance between trust and control so as to encourage rather than alienate partners in care;
- Avoiding mandating change from the 'top-down' but to maintain it through peer-led approaches; yet, there is a tendency for professional and organisational capture of activities by dominant 'elites' that need to be avoided;

- Promoting mutual interdependencies, for example through joint targets on care outcomes or quality improvement targets; yet networks need to continue to provide 'net worth' to participants to ensure their engagement;
- Driving change through senior managers, yet recognising the relationship between physician leaders and managerial leaders remains underdeveloped (6 et al. 2006)

The major problem in building support for change, therefore, is one of control as all activists for integrated care realise that they have relatively little direct power (e.g. hierarchical, financial, knowledge) and so suffer from a lack of authority. As a result, managers need key skills in brokering inter-personal relationships and act as 'boundary spanners' that help to connect people together or unlock barriers to partnership working.

Ultimately, overcoming the 'governance gap' requires the network members themselves to sign-up voluntarily to collective governance rules, for example through a network constitution based on the notion of dual accountabilities. Contracts across care pathways or disease-based programmes appear less easy to maintain than those which focus on population health. Harmonising incentives, targets, audit and governance are important, but come after network members have provided the 'mandate to be managed' both technically and culturally.

At a more local level, even with the establishment of a guiding coalition, evidence demonstrates that there can be considerable resistance to change towards integrated care amongst professional groups and providers. This is not simply an issue related to differing funding and incentives or pre-existing professional roles and tasks, but a more deep-rooted concern related to the lack of understanding of the importance of integrated care and why change should be embraced. This demonstrates the importance that needs to be paid to pre-existing cultures, norms and values and how to potentially understand and recognise such issues when introducing change at a local level. Building support for change at a local level is thus essential and requires participants and stakeholders to be included in the design and development of solutions to ensure a collective vision and common understanding for change so that new ways of working have a greater chance of success. In theoretical terms, the process might be termed as a 'soft systems methodology' which understands that, in the real world, a complexity of relationships exists and which need to be actively explored. Hence, understanding relationships and building social capital is an explicit activity that requires understanding the challenges of integrated care without first imposing a preconceived structure or solution to the issue. As explored above, empirical evidence suggests that avoiding 'mandated partnerships' and 'top-down' imposition of new ways of working is important for integrated care to become an accepted idea, and that inclusiveness of people in the design and development of new approaches to care is important in the process (as is the subsequent assessment of impact and ideas for continuous improvements and change).

Building support for change is therefore an explicit component that requires understanding of the challenges of integrated care to promote inclusiveness and fostering a collaborative culture that builds the commitment of local leaders, staff, managers and the community (Goodwin 2015). The experiences of key people who have led the process of health service transformation commonly cite that achieving clinical integration is fundamentally about changing the culture of health care; it is more sociological than technological (Bengoa 2014; Kizer 2014; Meates 2014). Healthcare culture, manifest in silo-based working in specific professional groups and organisations, appears to be the biggest barrier to change and requires new ways of thinking and new competencies including systems thinking; collaboration in teams; quality management and process improvement science (Kizer 2014).

16.6.3 Developing Collaborative Capacity

The changing needs of patients with more long-term and complex problems highlight the need for care delivery to become reliant on a greater number of care professionals and organisations. Such changes clearly carry a greater risk to patients given the problems that might result from fragmentations in care. Developing effective and reliable multi- and inter-disciplinary teams and care networks is therefore important, yet the process is not always achieved with great success due to problems in team-based skills with the right skill mix (Baker et al. 2006).

Evidence suggests that consistent efforts need to be taken in the long term to help build the collaborative culture necessary to take integrated care forward at a local level. Creating effective teams is a change management process in its own right, and the development of evidence-based approaches to supporting effective teams and team building has become widespread across Europe (Mayer et al. 2001). Such support has been shown to be successful in breaking down silos and promoting interprofessional education and learning (Margalit et al. 2009). This task can be supported by a number of component strategies including education and training in multi-disciplinary working to support effective networks and teams.

The issue of developing a collaborative culture has often been put forward as a key ingredient to making a success of integrated care. A characteristic underpinning the success of case studies of integrated care is often the personal commitment of staff—both managers and professionals—to go that 'extra mile' by working beyond the boundaries of their job description in order to achieve the best results for their clients and in supporting colleagues to do the same. Lying behind this finding is a range of explicit strategies that promote a strong ethos amongst staff to 'do the right thing'—for example: promoting the needs of clients before them- selves; supporting knowledge-sharing; and enabling role-substitution and subsidiarity through staff empowerment (Goodwin et al. 2014).

There have been concerns about the time and cost implications of this kind of approach to change management given the lack of any guarantee that stakeholders can be sufficiently motivated to support change. Hence, the problem with promoting the idea that a value-driven approach should be a pre-requisite to the successful adoption of integrated care is that the weight of both evidence and experience predicts that such a process requires considerable time and effort. Moreover, given the mismatch of motives that exists when integrating the work of professionals and organisations, such efforts often go unrewarded and/or require continual negotiation. Hence, rather than being perceived as a catalyst for change, leaders and managers tasked with applying integrated care 'at scale and pace' might instead focus on driving forward the organisational solution or introduce various financial inducements in the hope this will be more effective. Given the evidence, such an approach would be a mistake. When looking at successful implementation strategies in integrated care, it is clear no short cuts exist—it takes vision and commitment over the long term to build the collaborative capacity necessary to take integrated care forward.

16.6.4 The Facilitating Role of Managers and Decision-Makers in Supporting the Process of Change

The evidence for the successful adoption of integrated care provides considerable emphasis on the role of individual managers and decision-makers in driving change forward. Lessons from evidence and experience strongly indicate that there needs to be a person, or team, with the necessary skills and responsibilities for facilitating partnerships and brokering effective networks of organisations and the development of well-functioning professional teams. Establishing collaborative practice requires hard work and effort to develop the necessary interdependencies between partners in care. Often, this requires challenging often well-established cultural ways of working to build-in collective values and thinking. Hence, the successful adoption of coordinated/integrated health services delivery in practice requires long-term and continuous effort to support and nurture change. As a managerial task, achieving care integration is as much about changing culture as it is about the management of resources or the application of technical processes.

Many studies have sought to examine the attributes and tasks that are needed of senior managers in this area (e.g. Ham and Walsh 2013; Bengoa 2013; Engineer et al. 2014; Kizer 2014; Meates 2014; Kotter 1996; Valentijn et al. 2015b; West et al. 2014, 2015), and these can be summarised as follows:

- Start with a coalition of the willing
- Inspire vision between partners in care—action is inspired through emotion
- Involve patients, service users and community groups from the beginning
- Build an evidence base to justify thinking
- Provide managerial decision-making 'across' the system so that it spans organisational and professional boundaries and promotes co-operation
- Develop a consensus style of management that includes and encourages all key stakeholders to participate as equal partners
- Engage clinicians and enable them to lead efforts for change with the freedom to innovate
- Foster 'collaborative capacity'

- Encourage long-term commitments from managers and decision-makers to drive through change
- Invest time and support in training people in these roles as they require specific skills in managing across diverse organisational contexts and boundaries.

16.7 Conclusions

The successful adoption and roll-out of strategies for the delivery of integrated care is to a large extent reliant on their being a receptive environment for change at both a national (political), regional and local level. Integrated care can be a highly challenging proposition to many individuals and organisations that may not value the change being advocated or feel threatened by its consequences. Moreover, in many cases, partnership working between different providers and professionals will represent an entirely new way of working, so requiring new skills to be developed and a change in outlook.

Figure 16.2 seeks to provide a visual representation of how these components fit together. On the left-hand side of the figure are represented the step-wise progression of change management tasks, whilst on the right are set out the need, over the timescale of implementation, the necessary 'relationship building' tasks that seek to create the enabling environment for change. It is important to recognise four key things:

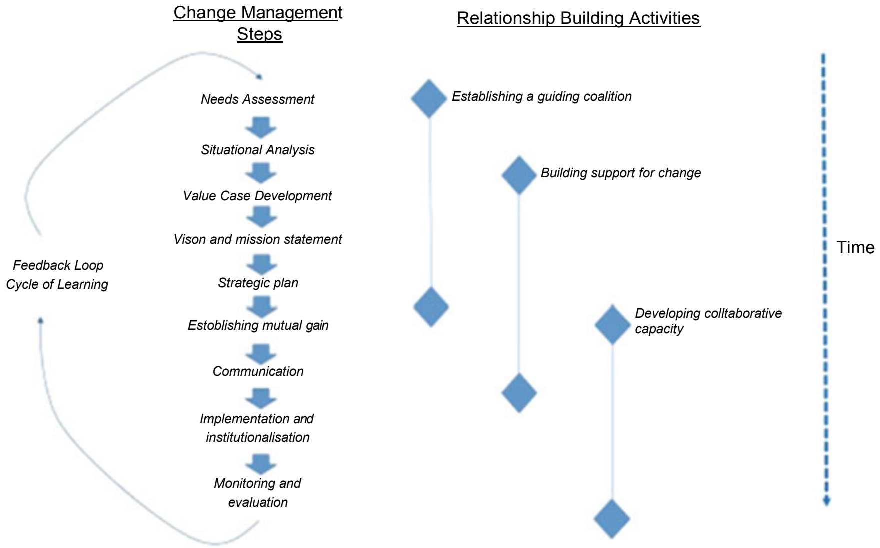

Fig. 16.2 Change management model for integrated care (adapted from Lewis and Goodwin 2017, Goodwin 2015)

1. the overlapping and continuous nature in how relationships are built over time;
2. the cyclical nature of the change management process itself in building and re-building strategies for change;
3. how mangers and key decision-makers are essential in facilitating the process of implementation over time; and
4. the evidence from experience in integrated care suggests that much has been achieved in different countries to establish a degree of consensus at a political level that may help to create an enabling environment through changes to financial and accountability rules. Yet, the evidence also shows that it is the professional barriers to change at a clinical and service level that remain the most persistent and most difficult to overcome.

This chapter has argued that the management of change towards integrated care requires the combination of two principle sets of processes: a step-wise progression of managerial tasks that come together to represent the core components of a change management plan ('management') and the ability to adapt these strategies for change in the context of the complex and multi-dimensional nature of practical reality ('environment'). Both tasks require key individuals with sophisticated managerial skills, and both have a strong relationship-building component and are inherently inter-related.

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How to Make Integrated Care Services Sustainable? An Approach to Business Model Development

17

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When developing and implementing integrated care services, decision-makers need to create complex business models involving many stakeholders across a range of sectors, both for profit and non-profit, and rely on reimbursement from statutory health- and social care bodies as well as on other revenue streams. The needs of these stakeholders have to be identified and duly balanced within the framework of what is possible. This requires the handling of a large amount of economic data, the capacity to anticipate future developments, and creativity in dealing with unintended consequences. Furthermore, the development of a business model is likely to involve stakeholders that are not economic experts. In this chapter, we present a combined approach to business model development that allows stakeholders to get acquainted with economic assessments while carrying out their own assessment and develop their business model.

17.1 Introduction

Developing business models for integrated care services means grappling with the complexities of the concept, with the needs and requirements of many different stakeholders and with the drivers and restrictions created by context. In addition, a large amount of data on economic and other impacts, both positive (benefits) and negative (costs), needs to be handled and brought together into one or more

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potential business model that can become the basis for negotiations with stakeholders. This often requires a certain amount of “looking into the future”, that is anticipating developments, testing different service deployment scenarios and seeing how they respond to changes in patient populations, changes in reimbursement regimes and changes to other factors. There can be unintended side effects or consequences, restrictions that were not known in the beginning and other factors requiring that initial assumptions (or aspirations) are adapted.

Furthermore, the development of a solid business model is likely to be a process of co-design, involving stakeholders other than managerial staff and accountants: health and social care professionals, IT staff, call centre personnel, and others, but also service users (clients or patients) and other persons involved in the service, such as family carers or volunteers. Depending on the service scenario, these stakeholders can be holders of valuable information in relation to work processes, the actual impacts of process innovation in day-to-day (working) life, as well as staff or end-user acceptance. While a narrower economic viewpoint might tend to exclude such factors from a business model, they are in reality just as crucial to success as immediate monetary factors such as revenues (see for example, Meyer et al. 2011; Goodwin and Alonso 2014 or Rigby 2014). At the same time, these stakeholders are usually no experts in business model development or economic assessment, since this is not part of their work or they are (in the case of clients/patient or family carers) possibly not even remotely involved in activities of this kind.

A business model development process that aims to involve these stakeholders is therefore faced with the additional challenge of communicating a complex subject matter to a non-expert audience with the aim of empowering them to make informed design suggestions or decisions.

This chapter presents an approach to these challenges that we are applying for more than 10 years now. The approach consists of two elements, building on each other. The *first element* is a method and toolkit for the assessment of socio-economic impacts in health, care and ageing, called ASSIST. The *second element* is a simulation tool based on real-life data that allows building an integrated care service and modelling how it responds to changes in economic factors. This second element we call the ASSIST Service Implementation Simulator. Both elements will be described in the following.

We would like to acknowledge the contributions made by partners in the two integrated care projects CommonWell (2012) and INDEPENDENT (2013) to the refinement of the original ASSIST method as well as the feedback given on their practical experiences made while going through assessment process. Thanks are also due to the partners of the integrated care projects BeyondSilos (2014a), CareWell (2014) and in particular SmartCare (2013) for being part of the testing of the ASSIST Service Implementation Simulator and freely sharing their experience, criticism and suggestions for improvement.

17.2 ASSIST: Socio-economic Impact Assessment Using Cost–Benefit Analysis

17.2.1 Background

The full name of the approach we apply is *ASSIST—Assessment and evaluation tools for e-service deployment in health, care and ageing* (empirica 2014), and it was originally developed for use in the context of telemedicine and telehealth services, specifically to assess the economic viability of telemedicine pilot projects funded by the European Space Agency (ESA). Its core aim is to support stakeholders in taking the step from a pilot project to routine service operation and in achieving a sustainable economic model where service benefits are equal to or higher than service costs.

In summary, the ASSIST approach consists of a methodology, a service assessment model and a software toolkit. The methodology covers the basic characteristics of the framework as well as descriptions of the empirical and economic methods used. The service assessment model consists of a generic set of stakeholders that can be involved in a service (divided into service users, service provider organizations and their staff, payers and IT industry), and of a set of cost and benefit indicators for each of these stakeholders. The software toolkit supports the adaptation of the service assessment model, the collection of data, the analysis and the presentation of results. Depending on its configuration, it can be used as a self-assessment tool without expert support or as part of a moderated assessment process. The whole approach revolves around a cost-benefit analysis (CBA) as for instance described by Drummond (2005). CBA is considered an appropriate tool for analysing the impact of investments and activities in domains of public interest, including social and health care, see for example the UK Treasury's Green Book (UK HM Treasury), Germany's WiBe (2014) and the White House Office of Management and Budget (White House Office for Management and Budget 1992). CBA enables the impacts on all stakeholders to be included in a socio-economic evaluation, over a defined timescale. Impacts can be financial but also include more intangible costs and benefits. For a stakeholder group a service can be beneficial as well as costly. What is beneficial to one stakeholder can be costly to another. This is why the tool differentiates stakeholders. CBA goes beyond cost analysis (CA), cost-effectiveness analysis (CEA) and cost utility analysis (CUA) but usually does make use of the data used for these as well.

Generally speaking, an ASSIST assessment is a comparison between a given status quo (usually an existing service or an established way of doing things) and a new or strongly revised intervention. We assume that this intervention is neither a single agent nor a single point in time but a process of changing care service delivery from one status to another, thereby covering multiple agents and including different stakeholders as well as IT systems. This puts an emphasis on the implementation environment and its impact on service delivery, as well as on the task of optimizing the service configuration to work in the given environment. The assessment goes along with this process, providing data and insights allowing the responsible stakeholder(s) to work towards a service model that is:

- Viable—working successfully
- Sustainable—maintaining a positive ratio of costs and benefits
- Scalable—working for all patients and not only the pilot population.

An in-depth description of the ASSIST approach, the underlying requirements and assumptions and the mathematics can be found in Hammerschmidt and Meyer (2014). We decided not to replicate this information here since it is not pertinent to the purposes of this chapter. Based on an example case, we instead focus on the practical assessment process as it is undertaken by stakeholders involved in setting up a new integrated care service or in transforming existing service provision along new, more collaborative lines. We also describe briefly ASSIST's stakeholder and indicator model for integrated care.

17.2.2 Assessment in Four Steps

An ASSIST assessment is done in *four subsequent steps* (see Fig. 17.1), following an implementation and deployment cycle leading from initial idea formulation to deployment either at pilot scale or in mainstreamed service provision. Such a cycle has for instance been described by Meyer et al. (2011), but similar models are also used in other domains such as software development and more generally in quality improvement studies (Davidoff 2008).

An overview of each of those four steps is given in the following. The next chapter contains an example case showing the practical applications of the four steps.

Step 1: Stakeholder Identification Work begins with the identification of all stakeholders *involved* in the service (i.e. playing an active role) or *affected* by the

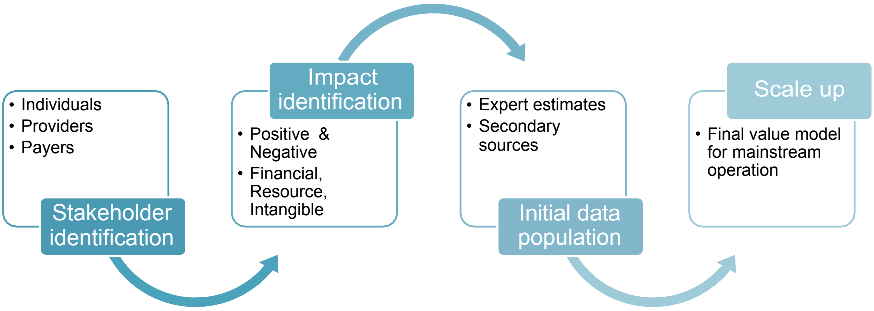

Fig. 17.1 Four steps of the assessment process

service (i.e. in a passive manner). Both cases, active and passive, are characterised by a stakeholder experiencing any kind of impact, negative or positive or both, due to the new or changed service. The main caveat at this initial stage is to be inclusive and to not neglect stakeholders, especially those that you presume to have a minor role. For example, this often concerns informal carers (family members, friends or neighbours), but also professionals outside the immediate care loop. Reasons for this can be simple oversight, or an unawareness of the capacities and competencies of these stakeholders, as well as factual concerns, e.g. about split of responsibility, skill levels, data security, etc. Practically, this first step in the process will usually consist of a series of meetings between project managers and stakeholders onsite.

Step 2: Impact Identification The second step is to identify all relevant positive and negative impacts for each stakeholder, as well as to define suitable indicators to measure each impact. The final shape of the impact model and indicator set depends on the local context. On the one hand, the indicators need to make sense in relation to the locally implementable service configuration and any given framework conditions that cannot be changed. At the same time, populating the indicator set with data needs to be practically feasible under the given circumstances.

Picking up the results of Step 1, work now is more systematic, with a view to ensuring a full coverage of all relevant impacts and a correct identification of indicators for each. This can be achieved by employing a causal chain linking the outputs and outcomes of the service to its impacts (see Fig. 17.2). Indicators are then defined that allow the measuring of each impact.

Step 3: Data Collection Data to populate the indicators defined in Step 2 usually comes from different sources. Primary sources include all data collected during an evaluated pilot period, such as log data stored in Information & Communication Technology (ICT) systems, administrative data, and time sheet data specifically gathered for the purpose of the project. Also, end-user/staff related data can be gathered by means of dedicated questionnaires where necessary, secondary data can also be used, e.g. data derived from official statistics, published studies or administrative databases.

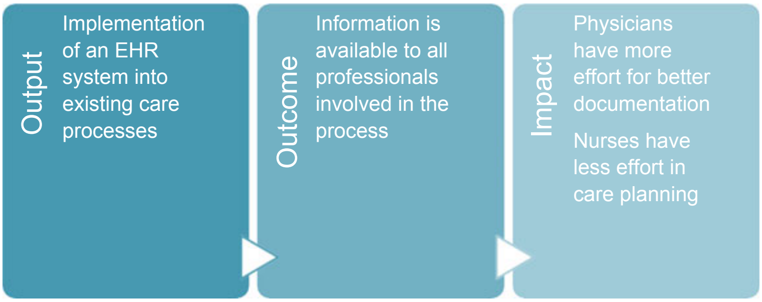

Fig. 17.2 Causal chain: From output to impacts

Step 4: The Value Case: Strengths and Weaknesses of the Services The final step of the approach focuses on analysing the quantified costs and benefits for each stakeholder. This includes the calculation of key performance measures such as "socio-economic return", "economic return" and "breakeven point". A more detailed description of these performance measures and their calculation is available in Hammerschmidt and Meyer (2014) and Hammerschmidt and Jones (2012). The analysis also includes identification of the key "adjusting screws" that are available to the pilot service for further optimising the value case under the given conditions.

Overall, the analysis of the results will allow the involved stakeholders to:

- ***Identify benefit shifts***: These occur frequently when new services are being introduced or existing ones are changed. Wherever such a change is to the disadvantage of a stakeholder, that one is likely to become a veto player which will reduce the overall utility and performance of the service, especially if that stakeholder holds a powerful role.
- ***Justify investment***: The analysis of the overall performance of the service will allow responsible service managers and other decision-makers to prove that the investment (both in terms of money and time) is worthwhile.
- ***Calculate breakeven***: When communicating the costs and benefits to involved persons, it is important to understand when the benefits surpass the costs. This will allow preparing stakeholders for a prolonged phase of investment, again both in terms of money (e.g. cost for equipment) and of time (e.g. staff time for training and adapting to the new way of working). In integrated care, as in health and care in general, services may often take a comparatively long time to arrive at breakeven. Time spans between 5 and 7 years are not uncommon (Stroetmann et al. 2006).
- ***Understand service impacts***: The understanding of all impacts (including secondary and long-term effects) may offer a new perspective on the service that is led by an economic and strategic view. This is a value in its own right as it complements a technical and organisational point of view and explains and predicts why stakeholders behave as they do.

17.2.3 A Cost—Benefit Indicator Set for Integrated Care

The assessment offers a pre-defined set of cost and benefit indicators for different potential stakeholders in a service, covering service clients/patients, informal carers, different types of health and care provider organisations as well as their staff, payers and the ICT industry. The indicator set was specifically developed to capture the impacts of integrated care services and to allow for the development of value or business models in this field. It is, however, also applicable to other service concepts that do not focus on vertical and horizontal co-operation of service providers.

The indicators cover the most common costs and benefits occurring in the implementation of health and care services, including efforts for service development, efforts for training (providing and receiving), costs for the procurement of hardware and software and other material goods, costs for the procurement of supporting services (such as installation or maintenance), different types of quality and efficiency benefits, as well as different types of revenue streams.

A core element consists of indicators covering the time spent (cost) on service provision (for providers) and service use (for clients/patients and informal carers), as well as time liberated (benefit), e.g. due to more efficient work processes, avoided hospital stays or visits to and by providers. This part of the indicator set is conceptually linked to two high-level pathways for integrated care, one covering short-term support (e.g. after hospital discharge), the other long-term support (e.g. for people with chronic conditions). Both pathways were originally developed in the SmartCare project (SmartCare 2015b) and further developed in the BeyondSilos project (BeyondSilos 2014b). Common activities defined in the pathways were used to construct the respective indicators.

17.3 Learning by Example: The Service Implementation Simulator

The *Service Implementation Simulator—Integrated eCare* was created in the framework of the SmartCare project as a tool to support the project's activities to develop sustainability models for the services being deployed. In practical terms, the Simulator can be considered an ASSIST software tool filled with exemplary data illustrating an exemplary service (see below).

The Simulator can be used to explore potential configurations of ICT-supported, integrated care services. With the Simulator, different ways of setting up a service (in terms of stakeholders involved, service processes, etc.) can be chosen. Using the tool, assumptions can be made for different types of service-related costs and benefits, ranging from direct revenue models to high-level societal goals. Both short- and long-term consequences of each design choice can be explored immediately. Furthermore, the Simulator can be used to get acquainted with the general ASSIST method.

It was particularly created for stakeholders who are no experts in economic assessments and cost-benefits analysis, but who still want or need to be involved in related activities. Following an "active learning" (Bonwell and Eison 1991) approach, the Simulator allows users to get into immediate contact with the content-related aspects of the assessment, while (initially) by-passing detailed methodological questions and the need for data collection. Since the Simulator is pre-filled with data already, a user can instantly delve into understanding the economic characteristics of the example case and begin modifying data to see how the sustainability model of the service reacts to changes in costs and benefits. While doing this, the user also gets acquainted with the functionalities of the ASSIST software tool and the underlying methodological assumptions. In the further course of the assessment of the user's own case, the Simulator can either be used by modifying the model data already present or by deleting all model data to start the own assessment from an empty tool.

17.3.1 Integrated ECare Example Case

The *Service Implementation Simulator—Integrated eCare*—is built around a model case scenario of an ICT-supported, integrated care service. The scenario was developed as part of the SmartCare project. In particular, it makes use of the integrated care pathways developed in SmartCare and the cost-benefit indicator set described above. Some elements of the scenario were developed based on actual integrated eCare services implemented in the CommonWell and INDEPENDENT projects.

17.3.2 Overall Service Model

The case scenario is built on a service supporting older people living with Chronic Obstructive Pulmonary Disease (COPD) and possible co-morbidities, as well as their family members or friends caring for them (informal carers). As an integrated service, it amalgamates services provided to patients and their carers by different stakeholders, including healthcare providers, social care providers and third-sector providers. ICT systems are used to support service delivery.

The service is supposed to be set-up in three stages, beginning with a 6-months development and implementation stage, followed by a 12-month evaluated piloting period, after which the service began routine operation.

17.3.3 Elements of the Service

The service is conceived of as a socio-technical system bringing together elements provided by (individual and organisational) human stakeholders and different ICT systems, both working in close relationship. It consists of three core elements:

1. An early supported discharge (ESD) programme for COPD patients following an exacerbation of their condition. The ESD programme uses home telehealth to provide monitoring and guidance to the patients after their discharge from hospital. Follow-up, e.g. in case of out-of-threshold telehealth readings, is relocated from primary care (GPs) to a social care providers. Patients can be re-admitted to hospital or referred to the GP if required.
2. Eligible patients are furthermore enrolled in a video-based physiotherapy programme to improve or maintain their physical fitness. Patients can participate in guided online physio sessions at regular intervals, using a computer with webcam and headset or microphone and speakers in their home.

3. A voluntary organisation (third-sector provider) supports informal carers (family members or friends) in caring for the COPD patients, by means of counselling, self-help meetings, information provision and other offers.

For the start of the service, the provider organisations involved agreed on a general collaboration mechanism that is based on a common care pathway. The pathway foresees joint care planning as well as sharing of relevant patient or client data in a joint care record. All providers have access to that record in compliance with data protection legislation and based on informed consent given by the patient. Informal carers can be granted access to parts of the record under the same conditions.

17.3.4 Assessment of the Example Case in Four Steps

17.3.4.1 Step 1: Stakeholders

The following stakeholders are either actively involved in the service or passively affected by it:

The *COPD patients* will usually be 60 years old or older, diagnosed with COPD and possible co-morbidities. A considerable share of the patients will be smokers. They enter the service after hospital admission following an exacerbation of their COPD and prior to hospital discharge. They pay a monthly fee to the Telehealth Call Centre and the physiotherapy provider. An evaluation of the service showed that patients are satisfied to very satisfied with the service and how it effects life with their chronic conditions.

The *informal carers* are family members or friends of the patient who have taken over some or all caring responsibilities for the patient. They will usually be 50 years or older, with at least half of them in part- or full-time employment. They can but do not have to live in the same household as the patient. They pay a nominal fee to the carer support organisation. An evaluation of the service showed that informal carers are by and large satisfied to very satisfied with the service and how it affects themselves and the people they are caring for.

The *Telehealth Call Centre* is a private business entity providing home telehealth to the patient. It is responsible for the provision and installation of the telehealth hardware, for training of the patients as well as for technical maintenance and support. They monitor telehealth readings, including technical triaging, and pass alerts on to the social care provider, the GP or the hospital, as the situation demands. The call centre receives a service fee paid by the COPD patients. Under the current service model, this fee covers about 50% of the costs.

The *primary care organisations* (GP practices) are private organisations reimbursed from a public budget (held by the health and social care payer). Usually, they provide day-to-day health care to the COPD patients. The early supported discharge programme means that a considerable amount of care is now being provided by social care providers. The GP remains responsible only for certain types of follow-ups requiring the attention of a doctor. As a consequence, the number of consultations that the COPD patients used to have at the GP practice is being reduced. As the GP is reimbursed on a Diagnosis Related Group (DRG) basis (i.e. per treatment), the immediate effect is a loss of income.

The *hospitals* are public institutions financed by their own budgets which they receive from the state. They provide care to the COPD patients, especially in case of exacerbations. The early supported discharge programme and the home telehealth monitoring substantially reduces admissions due to exacerbations as well as readmissions. For the hospitals, this means that a considerable amount of staff time is being saved, beds are freed, and the waiting lists shortened. Since the hospitals' budgets remain unchanged, this is an immediate benefit for them.

The *physiotherapy provider* is part of a larger public institution providing different types of health and social services, not only to older people but also to children, people with disabilities and people receiving welfare benefits. The whole institution finances itself via a budget received from the state. For the physiotherapy team, the introduction of video training allows them to take on more clients than before. Clients pay a monthly fee for the video service, which however is not intended to cover the operational costs.

The *social care providers* are private business entities, financed from a state budget on a case basis. They take on the immediate follow-up of the COPD patients, based on the technical triaging done by the Telehealth Call Centre. They take over much of the work originally done by primary care organisations and receive additional reimbursement for this, allowing them to break even on the new service after about 1.5 years.

The *carer support organisation* is a volunteer organisation that funds itself through membership fees, fundraisers and various state aid schemes. Furthermore, informal carers receiving support pay a nominal monthly fee. A major part of the support services provided is delivered by unpaid volunteers. A small core team of employed staff deals primarily with managerial and administrative work. For the carer support organisation, the new service resulted in the wide-spread implementation of IT (mostly computers and mobile devices) into their offices and work processes. After initial problems, this has led to considerably efficiency gains in the organisation's administration.

17.3.4.2 Step 2: Impact Identification

To show how the identification of impacts is done using the example case, we focus on two stakeholders: the COPD patients receiving the service and the GP practices that, under the new service, are responsible for certain types of follow-ups. For the sake of the example case let us assume that impact identification was done by the team implementing the new service based on interviews with GPs and practice nurses as well as a focus group with patients.

Consideration of the different elements of the service as well as consultation with older people suffering from COPD in a focus group showed that the main negative impacts of the new service would be:

- Inconvenience related to the time it takes patients to learn the use of the telehealth devices
- Inconvenience related to the time it takes them to receive support from the social care provider and the time it takes them to do their daily telehealth readings

Furthermore, it is being considered to introduce a patient-payable fee or co-payment for the telehealth service, which would be an additional cost factor

On the positive side, the following impacts were considered likely:

- Intangible benefits perceived by patients, such as an increased feeling of safety, improved capacity to live with their own condition, satisfaction with a more coordinated way of providing care to them
- Convenience related to the time saved due to avoided visits to the GP.

For the GP practice, the impact identification showed that the main negative impacts were likely to be:

- The time spent by the GP and the practices nurses on the development of the service, especially the definition of work processes
- The extra time spent by the GP and the nurses to contribute to the joint care plan for each patients
- The loss of income from practice consultations and home visits that are being relegated to the social care provider.

On the positive side there are:

- Time saved due to the consultations and visits relegated to the social care provider
- Travel costs saved in relation to the relegated home visits.

17.3.4.3 Step 3: Data Collection

Data are collected, e.g. in the course of an evaluation of the service pilot and entered directly into the ASSIST tool. In the example case, data on the time spent by patients for training and for using the service, as well as on time saved due to the avoided GP visits is collected by means of a quantitative survey using a questionnaire including questions on time use. The resulting data are therefore based on patients' recollection of the time they spent or saved. The questionnaire also covered the perception of intangible impacts. In order to have an empirical basis for the co-payment amount, a willingness-to-pay questionnaire was furthermore carried out. Table 17.1 shows the data collected on the different variables making up each impact.

Table 17.1 Patient impact data

Negative impacts	Value	Unit	Time period
Fee for services			
Service fee paid by Clients/Patients 1 to Telehealth call centre	20	€	Per month
Service fee paid by Clients/Patients 1 to Physiotherapy providers	10	€	Per month
Inconvenience: training time			
Time spent by Clients/Patients 1 receiving training	0.5	hours	Per new patient/client
Inconvenience: extra time for service use spent by Clients/Patients 1			
Average (extra) time spent by Clients/Patients 1 receiving social care, per session.	45	min	Per session
Number of (extra) sessions of social care of Clients/Patients 1	6	Number	Per patient/client per year
Average (extra) time spent by Clients/Patients 1 receiving remote care, per session.	10	min	Per session
Number of (extra) sessions of remote care of Clients/Patients 1	365	Number	Per patient/client per year
Positive impacts	Value	Unit	Time period
Valuation of intangible benefits by Clients/Patients 1 according to eCCIS			
Average score for specific benefits (SBS) by Clients/Patients 1	1.75	Score	
Average score for overall assessment (OAS) by Clients/Patients 1	1.34	Score	
Degree of uncertainty (DU) for assessment by Clients/Patients 1	15%	%	
Convenience: time saved for service use by Clients/Patients 1			
Average time saved by Clients/Patients 1 receiving health care, per session.	12,240	min	Per session
Number of sessions of health care saved by Clients/Patients 1	2	Number	Per patient/client per year

A Note on Data Handling: The cost–benefit analysis is solely based on monetary values. This is straightforward for monetary impacts, such as the fee for service in this case. Both inconvenience related to time spent (and convenience to time saved) are intangible effects which are here approximated by the amount of time and then monetarized using the average individual income of the patient target group. The results of the survey on the perception of intangible impacts were aggregated into a standardized score and then monetarized relative to the costs the service causes to the patients, i.e. in this case the inconvenience for the time spent using the service. For a more detailed description of the approaches used, see Hammerschmidt and Meyer (2014).

Data for the GP practice were collected by means of a staff time protocol analysis for the extra staff time and time saved and by means of an analysis of accounts for the number and costs of avoided consultations and home visits. Data on saved travel cost were gained through interview with several GPs. Table 17.2 again shows the data collected on the different variables making up each impact.

A Note on Data Handling: Other than for the patients above, extra time spent and time saved at the GP practice are not intangible impacts but resource impacts. By way of labour cost (wages plus employer contributions), they are more or less direct financial impacts for the practice. Accordingly, they are monetarized using labour cost.

17.3.4.4 Step 4: Analysing the Value Case

Based on the data entered into it, the ASSIST tool calculates the costs and benefits for each stakeholder and for the overall service. Two important elements are added in the calculation: the first is the number of patients, staff members and other individuals involved by which the costs and benefits are multiplied as applicable. The second element is a projection of the data over time, modelling the development of the costs and benefits depending on the inclusion of patients and further individuals as the service progresses.

The result is a graph showing for example what is called the cumulative socio-economic return rate, i.e. the relation of costs and benefits over time, as shown for the COPD patients in Fig. 17.3.

The projection covers a time period of 7 years, from January 2015 (at which time the development of the model case is supposed to have started) until December 2021. With the begin of the service operation in June 2015, the socio-economic return immediately rises to somewhat more than 50%, indicating that the benefits to the patients outweigh their costs by about a factor of 0.5. This rate steadily decreases as a result of depreciation, but always remains above 0%. There is a notable dip in July 2016 when the pilot project is supposed to end and the service transferred to mainstreamed operation. At that point in time, the patient-payable fee of 30 € per patient and month is introduced, reducing the total benefits.

The grey dotted line shows an alternative scenario, by which the patient-payable fee is 50 € per patient and month instead of 30 €. As the graph shows, even under these conditions, the benefits would be higher than the cost and the option of a higher fee would seem viable in principle. This should however be supported by according findings in the willingness-to-pay analysis indicating that such an amount would be acceptable.

The alternative scenario shows how results of the analysis (and the data in the Simulator respectively) can be changed to develop different scenarios and how they impact on the stakeholders in the model.

For the GP practices, Fig. 17.4 shows the cumulative net-benefit, i.e. the sum of all costs and benefits (excluding intangibles). Cumulative net-benefit is usually used as the key performance measure for profit stakeholders.

Table 17.2 GP practice impact data

Negative impacts	Value	Unit	Time period
Staff time spent on service development			
Time spent by General Practitioners on service development and implementation	12	hours	Per month
Time spent by GP nurses on service development and implementation	6	hours	Per month
Duration of development period	6	months	
Extra staff time for service provision (assessment/planning) by General Practitioners to Clients/Patients 1—actual time			
Average (extra) time spent by General Practitioners on discharge planning for Clients/Patients 1	15	min	Per session
Number of (extra) discharge planning sessions of Clients/Patients 1 done by General Practitioners	1	Number	Per year
Extra staff time for service provision (assessment/planning) by GP nurses to Clients/Patients 1—actual time			
Average (extra) time spent by GP nurses on discharge planning for Clients/Patients 1	15	min	Per session
Number of (extra) discharge planning sessions of Clients/Patients 1 done by GP nurses	1	Number	Per year
Forgone income from avoided practice consultations			
Reimbursement lost due to avoided practice consultations at the Primary care organisations by Clients/Patients 1	100	€	Per patient/client per day
Number of practice consultations avoided for Clients/Patients 1 at the Primary care organisations	4.00	Number	Per year
Forgone income from avoided home visits			
Reimbursement lost due to avoided home visits at the Primary care organisations by Clients/Patients 1	120	€	Per patient/client per day
Number of home visits avoided for Clients/Patients 1 at the Primary care organisations	2.00	Number	Per year
Positive impacts	Value	Unit	Time period
Resource liberation (intervention) for General Practitioners working with Clients/Patients 1—actual time			
Average time saved by General Practitioners on consultations with Clients/Patients 1	30	min	Per session
Number of consultations with Clients/Patients 1 saved by General Practitioners	4	Number	Per year
Average time saved by General Practitioners on home visits to Clients/Patients 1	60	min	Per visit
Number of home visits to Clients/Patients 1 saved by General Practitioners	2	Number	Per year
Resource liberation (intervention) for GP nurses working with Clients/Patients 1—actual time			

(continued)

Table 17.2 (continued)

Positive impacts	Value	Unit	Time period
Average time saved by GP nurses on consultations with Clients/Patients 1	15	min	Per session
Number of consultations with Clients/Patients 1 saved by GP nurses	4	Number	Per year

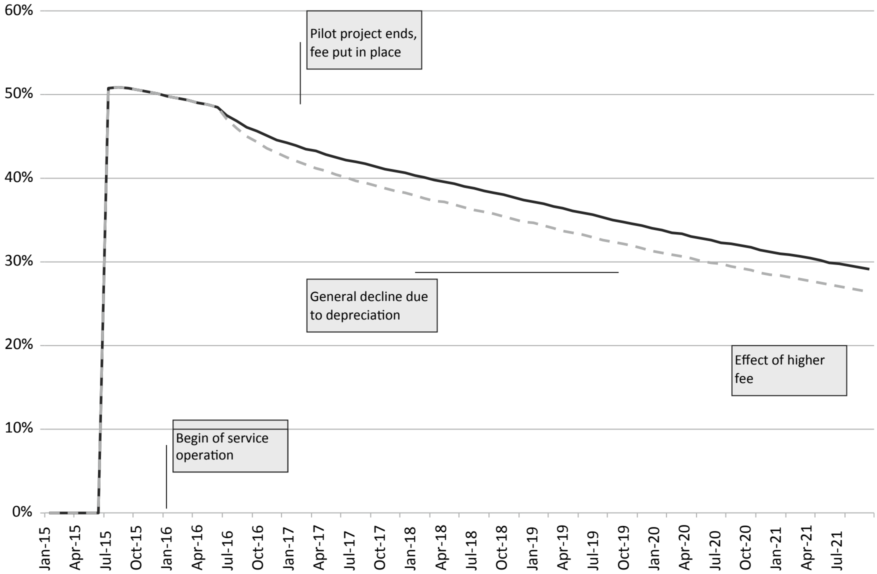

Fig. 17.3 Socio-economic return for patients

The picture that emerges for the GP practice is considerably different from one for the patients. From the start of service operation, the net-benefit decreases steadily to reach a minimum of below 400,000 € towards the end of the 7 year period. This means that for the GP practice the costs of the new service are constantly higher than the benefits. This is the direct result of the follow-up visits relegated from the comparatively high-cost GP practice to the comparatively low-cost social care provider. Under these conditions, there is a high probability that GP practices will not be in favour of the new service and are actually likely to actively work against its implementation.

An alternative to this scenario is again shown by the grey dotted line. In that case, what can be called a balancing payment from the healthcare payer to the GP practices is introduced, to compensate for the losses caused by the relegated consultations and home visits. This might well be acceptable to the payer, given that the service as a whole leads to considerable cost savings due to avoided hospitalizations.

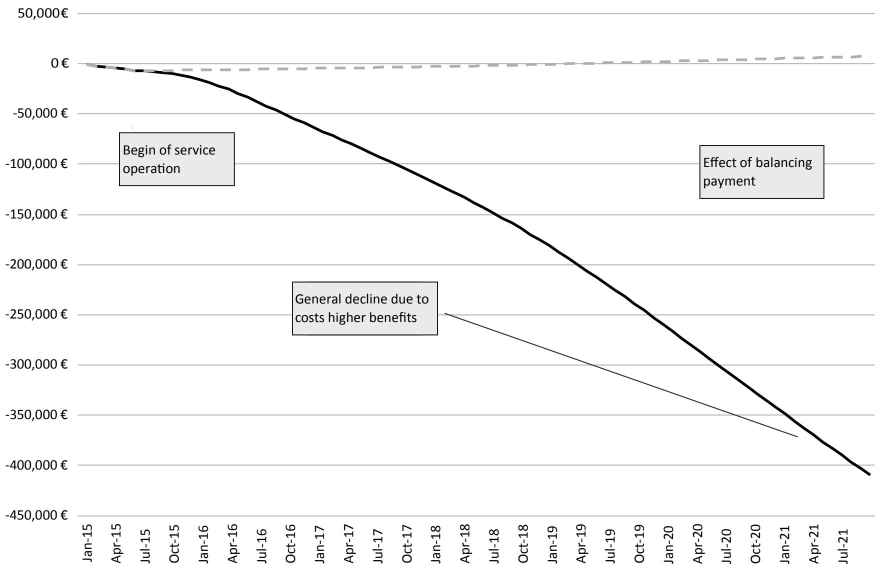

Fig. 17.4 Cumulative net-benefit for GP practice

Again, this shows a way of developing and testing different scenarios with the aim of achieving an overall model that satisfies the needs of most if not all stakeholders.

17.3.5 A Set of Lessons to Be Learned

The example presented above shows two ways how the Simulator can be used for business models development and the associated learning. Further to this, the Simulator comes with guidance material (SmartCare 2015a) containing a number of lessons to be learned by its users. Following the “active learning” approach these lessons are designed to make the users acquainted with the software tool and then to carry out a series of ever more complex tasks. These tasks take the user on a journey of first understanding how the service works in economic terms and second identifying and then solving a number of problems that were built into the service’s sustainability model.

Currently, there exist five lessons and further lessons are being developed. The *first lesson* addresses some basic functionalities of the ASSIST software tool, allowing the user to navigate through the tool, include or exclude stakeholders from the assessment as well as activate or deactivate indicators from the existing set, depending on whether those will be needed or not. A *second lesson* addresses challenges to the business model of the (profit oriented) Telehealth Call Centre resulting from a lack of revenues. A *third lesson* deals with the benefit shift phenomenon already briefly described above. It confronts the user with a (potentially powerful) veto player that could jeopardize the overall service model and explores ways how this veto player could be included in the service in a sustainable manner. A *fourth lesson* addresses a problem that is common in economic assessments involving public bodies financed from a larger budget (such as a national health service). In such a situation, it can be difficult to determine what share of the budget is being used for the new service. In practical terms, this could mean that there is no immediate benefit to set against cost caused by the new service.

A *fifth lesson* explores ways how a user can deal with uncertainties in the data to be used that might results from a lack of suitable data, the workload of the staff to be involved or other factors. Inter alia, the ASSIST tool incorporates a mechanism for sensitivity analysis using Monte Carlo simulations that can be used to address such issues.

Each lesson in the guidance begins with a description of the problem, followed by a series of ever more concrete hints as to how the problem might be solved. The lessons are generally designed to be solved by working alone, but a group setting can also be used. The latter can be considered particularly useful for those lessons where no single solution exists, but there are rather alternative options, each with its own advantaged and disadvantages. Since the ASSIST tool carries out all calculations on-the-fly, the impact of any solution on the relevant key performance measures can be checked by the user immediately and without need of feedback from a "teacher".

17.4 Conclusions

The ASSIST approach and the Service Implementation Simulator are currently (as of early 2021) in active use both in EU- and national-level deployment activities, with use cases ranging from the implementation of complex integrated care pathways to palliative care for oncology patients. Both tools are available for free use under the GNU General Public License (GPL) and can be downloaded from empirica (2014) and SmartCare (2015a), respectively.

With the number of both integrated and ICT-supported services being on the rise across Europe, ASSIST remains a useful tool for researchers and implementers to use in order to arrive at a sustainable business model for any complex intervention. In particular, when it comes to implementing complex interventions such as integrated care schemes within day-to-day settings, it is challenging to predict the final outcome of a multi-dimensional service innovation which is typically required to be pursued with sufficient certainty. The case for change should be as robust as possible, especially with respect to expected gains in relation to service effectiveness and efficiency, if a wider mainstreaming of the envisaged service innovation is to be ultimately achieved.

A key challenge concerns the fact that there is a limit to how much one can prove things during the service development and early implementation stage. The conceptual approach adopted for the ASSIST methodology and the design of the associated software tools unfold their strengths not at least in the context of a formative evaluation of complex service innovations, as illustrated by the application examples discussed above. Nevertheless, ASSIST has also been successfully used for ex-post evaluation purposes. Independent which evaluation perspective is ultimately to be adopted, the ASSIST methodology and tools enable an evidence-based assessment of complex service innovations in terms of "nested" innovations by simultaneously paying attention to the different stakeholders involved, their particular working models and the technology to be deployed.

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Planning

18

Susanne Ozegowski

> *Plans are worthless, but planning is everything* (Dwight D. Eisenhower, 1957).

18.1 Introduction

18.1.1 The Need for Planning

Resource planning plays a central role in health care. There are many supplies which we consider essential to our daily lives, such as food, clothing, fuel. Nonetheless, there is no public planning of supermarkets, warehouses, or gas stations. Health care, however, is different: firstly, there is a broad consensus in many societies that prices and volume in health services markets should not be determined (solely) by supply and demand as health is a fundamental human right (Dussault et al. 2010; WHO 2013). Equitable access to health care is deemed to be one of the central building blocks of that right (WHO 2013). Thus, in the context of this rights-based framework planning is required in order to allocate resources to health care by normative and ethical standards and not simply market mechanisms. Another reason for planning in health care is the need for excess capacity in order to be prepared for emergency situations. Since the time to treatment can be a decisive factor in emergencies, excess capacity for healthcare provision is necessary,

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especially in locations where it would not be efficient by market standards. That applies, for instance, to workforce planning: on the one hand, policymakers do not want to risk a shortage of health professionals which would put a timely provision of health care at risk. On the other hand, payer organizations and the (healthy) population seek to avoid a costly oversupply. Therefore, the challenge lies in estimating exactly the "right" number of health professionals required in future. This is especially difficult for the physician workforce as medical education takes up to 15 years, meaning that forecasts have to be made for a considerable time span in order to bridge the time lag between recognizing a gap between supply and demand and being able to close that gap (Dussault et al. 2010).

18.1.2 Planning Taxonomy

The allocation of healthcare resources and the planning process can be looked at from a variety of angles:

- By stakeholder: Who is planning?
- By time frame: What time span does the planning process cover?
- By geography: Which catchment area is covered?
- By criteria: By what criteria and methodology are resources allocated?
- By subject: Which resources are considered?

In terms of stakeholders, the responsibility for planning can lie with national, regional, and/or local governments. It can be devolved to public authorities (like the National Health Service (NHS) in the UK) or multi-stakeholder bodies (such as the Joint Federal Commission in Germany assembling insurers and providers) (Ono et al. 2013). It can also be up to insurers, provider organizations, or integrated care providers.

The time frame for planning varies widely based on the specific subject of planning. As elaborated above, modifying the intake of medical students is rather a long-term measure in order to influence the future number of available physicians. Changing the number of nurses in an intensive care unit, on the other hand, has an immediate effect on the quality of care.

Planning can take place on all geographical levels: large pharmaceutical and medical technology companies, for instance, are serving the global market. Therefore, when the avian influenza virus H5N1 started to spread in the early 2000s, the World Health Organization (WHO) issued a recommendation to all governments to stockpile the antiviral drug Tamiflu® for at least 25% of its population. As many countries followed that recommendation, the licence holder Roche ran into considerable shortages of the drug on a global level (Greene and Moline 2006). Many other planning activities take place on a national, regional, or local level. Medical student intake, for instance, is determined at a national level in many Western countries (Bloor and Maynard 2003). Training posts for nurses, on the other hand, are either planned on a national, a regional level or not at all, as an overview by the Organisation for Economic Co-operation and Development (OECD) showed (Simoens et al. 2005). The planning process for a certain type of resource does not necessarily have to rest exclusively with one institution for a certain catchment area. Instead, there may be competing or coexisting organizations which are planning healthcare resources for the same catchment area. In the Netherlands, for instance, competing insurance companies sign contracts with different hospitals based on their own criteria—yet, all of the companies have to ensure adequate access to hospital care for their insured (Krabbe-Alkemade et al. 2017).

Planning criteria also differ immensely. Allocations of healthcare resources are planned to ensure accessibility in terms of quantity, quality, and an adequate distance. At the same time (cost) efficiency and profitability of healthcare institutions also plays an important role as resources are limited. The goals of service provision can easily contrast with financial objectives, requiring decisions between competing criteria. In addition, there are typically complex webs of regulatory requirements that need to be observed. In Germany, for instance, hospitals are subject to minimum-volume standards for certain complex surgeries, e.g. hospitals are required to demonstrate 20 liver transplantations and 50 knee arthroplasties per year in order to be allowed to perform the respective intervention (de Cruppé et al. 2015). On January 2016, a new law was enacted, which excludes those hospital services not meeting the standards from reimbursement (Art 136b para. 4 German Social Code V). In addition to the two sometimes competing criteria addressed above, insurers and providers are usually motivated to maintain positive reputations —both in terms of patient satisfaction and as employers. These considerations can also influence decisions on resource allocation.

Finally, the question of what is being planned is, of course, crucial for any of the variables mentioned before: there are various resources that are subject to planning: infrastructure, such as hospitals, emergency care units, medical devices, and further equipment need to be sufficiently available. Denmark, for instance, has recently sought to strengthen the efficiency and quality of its inpatient care by cutting the number of hospitals by at least half and re-building many older hospitals according to state-of-the-art equipment and technology (Møller Pedersen 2009). Schools and faculties for medical studies and other healthcare professions are also an important resource. In addition, budget planning plays an important role: investments in infrastructure, technology, and human resources require sufficient levels of financial resources. However, in the largely publicly owned or public policy-driven healthcare sector, funding may not necessarily be available when needed and be subject to political cycles (e.g. elections) and the general economic environment (as both taxes and contributions to the statutory health insurance suffer during an economic downturn).

Many of the examples cited above relate to workforce planning as it is one of the most central resources in health care—due to the fact that health care is highly labour-intensive (Baumol and De Ferranti 2012). The healthcare workforce includes a large variety of professions: medical doctors, dentists, nurses, midwives, physiotherapists, and many others—with each profession containing many different sub-specializations. These complexities make workforce planning a great challenge. At the same time, workforce planning is also difficult since human capital cannot be easily shifted from one location to another and their output is challenging to quantify. Therefore, this chapter will largely focus on workforce planning.

Workforce planning would be impossible without a sound estimate of patient numbers and interventions both for the present and the future. Understanding (future) demand is essential to avoid both excess capacities and shortages. Therefore, this aspect will also be looked at in more detail throughout this chapter.

18.2 Workforce Planning Methodologies

Workforce planning always pertains to two essential components: supply on the one hand and demand/need on the other (Roberfroid et al. 2008). We require an estimate for both components in order to identify possible gaps between the two and define appropriate actions.

As straightforward as this model is—the crux of planning lies in the details. The selection of variables for the forecasting model, the size of the catchment area as well as the choice between forecasting either expected actual utilization of healthcare services or expected need for services are not only technically complex, but they also rely on fundamental normative assumptions regarding equity, access, and health system responsiveness.

This purpose of this section is to give a broad overview of the different methodologies and their pros and cons, especially as it relates to health workforce planning in an integrated care setting.

Researchers differentiate between four different methodologies of workforce planning (Roberfroid et al. 2008): many workforce plans start by forecasting physician and/or non-physician workforce supply. Then, there are demand-based and needs-based models projecting the population's future healthcare requirements. A fourth approach to forecasting lies in benchmarking which relates to both, the supply and the demand side.

18.2.1 Planning of Supply

Supply analyses usually rely on a stock inflow–outflow model. Based on the current number of health workers (differentiated by specialty), the following drivers of future supply are quantified (Ono et al. 2013; Roberfroid et al. 2008):

- *Education*: The number of graduates from medical studies, training posts for medical specializations, and figures for the various non-physician training programmes (nurses, midwives, physician assistants, physiotherapists, etc.) need to be taken into account. In addition, their location should also be a matter of concern: studies show that maintaining medical schools and training posts in or close to rural, remote, or underserved areas increases the chance of a more equitable geographic distribution of staff (Laven and Wilkinson 2003; Wilson et al. 2009).

- *Migration:* Immigration rates of health professionals from other countries and emigration of health professionals trained domestically need to be considered. Mobility within a country becomes relevant when workforce planning is to be applied to a certain region only.
- *Retirement and retention/attrition*: The number of health professionals retiring from work as well as those leaving the medical field to work in other industries are decisive variables.
- *Productivity*: The change in workload carried by health professionals is an important variable. Recently, this aspect has moved to the centre of attention, as the generation of the so-called Millenials is less willing to work long hours and puts greater emphasis on maintaining a work-life balance. Therefore, even with a stable headcount, overall productivity may decrease, so it becomes highly important to measure health professionals not in terms of headcount, but rather as full-time equivalents (FTEs) (Ono et al. 2013). Ideally, FTEs should not be measured by the budgeted but rather by actual working hours. That is particularly relevant for physicians and other health professions who do not work on a salaried basis. As data on working hours is often unavailable, many forecasts estimate FTEs by benchmarking individual service provision against a peer group average (JAHWPF 2015; Roberfroid et al. 2008). Alternatively, productivity gains may be achieved through new treatment methods, higher quality of care (e.g. avoiding readmission), the use of technology (e.g. clinical decision support systems), and larger practice size with more efficient processes (Cunningham 2013). In a systematic review, Weiner et al. (2013) estimated that health information technology (IT)-supported workflow changes may lower the number of required physicians by 4–8% (assuming that 70% of physicians make full use of health IT available, such as electronic health records and clinical decision support).
- *Delegation of tasks*: Delegation of tasks from higher to lower qualified personnel as well as an increasing differentiation of health professions may significantly reduce the need for highly qualified professionals: Altschuler et al. (2012) modelled three different scenarios varying by the degree of delegation. Based on their models, they identified a potential for increasing panel sizes per physician (and team) by 40–100%. Weiner et al. (2013) estimated that health IT-induced delegation from specialists (SPs) to general practitioners (GPs) or from GPs to nurses may decrease the need for physicians by a total of 12–26% (again at 70% penetration).

The reliability of supply models is, of course, highly dependent on the reliability of these driver variables. While some of these input variables are fairly predictable or controllable, such as retirement rates or number of graduates, other variables are less reliable: macroeconomic trends impacting the labour market, generational trends (such as “Millenials”), and the potential of health IT are difficult to accurately forecast. An important determinant for the reliability is the longevity of the forecast: in order to account for the uncertainties inherent in long-term forecasts, many workforce plans calculate multiple scenarios (Crettenden et al. 2014).

Another aspect to consider is the geographic area for which the supply model is estimated: within the geographic area, qualifications and degrees should be largely recognized and there should be a reasonable degree of mobility of health care professionals. Otherwise, the overall supply may appear sufficient but large geo-graphic variations could arise.

18.2.2 Demand-Based Planning

The demand-based or utilization-based approach aims at projecting future demand for health care in the population. It is based on current and/or historical utilization data, e.g. from claims data, and tries to project that information into the future. Basic models only take into account demographics; however, there are also highly complex forecasting models in order to account for various dynamics:

- *Demographics*: The change in size, age, and sex structure of the population is the most common variable in demand projections. However, the impacts of these shifts are not always understood. For instance, it is up for debate whether the ageing of the population will lead to a compression or expansion of morbidity as there is evidence for both hypotheses (Crimmins and Beltran-Sanchez 2011; Fries et al. 2011). Therefore, the Swiss Healthcare Observatory has, for instance, modelled separate scenarios for both hypotheses in its projections of health workforce requirements until 2030 (Seematter-Bagnoud et al. 2008).
- *Socioeconomics*: People with a lower socioeconomic status suffer from higher morbidity and mortality rates that in turn lead to higher utilization of healthcare resources. There is mixed evidence on the level of healthcare utilization when controlling for morbidity: Shadmi et al. (2011) found no difference in utilization by socioeconomic status among the Israeli population when controlling for morbidity. Thode et al. (2005), on the other hand, concluded that persons with the same morbidity level, but low socioeconomic status consult more GPs compared to people with a high socioeconomic status while the effect are reversed for SPs.
- *Technology*: Health IT is accredited an enormous potential to fundamentally change the delivery of care. Not only could it affect the supply side (in terms of communication efficiency between healthcare providers), but it could also change communication and utilization patterns between healthcare providers and patients. Weiner et al. (2013) concluded that health IT may decrease physician demand as it enables more self-care, and it allows for asynchronous care. This might reduce physician demand by 4–11% (at 70% penetration rate of health IT) (Weiner et al. 2013).

- *Health System Changes*: Health system variables have an important influence on utilization. For instance, limitations on direct access to certain providers or changes in the patients' benefits package have a good chance of influencing (supplier-induced) demand. One example is gatekeeping: gatekeeping is generally thought to have the potential to optimize patient pathways, thereby leading to fewer unnecessary visits to SPs. In a systematic review, Garrido et al. (2011) found a decrease in specialized care utilization and mixed evidence on the effect of gatekeeping on overall ambulatory care. Thus, if regulators chose to introduce (or incentivize) gatekeeping, this may have an impact on the demand for health services. Another example for the effect of a change in the benefits package is the reimbursement of chemotherapy drugs in the USA: as of 2004, the Medicare Prescription Drug, Improvement, and Modernization Act cut payment rates for chemotherapy drugs administered to Medicare patients after Congress realized, there had been a significant overpayment for certain drugs. Prices for some drugs were reduced by as much as 90%. In consequence, Jacobson et al. (2010) showed that prescription patterns of physicians changed while overall access to chemo-therapy was not hampered.
- *Insurance Status*: Data from the USA show that utilization rates of health care vary significantly by insurance status (Bureau of Health Professions 2008): namely, patients with "traditional" insurance contracts remunerating physicians on a fee-for-service basis displayed significantly higher levels of service use as opposed to patients enrolled in Health Maintenance Organizations (HMOs). That gap was even more apparent when comparing these figures to those that are uninsured: for instance, service use levels for surgery and internal medicine was between to three- to fivefold higher for people in traditional contracts compared to uninsured persons (Bureau of Health Professions 2008). Therefore, the reduction in number of uninsured persons resulting from the Affordable Care Act is expected to impact physician demand (Petterson et al. 2012). In addition, the US is one of the most dynamic healthcare markets when it comes to provider models. Medicare as well as private insurers have experimented with new models of care, e.g. through HMOs, Accountable Care Organizations (ACOs), Patient-Centered Medical Homes (PCMH), and Preferred Provider Organizations. These models are aimed at managing the patient and his or her pathway through the healthcare system and realigning provider incentives accordingly. Therefore, they have a significant impact on the required number of health professionals (Weiner 2004; Weiner et al. 1986). As the share of the population registered in these different provider models has seen relevant fluctuations, demand forecasts also need to take these changes into account.

The fundamental critique of demand-based models lies in the fact that current levels of healthcare utilization are strongly influenced by current supply levels and structure: a shortage of locally accessible physicians may lead to lower utilization in ambulatory care and, possibly, in a higher number of hospitalizations (Ozegowski and Sundmacher 2014; Sundmacher and Kopetsch 2014). An oversupply of physicians may, as explained above, induce higher utilization than “objectively” needed. Remuneration systems are also known to have a considerable effect on utilization of care: fee-for-service models increase utilization, while health systems with capitation or salary-based remuneration usually have lower utilization rates (Gosden et al. 2000). Quarterly lump-sum fees might induce physicians to set the next appointment for their patients for the next quarter even when a lower (or higher) frequency would be appropriate.

Therefore, demand-based models have a tendency to reproduce current levels of over- or undersupply rather than estimating an optimal allocation of resources.

18.2.3 Needs-Based Planning

Needs-based planning is an attempt to overcome the problems rooted in demands-based models and, therefore, takes a fundamentally different approach.

The United States’ Graduate Medical Education National Advisory Committee (GMENAC), which undertook one of the most comprehensive efforts in setting up a needs-based model, defined “need” as “that quantity of medical services which expert medical opinion believes ought to be consumed over a relevant time period in order for its members to remain or become as healthy as possible given by existing medical knowledge” (GMENAC 1980, 5). This definition implies that there is a “right” level and type of healthcare services for each patient and that these decisions are not made by the patient him- or herself but rather by an “objective” medical expert.

In order to arrive at a needs-based estimation of healthcare services, it is necessary to approximate the morbidity of the population, the type and complexity of care (per provider) required for each morbidity, and to project future changes in both morbidity and (evidence-based) healthcare service provision.

Case Example 1

The GMENAC was chartered from 1976 to 1980 by the US Department of Health and Human Services to develop such an approach. The committee was comprised of 22 health care experts and it was supported by more than 300 consultants (McNutt 1981). Its goal was to estimate physician requirements for 23 different specialty groups as of 1990. In order to do so it set up Delphi panels for each physician specialty group consisting of 8–10 experts with different professional backgrounds. Each of these Delphi panels applied the following methodology (GMENAC 1980):

- It identified the incidence and prevalence of the major diseases based on epidemiological data;
- it determined the relevance of each disease for the specific specialty based on utilization data and expert judgment;

- it projected the changes in morbidity for each disease considered until the year 1990 based on changes in population size and (age- and sex-specific) structure;
- it adjusted for known measurement problems;
- it took into account the "knowledge of the realities of provider and consumer behavior" (GMENAC 1980, 11), i.e. supplier- or patient-induced oversupply as well as undersupply from unmet needs, e.g. due to the limited ability to pay;
- it added a lump sum for the diseases which were not considered specifically.

These steps left each panel with an estimation of the burden of disease relevant for the health system. In the next step, it converted these figures into resource requirements:

- It estimated the number and time of required units of care;
- it adjusted these findings by assumptions on increased potential for delegation of services to non-physician practice staff;
- it estimated physician productivity.

Thereby, each panel arrived at an estimation of the number of physicians required for each specialty. In order to account for the uncertainties in the model, the panels phrased their outcome in terms of a range of required physicians. The size of these ranges oscillated between 1% (hematology/oncology) and 25% (psychiatry) (own calculations based on GMENAC 1980, 22). Overall, the committee came to the conclusion that there would be a 15% surplus in physicians by 1990 and a 30% surplus by 2000.

The GMENAC was chartered from 1976 to 1980 by the US Department of Health and Human Services to forecast future physician supply requirements based on a needs-based planning approach. In a complex process that took more than three years to be completed, it developed an analytical framework based on projecting changes in morbidity and applied it to all major physician specialties (see Case Example 1 for further details). The GMENAC findings led to an outcry at the time of publication and have been questioned by stakeholders (Reinhardt 1981). Harris (1986) brought forward many examples where the GMENAC projections were significantly off the reality (e.g. with regards to HIV, caesarean sections, etc.). Especially since the 2000s, many feared a shortage of physicians rather than a 30% surplus, mainly due to an expected surge in demand and lower productivity per physician (Cooper 1995; Weiner 2002). Nonetheless, the GMENAC work has remained the largest effort in implementing an (adjusted) needs-based model to date. The physician–patient ratios the GMENAC predicted are still used by providers today despite the heavy criticism and the fact that they were only updated once in 1990 (Camden Group 2011).[1]

18.2.4 Benchmarks

A fourth approach to workforce planning is benchmarking. Benchmarks are formulated in terms of physician–population ratios, nurse–population ratios or other ratios of health professionals set in relation to the population. The degree of refinement of benchmarks can vary immensely: on the broadest level there may be a health workforce-to-population ratio. On a very refined level, it is possible to derive benchmarks for each specialty health professional group in relation to age- and sex-specific population cohorts.

There are various sources for benchmarks: the GMENAC ratios are still used, as mentioned above. Other benchmarks have been retrieved from HMOs or hospital referral regions (Goodman et al. 1996). A clear advantage of benchmarks is that they are simple to use and easy to apply. Also, they may avert some of the problems rooted in demand-based models: namely, demand-based models usually rest on the assumption that current utilization and supply levels reflect optimal care, without proving that assumption. Benchmarks, on the other hand, are drawn from integrated care systems which are deemed best practice (e.g. HMOs), from national average ratios or they rely on scientific evidence (e.g. GMENAC ratios). These benchmark staff ratios are then applied to the specific setting of the workforce planner, possibly after being modified to reflect the specificities of the setting. While this approach is easy to implement, it also has its disadvantages: benchmarks show an immense variation based on their source. Therefore, the choice of the "right" benchmark is highly critical. Weiner (2004) compared three different HMOs (Kaiser Permanente, Group Health Cooperative, HealthPartners) against the national US average health workforce density. Despite adjustments for differences in demographics and services provided, HMO ratios ranged between 62 and 86% (primary care physicians), 63 and 71% (specialist physicians), and 63 and 93% (non-physician health professionals) compared to the US average. In an older survey of 54 HMOs, Dial et al. (1995) also reported wide variations in physician-population ratios between HMOs and identified the HMO size to be one of the critical determinants for staffing ratios: HMOs with more than 80,000 enrolees were much more homogeneous in their physician-to-population ratios than were smaller ones. In a more recent comparison between nine patient-centred medical homes[2] (PCMH), Patel et al. (2013) found a

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[1] To the merit of the GMENAC, it should also be said that the US healthcare system is probably one of the most difficult for which to forecast physician supply requirements. First of all, it is a very large country with many different subcultures affecting health demand and patient preferences. Secondly, the provider structure is highly fragmented leaving providers with very different abilities in managing patient demand.

[2] PCMH is a model of care from the USA which puts primary care in the centre and rests on the notion of transforming health care structures to ensure patient-centred, accessible, and coordinated health care (Agency for Healthcare Research and Quality, n.d.).

variation in panel sizes from 625 to 2500. Even within one HMO (Kaiser Permanente), differences in panel sizes between sites were reported due to different models of care (Neuwirth et al. 2007).

Therefore, the use of benchmarks is certainly helpful as it reduces complexity of planning. However, the applicability of a benchmark ratio should be critically reviewed when used in a different setting.

18.2.5 Limitations of Current Planning Approaches in Integrated Care Settings

Despite the extensive research and practical experience, workforce planning remains a difficult task. The fundamental challenge to workforce planning is that it is subject to a large degree of uncertainty. Planning models have dealt with that uncertainty by applying one of two available strategies: they have either used very simple models, e.g. benchmarks or rules of thumb, which were then adjusted in the daily operations or timeline models extrapolating future trends based on past levels of physician demand and supply (Dial et al. 1995). A second strategy is to build complex models assessing all possible influencing variables and requiring the planner to make assumptions for those variables that are uncertain. An example of that is the needs-based approach.

A study estimating the future need for otolaryngologists in the USA has illustrated these challenges: applying the demand-based model by the US Bureau of Health Professionals, the needs-based model according to the GMENAC methodology and benchmarks from different HMOs, Anderson et al. (1997) resulted in a large variability of results both within and between models. Each model could predict both, a considerable shortage or a considerable oversupply of otolaryngologists, based on the precise assumptions and despite the fact that the forecasting period of six years was rather short. Similarly, in a retrospective analysis of different forecasts, Roberfroid et al. (2009) found considerable margins of error between forecast and reality. This underlines that workforce planning will never become an exact science but should be seen as a dynamic process requiring regular re-evaluation in the light of actualities.

A second challenge in these modelling approaches arises with respect to integrated care: these models are rooted in systems with a single physician at the nexus of care. Hence, these planning models attempt to estimate the “right” number of each physician specialty and non-physician provider separately. This ignores the fact that many patients suffer from multiple chronic conditions requiring team-based approaches to care. Dial et al. (1995) showed that the model of care played a large role for staffing levels of HMOs: HMOs with fewer primary care physicians had a much higher ratio of advanced practice nurses in comparison and vice versa. Thus, applying the primary care physician ratio of one HMO to another setting may be very misleading if the models of care are different.

Thirdly, recent changes in models of care also involve a shift in the physician–patient relationship which in turn clashes with some of the planning models outlined above (Institute of Medicine 2001). The needs-based planning model in particular is rooted in a paternalistic notion of the physician–patient relationship: it is the physician who determines by "objective" criteria the "projected biologic requirements" (GMENAC 1980, 6) of patients. Taking into account patients' preferences and subjectively perceived needs, which is standard in a physician–patient relationship with shared decision-making, is in clear contradiction to that planning model.

18.3 New Approaches to Workforce Planning in Integrated Care

In order to address these limitations, new approaches have evolved over the past several years. With regard to integrated care, the techniques applied by managed care-based provider models, such as HMOs and PCMHs, are of interest.

18.3.1 Team-Based Workforce Planning

As outlined above, modelling the demand for single professional groups has serious limitations in an integrated care setting. As integrated care relies on the notion of sharing the patient across different professional groups—both physicians and non-physicians—according to the specific qualification of each professional role, the team-based model of care also needs to be reflected in workforce planning. The Veterans Health Administration in the USA has adopted such a team-based planning model. Each team consists of 1 FTE primary care practitioner (PCP) and a support staff of 2.17 FTE (such as registered nurses, pharmacists, medical assistants) and is expected to handle a panel size of 1200 patients of an average case-mix. However, teams with larger support staff are encouraged: for every additional (reduced) 10% of FTE support staff, panel sizes are expected to increase (decrease) by 2.5%. If the PCP is not a medical doctor, but a nurse practitioner or physician assistant, expected panel sizes are decreased by 25% (Department of Veterans Affairs 2009). These benchmarks have been collected over time from the Veterans Health Administration.

Are these benchmarks applicable to other providers? A comparison of several studies of integrated healthcare delivery systems showed that the fraction of primary care visits handled by nurse practitioners varied between 9 and 70% (Green et al. 2013). Such large ranges are also found for advanced practice nurses (Grover and Niecko-Najjum 2013). These variations clearly illustrate that it can be very misleading to pick out benchmarks for just one professional group from an integrated healthcare delivery system. Instead, the benchmarks can only be reliably copied when the entire model of care is comparable.

Another challenge for learning from international best practices in team-based workforce planning lies in the differences in regulatory requirements. In the USA, for instance, each state has different regulatory requirements for non-physician professionals, which makes workforce planning and transferability of proven models of care rather difficult (Grover and Niecko-Najjum 2013). In Germany, both regulatory and political aspects play a large role when it comes to non-physician healthcare professionals: there is strong opposition to a greater differentiation of health workforce qualifications. Especially the Physicians' Chamber and the Federal Association of SHI Physicians fear that physicians may lose their exclusive right to the vast set of tasks that they perform today, and that they might in conjunction have to render a share of their budget to other professional groups. Therefore, the recent setup of academic programmes for physician assistants has been met by an outcry by the Federal Association of SHI Physicians (Beerheide 2014). In that context, workforce planning becomes a real challenge: on the one hand, the Associations of SHI Physicians have the obligation (as public institutions) to ensure adequate access to outpatient care, which is a challenge for primary care in many rural areas. On the other hand, the associations represent the political interests of outpatient care physicians and, therefore, combat any changes that (seemingly) dilute current privileges of physicians.

18.3.2 Proactive Management of Healthcare Utilization

The application of managed care instruments, such as gatekeeping, case management/panel management, disease management, and financial incentives, plays a large role in patient pathways and influences actual utilization patterns. Kaiser Permanente has, for instance, developed the concept of total panel ownership which advocates a proactive role for primary care teams in identifying unmet patient needs (Livaudais et al. 2006; Neuwirth et al. 2007). GroupHealth, an integrated care provider based in Seattle (USA), piloted a project in 2006 in which it significantly reduced panel sizes for primary care physicians, extending the time physicians spent with each patient by 50%, and introducing further care modules, such as Chronic Care Management, to its model of care. These reforms resulted in a significant decrease in emergency care visits, an increase in patient satisfaction, and a decrease in total costs compared to other GroupHealth sites (Reid et al. 2010).

Another important factor is the degree of integration, e.g. whether long-term care providers and social services are also part of the system. Montefiore Medical Center, which serves 500,000 residents in the Bronx, one of the poorest urban communities in the United States, has tightly integrated health and social care services (Chase 2010). It considers this as one of its key success factors as it shifts demand from physicians to nurses and social workers, which conserves physician resources and is expected to be more sustainable in the long-term.

Finally, during the 1990s and early 2000s, many HMOs struggled with significant wait times for their patients, which both hurt their reputation as a provider among patients and as an employer among health professionals (Murray and Berwick 2003). In response, the model of "advanced access" (or "open access") was developed. It was based on queuing theory which shows that transferring work to the future leads to inefficiencies. Thus, advanced access rejects appointment-based practice management and triage systems and, instead, relies on the idea of “doing today’s work today” (Murray and Berwick 2003). Any patient who calls for an appointment is offered an appointment on the same day with his or her preferred provider. Implementing advanced access has significant consequences for panel sizes and, thus, workforce planning (Murray et al. 2007). However, empirical results of advanced access are mixed: while some provider-specific studies reported significant improvements in workforce productivity (Lewandowski et al. 2006), a systematic review reported mixed results on patient satisfaction and patient outcomes (Rose et al. 2011). Thus, it remains to be seen to what degree advanced access models will be implemented in future.

18.3.3 Tackling Geographic Variations Through Technology

The use of technology and its (future) impact on health services has been commented on several times. One of its potentials lies in alleviating problems related to the geographic location of healthcare providers. A recent Cochrane systematic review illustrated that interactive telemedicine can substitute for face-to-face care while health outcomes remain comparable to usual care or improved (Flodgren et al. 2015). Structured telephone support, telemonitoring and text messaging have also shown to improve outcomes compared to usual care (Free et al. 2013; Inglis et al. 2010).

Kaiser Permanente Hawaii introduced two new elements in its delivery system: (1) an electronic health record to facilitate communication and coordination between health professionals, and (2) telephone access and secure messaging services between patients and their PCP. An initial study revealed that the number of total office visits decreased by 26% within three years; at the same time, scheduled phone calls and secure messaging rose considerably (Chen et al. 2009). Overall, ambulatory care contacts rose by 8% within the 3-year study period. Unfortunately, as the study did not include a control group, it remains unknown whether previously unmet needs were addressed by the new delivery model. Also, possible effects on process or outcomes quality were not assessed. However, this study and the systematic reviews cited above illustrate that the importance of geographic vicinity for service delivery may be reduced through the use of technology. This also impacts workforce planning: if patients need to visit their healthcare provider less frequently, longer travel times may be acceptable, which in turn allows for larger catchment areas in the planning process. In fact, if certain services no longer require face-to-face visits, geographic vicinity would no longer be a constraint for these services/providers.

18.4 Conclusion

Planning, especially workforce planning, has been high on the agenda of health policy makers, practitioners, and researchers for the past 40 years. Various methods have been developed and become more and more refined. Recent changes to models of care have again called into question much of the established methodologies. That applies in particular to integrated care where clearly specified tasks for single practitioners are replaced by a team-based, proactive approach to care delivery.

Where does that leave us in terms of planning? I propose four key lessons:

(1) Setting objectives and standards of care

Before making a plan, it is central to formulate the objectives and minimum service level standards of the specific delivery system—either in terms of structural and process indicators (such as minimum service level standards, geographic catchment areas, or maximum wait times), and/or in terms of health outcomes. This step is essential for assessing the performance of a plan—especially, if we accept the hypothesis that demand for healthcare services is infinite and will thus never be fully met.

(2) Aligning planning approaches with the specific model of care

As we have seen, there is not one perfect methodology for workforce planning. A number of methodologies exist all of which have their pros and cons. The chosen planning approach and in particular the use of benchmarks should be tightly linked to the specified objectives, the specific model of care, and its particular setting.

(3) Monitor and adapt constantly

Workforce planning is not a one-time exercise, but should be seen as a dynamic process which serves to (1) set a baseline for the required (human) resources at the start, and (2) on a meta level establish an agreement on the objectives of the delivery system and consistently verify and re-negotiate that agreement. Once adopted, the assumptions made in the workforce plan should be monitored against reality and adapted accordingly.

(4) Integrated care calls for integrated planning

Integrated care moves away from the narrow focus on physicians as the central providers of health care, makes extensive use of technology, and aims for patient-centred, proactive models of care. Such a fundamental change in the understanding of health care also implies a fundamental change in workforce planning: it requires team-based, integrated planning approaches, it involves taking into account all the available communication channels, and it implies a shift of resources towards care coordination as well as fast and easy access to primary care in order to avert unnecessary utilization of highly-specialized (and often costly) care providers.

The views and opinions expressed in this article are those of the author and do not necessarily reflect the official policy or position of Techniker Krankenkasse.

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Towards Sustainable Change: Education and Training as a Key Enabler of Integrated Care

19

K. Viktoria Stein

19.1 Introduction and Background

Integrated care has come into its own in many countries around the world, but sustainable change is still elusive. One of the key problems remains the fact that education and training have not yet caught up with the multifaceted changes in the provision of services. This chapter will explore how education and training must change in order to foster the development of a continuous learning environment, which will, in turn, support sustainable change.

19.1.1 The Parallel Universes of Education and Health Systems

A lot has been said and written about the difficulties of changing a century-old system like health. But what is true for the institutions in health care is equally true for our education systems. From kindergarten through to postgraduate education, fragmentation and entrenched cultures prevail. And instead of redesigning the whole system to make it fit for our current and future needs, new concepts, organisations and courses are added piecemeal onto already exhausted institutions. The cuts to public budgets and the lack of investment in schools and universities mirror the lack of investment into fit for purpose health and care services around the world. Similarly, while private hospitals and practices or community organisations fill the gaps left by the public health and care systems, so do private schools and tertiary education centres. In both instances, this further widens the gap between

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those who can afford to pay for these services, be it home care or child care, and solidifies the pressure put on families and communities. From a macroeconomic point of view, sustainable, equitable economic growth can only happen when there are sustainable, equitable health, care and education systems in place (e.g. Sen 1999; Rice 2004; Marmot et al. 2008; Brown and Harrison 2013).

But what has this to do with integrated care? The simple answer is "everything".

19.1.2 A Workforce Under Constant Pressure

Integrated care has at its core the principle of people centredness, explored in more detail in the chapter of the same name in this book. This entails addressing the needs of people and communities in their entirety, taking the social determinants of health into account and looking at the continuum of care along the life course. And education as and income and socio-economic strata are key determinants of health (Marmot et al. 2008; Brown and Harrison 2013). To address these complex topics, additional competences, such as multidisciplinary team work, shared care planning or role sharing are needed (Busetto et al. 2018). Yet, health and care professionals are still largely educated in siloed systems, mostly established a century ago, and adhere to rigid professional and organisational boundaries and cultures (e.g. Miller et al. 2016; Halvorson 2007; WHO 2006; Chap. 1). Instead of more investments into education and continuous training for the workforce, many systems have reduced numbers and resources, making the working environment even more challenging than it is by nature. In the World Health Report 2006, WHO estimated that there was a lack of around 4.3 million health professionals worldwide, especially in rural, vulnerable communities and primary care. In addition, burn out rates and suicides among specialist doctors and health professionals are among the highest of all professions (West et al. 2016; Editorial 2017; Dutheil et al. 2019), and they are increasingly at risk of physical and verbal abuse from patients and family members (WHO 2006, Chap. 4). As a consequence, many young professionals never enter their intended professions after graduating or move to countries with better working environments. Lastly, stressed and overworked professionals are not only a risk to themselves, but also to the quality of care they provide (Busetto et al. 2018; West et al. 2016; Editorial 2017).

19.1.3 The Workforce as a Barrier to Integrated Care

On the other hand, the health and care workforce has long been identified as a key barrier to change (Halvorson 2007; Miller et al. 2016). As the "frontline workers", they are the ones who need to implement and sustain any changes in processes or service delivery. Yet, they are often not included in the design and implementation of integrated care and do not receive any training to be able to adjust their routines to the new ways of working and collaborating. New technologies, electronic health records, cross-sectoral collaboration, inclusion of families in care planning, all are intended to save time and reduce the burden of the individual professional. But often, these tools create more barriers than they overcome (Busetto et al. 2018; Miller et al. 2016; Suter et al. 2009; Stein 2016; Halvorson 2007). In their study to explore the barriers to workforce changes in integrated care, Busetto et al. (2018) conducted a systematic literature review, expert interviews and case studies. The most commonly cited barriers to successful implementation of integrated care across all study methods were delivery structures and health professionals themselves. But even within the delivery structures, most barriers are directly related to the workforce, with staff capacity and high staff turnover on the list, while the barriers among health professionals are related to a lack of knowledge, skills and understanding of what they were asked to do, e.g. in integrated diabetes education or correctly using telemedical applications.

Given the obvious relevance of a highly trained and qualified workforce for integrated care implementation and sustainability, it is astonishing to think that, until the publication of the European Framework for Action on Integrated Health Services Delivery (WHO 2016), no framework or strategy had addressed the need for comprehensive workforce changes and additional education and training as a key enabler to implement integrated care. Recognising the lack of attention, which is paid to the health and care workforce, Bodenheimer and Sinsky (2014) suggested to add workforce satisfaction as a fourth aim of high-quality health systems. They argued that high-quality care can only be delivered by enthusiastic, engaged and confident professionals. As they expressed it in their title: “Care of the Patient Requires Care of the Provider” (Bodenheimer and Sinsky 2014).

So what needs to change to ensure that the workforce are well prepared to deliver high-quality, integrated, people-centred care?

19.2 The Principles of Learning

Plato (428 BCE-347 BCE) first asked the question: How does an individual learn something new when the topic is brand new to that person? Over the centuries, the answer usually was through learning by heart and constant repetition. The focus was on transferring knowledge, often abstract and not directly applicable to the students’ life. That this is not the most conducive or effective approach to teaching and learning, first became apparent in the late nineteenth century. “The Forgetting Curve”, published by German mathematician Hermann Ebbinghaus in 1885 (Ruger 1913), for the first time stipulated that people forget 50% of input after one hour, and 75% after six days, if it is not applied into practice. Other influencing factors he found were sleep, stress and the meaningfulness of the subject learned. While some contemporary authors started discussing behaviours, environments and external factors conducive to learning, it was not until the twentieth century that education theory really started making headway. This was in close connection with expanding research on so diverse subjects as culture, the brain and social learning.

19.2.1 Learning Is an Active Process

Many of us have experienced learning as a very passive and hierarchical affair, listening, taking notes and, at intervals, reproducing what we remember in oral or written exams. On the other hand, we usually remember those teachers, and contents best, which engaged us, challenged us and made the topic seem relevant to us and our lived experiences. Learning, thus, is an active process (Dewing 2010; Piaget 1936; Vygotsky 1978), for which the psychologist Edward Thorndike (1874–1949) propounded three "Laws" (Thorndike 1932): Readiness, Exercise and Effect. Throughout the twentieth century, these have been tested and universally accepted, and four more have been established in educational psychology:

- *Readiness*—learners need to be physically and mentally ready to learn. Stress, lack of sleep or lack of time is not conducive to a learning event.
- *Exercise*—learners need to apply the knowledge or skills gained as soon as possible.
- *Effect*—learners should experience learning as an achievement or a success.
- *Primacy*—the presented material must be in logical order and make sense.
- *Recency*—the last thing learned is the easiest to remember.
- *Intensity*—the more senses are used during the learning experience, the more examples and analogies are used, the better stories are told, and the easier it is to learn something.
- *Freedom*—learning only happens on a voluntary basis. As it is an active process, learners need to have freedom of choice: when, where, what and how to learn.

In addition, learning usually occurs in a complex social environment. As we learn from experience, we need to interact with others to imitate and receive feedback in a cultural context (Bransford et al. 2006; Rogoff et al. 1996). While it is obviously not possible to fulfil all the principles all the time, it is, however, a very useful guide to question the way education and training programmes, as well as continued professional development programmes, are set up and offered.

Box 1. The Relationship Between Learning, Education and Training

Learning is "a process that leads to change, which occurs as a result of experience and increases the potential for improved performance and future learning" (Ambrose et al. 2010, p. 3). The change in the learner may happen at the level of knowledge, attitude or behaviour. As a result of learning, learners come to see concepts, ideas and/or the world differently.

Education derives from two different Latin roots: educere "to bring out, to lead out" and educare "to mould, to train". This is also reflected in the different approaches to education, whether it is an emphasis on the acquisition of knowledge or the development of critical thinking (Bass and Good 2004).

Training is usually defined as job-specific, shorter-term and goal-oriented, e.g. Dale S. Beach defines training as “the organised procedure by which people learn knowledge and/or skill for a definite purpose”.

Combining the principles of learning with learning objectives, another useful tool to categorise different levels of learning is Bloom’s Taxonomy. First published in 1956 by Bloom and colleagues, it has been the guiding framework ever since for schools and universities alike, when defining learning objectives, creating curricula and developing courses. The key categories are knowledge, comprehension, application, analysis, synthesis and evaluation. In 2001, a revised taxonomy was published by a group of cognitive psychologists, curriculum theorists, educational researchers and assessment specialists, to update the taxonomy and create a dynamic version, substituting subjects with action words and describing the cognitive processes behind the learning categories (Anderson and Krathwohl 2001). There are numerous versions of these taxonomies available, and Fig. 19.1 gives an example.

Learning, education and training are thus core elements of any human society, whether formal or informal, and inherently have an interactive and purposive nature. The past century has not only brought a better understanding of the mechanisms of effective learning and teaching, but also developed a plethora of useful tools to support the principles of learning. Unfortunately, not many countries and institutions use them strategically yet.

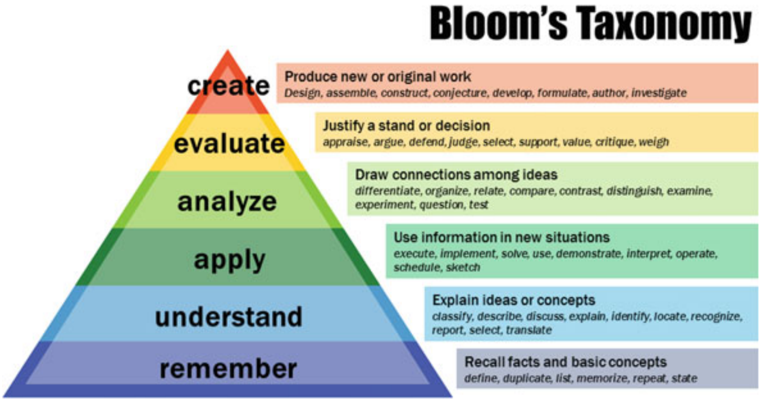


Fig. 19.1 Bloom’s taxonomy. *Source* Released under the creative commons attribution license by Vanderbilt University Center for Teaching

19.2.2 What Are Competences?

Another term, which is closely related to education and training, is competency. "Knowledge, Skills and Attitudes are the abilities and characteristics that enable a job holder to accomplish the activities described in a task statement that describes what the job holder does" (Quinones and Ehrenstein 1997, p. 154). For any role or profession, a combination of knowledge, skills and attitudes is necessary, which combined forms the relevant competences. They bring together the learning principles described above, in that they address the knowledge acquisition, skills training and the development of attitudes, only possible by learning from ones' peers and teachers. Put in simple words, competences form by engaging the head, the hands and the heart (Fig. 19.2).

Competency frameworks have been developed to inform curriculum development, assessment and recruitment for a wide range of professions. Based on previous research in educational psychology and pedagogy, McClelland's (1973) eponymous work established competency-based education. He distinguishes between *technical competences*, i.e. the knowledge and skills, which we can see and experience and directly learn and *behavioural competences*, i.e. the values, traits and attitudes, with which we grow up and which are reinforced indirectly. His so-called Iceberg Model of Competences (Fig. 19.3) called for the definition of clear and specific learning outcomes, divided into the knowledge, skills and attitudes necessary to be able to fulfil a future role. Recognising that behavioural competences cannot be directly taught, but are nonetheless acquired by observation, imitation or reinforcement, underlines the key role that not only teachers play, but everyone. This is where the interplay between education, training and culture come in; see also Chap. 9 in this book. A new colleague will quickly pick up on the tone, organisational and professional culture, which is demonstrated in their new workplace, be it hospital, care practice or social service organisation. If this is marked by disrespect and mistrust towards other professions, patients and families, it will be

Fig. 19.2 Competences form the head, the hands and the heart. *Source* Based on Stein (2016) and Quinones and Ehrenstein (1997)

very difficult to resist falling into the same pattern. On the other hand, it reinforces the role of senior colleagues, mentors and supervisors as teachers and role models—a function hardly anyone in health and care is aware of.

Competences can thus be seen as the outcomes of the processes of learning, education and training. As the basis of continuous professional development programmes and reaccreditation requirements in many health and care professions, they inform the knowledge, skills and attitudes, which are deemed vital for the fulfilment of the relevant jobs. It is therefore crucial to look at the competences relevant to integrated care and adjust education and training programmes accordingly.

19.3 Competencies for Integrated Care

In Chap. 20 of this book, Busetto et al. describe the changing working environment, roles and responsibilities that go along with introducing integrated care. In order to be able to fulfil these new roles and work in an integrated, coordinated and cross-sectoral environment, very different competences are required, in addition to the ones currently taught in medical schools and graduate programmes. To systematically address these additional competences peculiar to integrated care, Langins and Borgermans (2015) conducted an extensive literature review and defined five competency clusters for integrated care (see Table 19.1). In essence, the health and care workforce need different skills in communication, working collaboratively, sharing responsibilities and being more flexible. As they describe it:

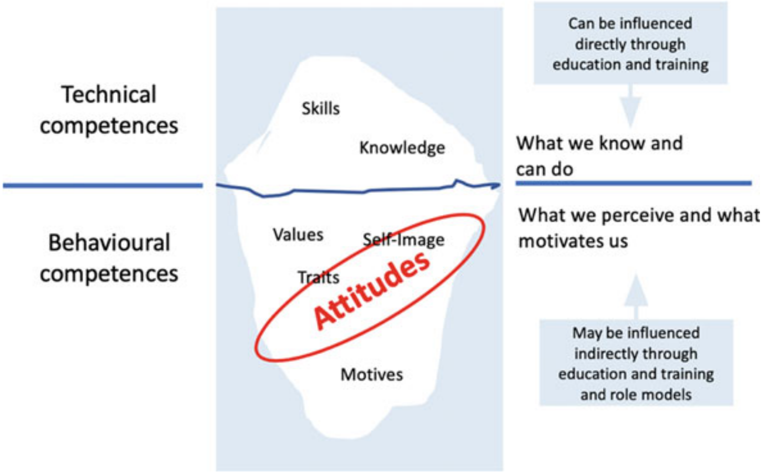


Fig. 19.3 Iceberg model of competences. *Source* Own illustration, based on McClelland (1973)

Table 19.1 Five competency clusters of integrated care

Competency cluster	Definition
Patient advocacy	**Ability to promote patients' entitlement** to ensure the best quality of care and **empowering patients** to become active participants of their health
Effective communication	**Ability to quickly establish rapport** with patients and their family members in an empathetic and sensitive manner incorporating the patients' perceived and declared culture
Team work	**Ability to function effectively as a member of an inter-professional team** that includes providers, patients and family members in a way that reflects an understanding of team dynamics and group/team processes in building productive working relationships and is **focused on health outcomes**
People-centred care	**Ability to create conditions for providing coordinated/integrated services** centred on the patients and their families' needs, values and preferences **along a continuum of care and over the life course**
Continuous learning	**Ability to demonstrate reflective practice**, based on the best available evidence and to **assess and continually improve the services** delivered as an individual provider and as a member of an inter-professional team

Source Adapted from Langins and Borgermans (2015)

> Competencies for integrated care need to engage professionals along a continuum of care, so they can uptake variable roles assigned in prevention and pro-active patient management, work towards management of multi-morbidities, work in teams across settings, specialities and sectors, protect and advocate for the vulnerable and ensure equitable provision of services. (Langins and Borgermans 2015, p. 5)

As this work was conducted for the WHO Regional Office for Europe, the authors had the health workforce in mind. But they can easily be transferred to any professional working in integrated care. Indeed, when one compares these to the core competencies defined for social workers (Box 2), no significant differences can be discerned.

Box 2. The Nine Core Competencies for Social Workers

Competency 1: Demonstrate Ethical and Professional Behaviour

Competency 2: Engage Diversity and Difference in Practice

Competency 3: Advance Human Rights and Social, Economic and Environmental Justice

Competency 4: Engage In Practice-informed Research and Research-informed Practice

Competency 5: Engage in Policy Practice

Competency 6: Engage with Individuals, Families, Groups, Organisations and Communities

Competency 7: Assess Individuals, Families, Groups, Organisations and Communities

Competency 8: Intervene with Individuals, Families, Groups, Organisations and Communities

Competency 9: Evaluate Practice with Individuals, Families, Groups, Organisations and Communities

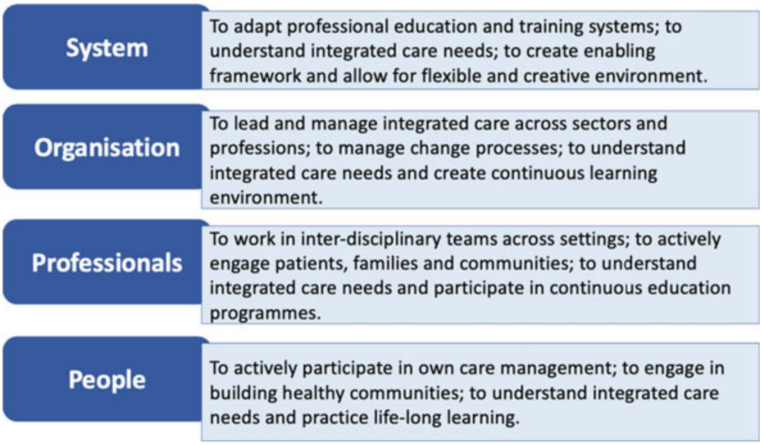
Source CSWE (2015).

It is interesting to note that both documents were published in the same year and that the emphasis on not only patient and family engagement, but also involvement of the wider community is very prominent in the core competences for social workers, but is still lacking in the work for WHO Regional Office for Europe. This may reflect the cultural differences, as well as the different settings of health professionals and social workers. But it also highlights the different perspectives in approaching integrated care and the urgency with which these differences needs to be addressed and overcome.

19.3.1 Competences on All Levels

In parallel to the argument throughout this Handbook and the literature, that integrated care needs to happen on all levels, so need the competences change and expand on all levels. Langins and Borgermans (2015) define the roles and responsibilities of the different stakeholders: on the system-level for example, regulators and educators need to transform accreditation and training requirements or mandate multidisciplinary learning; while on the service level, for example, professional organisations and managers need to ensure competency-based recruitment and continued professional education programmes reflect the competences necessary for integrated care service delivery. Reframing this and aligning it with the management literature, Stein (2016) distinguishes between the organisational or management level, which needs to ensure the system-level policies are translated into adequate working environments, recruitment policies or organisational cultures, and the professional level, which are the service providers themselves, who need to work in multi- or interdisciplinary teams, across sectors and together with patients and communities. The ‘people’, patients, families, informal carers, communities and their organisations are identified as a separate level to reinforce their role and importance as partners for all other levels (see also Chap. 2 in this book). Figure 19.4 summarises the roles and responsibilities as described by Langins and Borgermans (2015), but further distinguishes between the different levels of health and care systems.

In order to achieve this system-wide transformation, a special focus should be paid to training and supporting the managers of integrated care. While the management literature abounds with lists of what competences are necessary to lead organisations through change processes and what good healthcare management



System

To adapt professional education and training systems; to understand integrated care needs; to create enabling framework and allow for flexible and creative environment.

Organisation

To lead and manage integrated care across sectors and professions; to manage change processes; to understand integrated care needs and create continuous learning environment.

Professionals

To work in inter-disciplinary teams across settings; to actively engage patients, families and communities; to understand integrated care needs and participate in continuous education programmes.

People

To actively participate in own care management; to engage in building healthy communities; to understand integrated care needs and practice life-long learning.

Fig. 19.4 Competences for integrated care on all levels. *Source* Based on Stein (2016), adapted from Langins and Borgermans (2015)

looks like, this has largely been ignored in the realm of integrated care. Only through the discussions in recent years about sustainability, transferability and scale of integrated care models, the question of how to effect cultural change and build environments conducive to integrated working, and the movement from pilot- and project-based interventions towards more strategic and organisational change, did the function of managing integrated care come into the spotlight. Similar to the workforce, in general, many managers have felt overwhelmed and left alone with the tasks of integrating services, collaborating across sectors and having to achieve goals, which were not wholly in their control. While other chapters in this book discuss these challenges in more detail (Chaps. 20), it is necessary here to highlight the evident lack of training programmes for integrated care managers. Based on semi-structured interviews conducted with leading integrated care managers, policy-makers and researchers from around the globe, Miller and Stein (2020) developed a first set of competences for managers of integrated care (Table 19.2).

They further concluded that organisations need to proactively identify and build future leaders and managers from the ground up. Organisations need to ensure that support systems are in place and that integrated care management is recognised as a separate function, not an afterthought (Miller and Stein 2020).

19.3.2 Building a Continuous Learning Environment

Bringing together the reflections on effective learning strategies and the roles and responsibilities of all levels to promote and implement integrated care from above, with the principles of continuous quality improvement and change management explained in Chap. 16, complex adaptive systems (Chap. 35), culture (Chap. 9) and

Table 19.2 Competences for managers of integrated care

	Competences
Knowledge	• Professional knowledge • Management theory and theories of innovation • Understanding of the overall system • Social determinants of health • Applying knowledge in the context of integrated care
Skills	• Taking a people-centred approach • Communication • Building and maintaining relationships • Distributive leadership and collaborative approach to management • Being a coach and a mentor • Managing culture change
Attitude	• Resilience • Courage • Humility

Source Miller and Stein (2020)

evaluation and monitoring requirements (Chaps. 32, 34, 36, 37), it becomes clear that a lot more is needed than a few certificate programmes or short courses on the principles of integrated care. Designing education and training to be fit for purpose for integrated care requires students, professionals, teachers, organisations and systems to become comfortable with emergent, flexible and only partially predictable working environments. This, in turn, necessitates robust evaluation, monitoring and feedback frameworks, which support a continuous learning cycle and enable individuals, organisations and systems to anticipate, adapt and adjust on a regular basis. As an integral part of a learning culture, transparent and open communication with all stakeholders enable interdisciplinary collaboration built on mutual trust and the recognition that the sum is greater than the parts. The potential to involve patients, informal carers and community members as teachers and mentors reinforces the people-centred perspective. For each and every one involved, this also entails the recognition that we are all peers, teachers, mentors and role models all the time; that there is always someone looking to us for guidance and support, even if only from a distance; which means, that we always need to reflect on our knowledge, skills and attitudes towards others as they so often get picked up, thus perpetuating the prevalent culture of fragmentation and professional boundaries. The system functions are thus also reflected in the roles and responsibilities of every individual as part of the health and care system, from student learner to mentor and supervisor (Fig. 19.5).

Like most other concepts in integrated care, the necessity for decisive change in the education and training of health and care professionals was already recognised decades ago. In 1969, the newly founded McMaster University in Canada set out to revolutionise the medical curriculum, based on the newest findings in conducive learning environments, effective assessments and the recognition that one health professional alone will never be able to address the needs of a patient holistically.

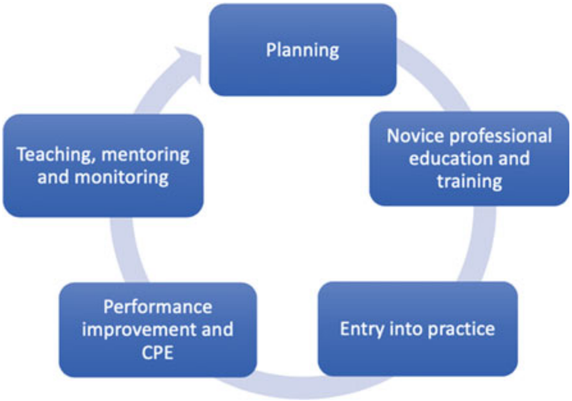


Fig. 19.5 Continuous learning cycle. *Source* Adapted from Langins and Borgermans (2015)

> If planning is done by individuals rather than by groups, by departments rather than by faculty interested in and working on topics of mutual interest, then an autocratic, discipline-oriented, fragmented curriculum is inevitable. The potentates will be department chairmen defending the boundaries of their discipline and vying for their share of recognition … to prevent the development of this situation, … **planning must be undertaken by groups,** not by individuals, and **by mixes of faculty members** who are approaching similar problems from various angles with a variety of methods, techniques and background experiences. … Qualities of **imagination, flexibility, adaptability and leadership** … become of paramount importance. (Spaulding 1969, highlighted by the author)

The McMaster model has since been replicated around the world and is still recognised as one of the vanguards in university education. But what held true then for medical education is today more relevant than ever in the context of integrated care as a whole.

19.3.3 Inter-professional Education and Training to Support Integrated Care

There has been a parallel development to integrated care in the field of inter-professional education (IPE) and training, which is all the more fascinating as the two topics are mutually reinforcing. The multidisciplinary team has long been identified as a central tool to implement integrated care (e.g. Wagner 1998; Suter et al. 2009; Miller et al. 2017; Jelphs et al. 2016), but the necessity to learn in inter-professional ways in order to be able to work in inter-professional teams has long since been ignored. Once again, definitions and terms are loosely used, but Box 3 gives an overview of the meanings from multidisciplinary to transdisciplinary.

Box 3. Denitions from Siloed Learning to Transdisciplinary Working

Multidisciplinary: those from different specialisms learning or working alongside one another

Multi-professional: those from different professions learning or working alongside one another

Interdisciplinary: those from different specialisms learning or working with each other

Inter-professional: those from different professions learning or working with each other

Transdisciplinary: specialists moving out of their own discipline to form new roles and undertake alternative tasks

As most of our education and training is still focussing on specialisation and fragmentation, most health and care professionals lack an understanding of the systems they work in and the roles, responsibilities and qualifications of the other professions they are supposed to collaborate with. Without this basic understanding, however, it is difficult to see how inter-professional collaboration could emerge, as every professional will be reluctant to share information and objectives with people they do not know. While the roles and careers of physicians and pharmacists are relatively clear around the world, it already becomes difficult with nurses and midwives, let alone allied health professionals. And apart from social workers, many supportive and key workers in community and home care have no accreditation or clear job profiles at all (Stein 2016, Amelung et al. 2020).

Inter-professional learning happens, when two or more student learners or service providers from different professional backgrounds come together, to learn about and with each other, to ultimately improve collaboration and quality of care (CAIPE 2002; Ewers and Schaeffer 2019). This interactive form of learning incorporates various learning principles mentioned above, especially intensity, exercise and the social environment. It also supports the development of new professional and organisational cultures, by bringing the different values and principles closer together and enabling the creation of a common understanding. Furthermore, inter-professional learning will support inter-professional team work and help overcome professional siloes (Hammick et al. 2007; Thistlethwaite 2012; Reeves et al. 2013). The better understanding of the interplay of different factors and actors in the health and care systems, as well as the knowledge about determinants of health and well-being, will ultimately also improve the quality of care and help achieve the Quadruple Aim (Bodenheimer and Sinsky 2014; CIHC 2010; Reeves et al. 2013; WHO 2010).

19.4 Education and Training as a Key Enabler for Integrated Care

This chapter has touched on many aspects from principles that are conducive to effective learning to building learning environments, from the additional competences necessary for integrated care to work on all levels to the key ingredient of inter-professional education and training. There is a plethora of literature available on many of these topics, but seldom in relationship to integrated care and even rarer in an interdisciplinary context. But if our health and care systems and organisations are moving towards networks and partnerships, if our professionals are asked to work together in inter-professional teams, if patients, families and communities are asked to contribute to the design and delivery of integrated care, then our education and training systems and organisations must fundamentally change to reflect these developments. That this is just as complex an undertaking as the transformational change necessary in health and care is evident. But it is a necessary one, if we want to achieve sustainability, and equip our workforce with the tools fundamental to the delivery of state-of-the-art integrated care, which is informed by the needs of the population. Or as Frenk et al. (2010) put it in their discussion on the need to transform education of the health workforce for the twenty-first century: "…all health professionals in all countries [need] to be educated to mobilise knowledge and to engage in critical reasoning and ethical conduct so they are competent to participate in patient and population-centred health systems as members of locally responsive and globally connected teams". Crucially, the health and care workforce need to be taken together, and their respective professional bodies need to collaborate and consolidate the different competences to create one framework, which reflects the additional knowledge, skills and attitudes required to work in an integrated environment.

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Integrated Care and the Health Workforce

20

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20.1 Background

The past decades have been characterised by the growing prevalence of chronic diseases, the rising number of older and often multi-morbid patients, and changes in the definitions of health and illness (Imison and Bohmer 2013; Calciolari and Ilinca 2011a). These developments have led to an increased demand for complex, long-term care (Vrijhoef 2014). However, most health systems are currently

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ill-equipped to respond to this demand (Chap. 18 in this Handbook). Specifically, chronically ill patients too often have to consult multiple providers who lack coordination among themselves and across settings, resulting in care that is ineffective and inefficient (Coleman et al. 2009). In addition, World Health Organization (WHO) statistics estimate that workforce shortage can amount to 9.9 million physicians, nurses and midwives globally by 2030 (World Health Organization 2021).

There is an obvious mismatch between the most prevalent health problems, i.e. (multiple) chronic diseases, and the preparation of the workforce to deal with them, since training in most countries still relies on models that emphasise diagnosis and treatment of acute diseases (Pruitt and Epping-Jordan 2005). This is likely to result in an imbalance between the increasing demand for complex long-term care and the low supply of health professionals equipped to work in these areas. Although this global crisis in the healthcare workforce has been noticed for more than a decade (Pruitt and Epping-Jordan 2005; World Health Organization 2004), new care models and initiatives to integrate care services have paid only minor attention to how to deal with this. Since these misalignments are likely to influence the quality of care negatively, changes are needed to cope with the necessity of matching knowledge and competences of the workforce with current and future needs (Imison and Bohmer 2013). According to Pruitt and Epping-Jordan, patients with on-going health problems are in need of

> … treatment that is continuous across settings and across types of providers; care for chronic conditions needs to be coordinated over time. Healthcare workers need to collaborate with each other and with patients to develop treatment plans, goals and implementation strategies that centre on the needs, values and preferences of patients and their families. Self-management skills and behaviours to prevent complications need to be supported by a workforce that understands the fundamental differences between episodic illness that is identified and cured and chronic conditions that require management across years (Pruitt and Epping-Jordan 2005).

Many health systems have endorsed integrated care strategies as a means to approach the above challenges. These are expected to lead to better outcomes, increased efficiency and improved access for service users (Center for Workforce Intelligence 2013). Generally, integrated care strategies include changes to patient–provider relationships, care process designs, communication infrastructures and staffing provisions. Given health professionals’ involvement in all aspects of integrated care, it is assumed that workforce and staffing interventions will affect the implementation of integrated care strategies profoundly (Imison and Bohmer 2013). Consider, for example, the additional demands that are put on the skill set of health professionals when they are expected to provide person-centred care to well-informed patients wanting to take part in decision-making processes. Or consider the differences in culture between those working in health care as opposed to community care, who are expected to cooperate closely and efficiently around complex patients. Another example is the adoption of information technology in health care whose implementation necessarily requires workers to adjust their skill sets and may sometimes even replace certain activities or tasks currently employed by humans.

The WHO argues that there is a need for new competencies to complement existing ones for caring for people with chronic conditions:

> First, the workforce needs to organise care around the patient, i.e. adopt a patient-centred approach. This focus has been described as one in which the provider tries to enter the patient's world, to see the illness through the eyes of the patient. Second, providers need communication skills that enable them to collaborate with others. They need not only to partner with patients, but to work closely with other providers and join with communities to improve outcomes for patients with chronic conditions. Third, the workforce needs skills to ensure that the safety and quality of patient care are continuously improved. Fourth, the workforce needs skills that assist them in monitoring patients across time, using and sharing information through available technology. Finally, the workforce needs to consider patient care and the provider's role in that care from the broadest perspective, including population-based care, multiple levels of the healthcare system and the care continuum (World Health Organization 2005).

Human resources in health care (hereafter also called *health workforce* or, simply, *workforce*) are "the different types of clinical and non-clinical staff responsible for public and individual health interventions" (Kabene et al. 2006). As explained by Glouberman and Mintzberg (2001a, b), the health workforce delivers health care in different professional "worlds" in terms of setting (e.g. acute or chronic care) or service focus (e.g. cure or care). A high degree of specialisation within these worlds can serve the interests of the patients, but only as long as the different worlds are appropriately integrated, thus keeping complexity under control at the point of service (Glouberman and Mintzberg 2001a).

As argued above, it has become clear that patients with complex health and social problems require a mix of providers that can collectively address their needs, as one provider cannot possibly have all the necessary skills. This involves two essential steps. The first step is to design the appropriate staff and skill mix of the group of health professionals providing care to a specific patient population; the second step is to organise and manage the interaction of this group of health professionals in practice.

20.2 Staff Mix and Skill Management

According to Dubois and Singh, health workforce management may entail strategies with regard to *staff mix* and *skill management* (Dubois and Singh 2009; Griffiths 2012). While the former concept is concerned with the different staff members that hold certain skills, the latter concept is concerned with the different skills that are held by the staff members. Or as Dubois and Singh explain, staff mix refers to "achieving a specific mix of different types of personnel", whereas skill management refers to "adapting workers' attributes (…) and roles to changing environmental conditions and demands" (Dubois and Singh 2009).

Specifically, *staff mix* concerns the mix of posts, grades or occupations in a system or organisation. It includes the following aspects:

a. *number of workers* in defined occupational groups, holding a certain volume of work assigned to staff members, e.g. number of full-time equivalent workers, such as nurses per patient;
b. *mix of qualifications* refers to the proportion of highly qualified staff members in the respective health workforce or occupational group, e.g. registered or specialised nurses, physicians with specialty certifications;
c. *balance between junior and senior staff members*, i.e. the proportion of experienced staff in the health workforce;
d. *mix of disciplines* refers to gathering together personnel from different professions and/or professionals with different specialties. In this respect, interventions are intended to foster comprehensive care through professional cooperation (Dubois and Singh 2009).

While staff mix aims at reaching a certain mix of personnel, *skill management* relates more specifically to how the use of staff members' skills can be optimised by adapting their roles, knowledge, skills and know-how. In doing so, skill management may entail two different areas of intervention, namely (a) *skill development* and (b) *skill flexibility*. Skill development does not entail adding functions from other professions. In particular, it concerns:

a. *role enhancement/enrichment*: enable groups of workers to acquire new competencies and skills by designing new roles for them, with expanded tasks and wider and/or higher range of responsibilities;
b. *role enlargement*: extending activities and taking on roles at parallel or lower levels (Dubois and Singh 2009).

Skill flexibility relies on multi-skilled workers who can switch from one professional role to another. It concerns:

a. *role substitution*, which refers to extending the practice scope by encouraging the personnel to work across and beyond traditional professional divides;
b. *role delegation*, which consists of transferring tasks from one grade to another by breaking down traditional job demarcations (Dubois and Singh 2009).

Organisations may not be able to control all aspects of the above staff mix and skill management strategies. For example, the maximum number of workers is probably limited by an organisation's budget, and the mix of qualifications may be limited by a workforce shortage in a certain health profession. Also, staff mix and skill management strategies are not independent choices, but often the feasibility of one strategy tends to influence the implementation of another, or the other way around. For example, if the total number of workers in a certain organisation is low, the number of skills that are needed may exceed the number of workers that are available. In rural regions, those skill-sets typically held by specialist doctors might not be available, but some of their skills might still be needed to provide appropriate care to the patient population. In those cases, instead of increasing the number of workers, it can be beneficial to invest in role enhancement or enlargement by means of provider education so that specialised nurses can perform certain tasks traditionally held by specialised doctors. This would ensure that a relatively wide range of tasks and responsibilities can be performed by a relatively small number of people (Dierick-van Daele et al. 2008).

It should be noted that it may not always be clear which of the above staff mix and skill management strategies one is concerned with in practice, as often the knowledge of a number of details is necessary to identify subtle distinctions between different strategies. Consider, for example, the inclusion of a case manager in an integrated diabetes care team. Does this change the number of workers, the mix of qualifications, the balance between junior and senior staff members, the mix of disciplines, or some or all of the above? Does it concern role enhancement, enlargement, substitution or delegation? To answer these questions, we would need to know whether the case manager role was introduced as a new, additional one (and thereby increasing the number of workers), or whether tasks were delegated from a higher grade to the case manager (and thereby constituting role delegation), and so on. In other words, extensive information on the intervention itself, as well as the situation prior to the implementation of the intervention, is needed to identify which type of strategy one is concerned with. It is therefore not surprising that the performance of certain tasks by nurses, which are traditionally held by general practitioners (GPs), has been used as an example for both role substitution and role delegation (Dubois and Singh 2009; Kislov et al., n.d.). Nevertheless, the above classification system provides a useful and comprehensive overview of the types staff mix and skill management strategies that are available and can be implemented in practice.

20.3 Multidisciplinary Team Work

Once the most appropriate staff mix and skill management strategies are identified and the group of providers with a certain skill set is assembled, organisations still need to organise the way in which this group of providers cooperates and delivers care in practice. Generally, this is referred to by the umbrella term “multidisciplinary team work”, which is an especially popular and frequently implemented intervention within integrated care strategies (Drewes et al. 2012; Meeuwissen et al. 2012; Elissen et al. 2012; Ouwens et al. 2005). Multidisciplinarity is also referred to as interdisciplinarity, multiprofessionalism or interprofessionalism (Nancarrow et al. 2013). These concepts are generally not used interchangeably, but it is difficult to provide clear distinctions, because different authors attribute different meanings to the concepts. Here, we will only use the term multidisciplinarity, by which we mean a group of health professionals from different disciplines or with different medical specialties.

Often team work is defined as or assumed to be multidisciplinary in nature, without this being explicitly addressed as such (Langins and Borgermans 2015; World Health Organization 2013, 2014; Nolte and McKee 2008; Firth-Cozens 2001). In contrast, a recent study on workforce interventions in integrated care strategies (Busetto et al. 2017a, b) has looked at the following three distinct aspects of multidisciplinary team work:

a. *multidisciplinary staff* refers to a group of health professionals from different disciplines or with different medical specialties;
b. *multidisciplinary protocols or pathways* refer to protocols or pathways that involve tasks for health professionals from different disciplines or with different medical specialties;
c. *team meetings* refer to a group of health professionals that works around a patient or group of patients and that meets on a regular basis to discuss the patients' treatment. These meetings may be real or virtual.

These three aspects are often implemented together in practice, but do not need to be necessarily. The differences between these concepts can best be demonstrated by using two practice examples. The first example relates to the delivery of integrated care for people with type 2 diabetes in the Netherlands. Here, care is facilitated by care groups, i.e. legal entities that establish contracts with health insurers and health professionals in order to coordinate the so-called care chain of chronic care from diagnosis to after care (De Wildt et al. 2009). Bundled payments are made by the health insurers to the care groups for the whole package of diabetes care per patient per year. However, the care groups are not care providers, but management organisations who pay health professionals to deliver the care included in the diabetes package. The content and price of these packages are negotiated in a stepped approach between the health insurers, care groups and health professionals. The main locus of diabetes care is the GP's practice. For services that cannot be performed at the GP practice, the patient is referred to other health professionals or to a hospital, but always goes back to the GP's practice that holds responsibility for the patient's continuous care.

A recent study has shown that the above described example of integrated care is characterised by two of the three aspects of multidisciplinary team work (Busetto et al. 2015). In the Netherlands, integrated care for people with type 2 diabetes is delivered by multidisciplinary staff. This includes practice nurses (PNs), GPs, diabetes nurse specialists (DNSs), internists, dieticians, podiatrists, pedicurists, optometrists, and sometimes physical therapists and pharmacists. These health professionals may, and often are, based at different locations. The PN and GP are located at the GP's practice, the DNS is located at the GP's practice and hospital, the internist and the optometrist at the hospital, and dieticians, pedicurists and podiatrists often have their own practices but may also be located in the GP's practice or at the hospital. The division of tasks between these health professionals is specified in multidisciplinary protocols. These are based on national care standards of good practice diabetes care and on the negotiations between the care group, health insurers and health professionals. However, team meetings do not take place. Instead, the communication between the health professionals involved is facilitated and formalised via the clinical information system, a common patient database that is used by the care group and all health professionals involved in the delivery of integrated diabetes care. The health professionals can access and enter patient data and the practice nurses can use the system to refer patients to other health professionals.

The second example describes integrated care as implemented by a geriatric hospital in Germany. The hospital was founded in 1999 and intentionally planned and developed as a multidisciplinary and integrated geriatric care centre. The hospital offers comprehensive services for patients with complex, multiple age-related conditions who are in temporary need of acute care. Patients generally stay at the hospital for up to 21 days, depending on their health status and potential for rehabilitation. They are then discharged to their home setting or transferred to a nursing home for long-term care. The hospital consists of five wards. On each ward multidisciplinary staff delivers care, which includes doctors, nurses, neuropsychologists, physical therapists, occupational therapists, speech therapists and social workers. Together, they perform a comprehensive geriatric assessment of each patient that is admitted to the hospital. Moreover, all patients are treated by the doctor, physical therapists and occupational therapists. They are also all cared for by the nurses and social workers. Whether patients receive further treatment by the speech therapists and neuropsychologists depends on their specific condition and wishes. A short team meeting takes place every morning with an extended one happening once a week. All health professionals are present during these meetings. During the morning meetings, the nurses report on occurrences during the late and night shift and the doctor introduces the new admissions of the day. The purpose of these team meetings is to keep everyone abreast of the latest developments of the patients on the ward and to give the health professionals the chance to ask questions and set priorities for the day’s treatments. During the weekly team meetings, every patient is discussed in detail and all health professionals comment in turn from their own professional perspective. Together, the team maps the patients’ development over time and agrees on a discharge plan, either to the patients’ home setting or in the form of a transfer to a nursing home.

The division of tasks between the multidisciplinary staff is not described in multidisciplinary protocols or pathways. There are job descriptions for each individual professional, and there are rules about which assessment each health professional has to perform as part of the comprehensive geriatric assessment. But there are no protocols that specify a division of tasks in relation to the tasks of the other health professionals. Instead, the division of tasks has developed over time and is addressed and discussed by the health professionals when there is overlap or disagreement. For example, overlap often occurs between the physical therapists and occupational therapists, the occupational therapists and neuropsychologists, and the neuropsychologists and doctors. This may cause frustration among the health professionals and activities or assessments may be repeated unnecessarily. Ideally, however, ambiguities may be resolved by agreeing on tasks through personal interaction between the different health professionals. This can lead to a higher quality of care because it includes more perspectives on the same problem (Busetto et al. 2017a, b).

20.4 Workforce à La Carte

From these examples, it can be concluded there are different and distinct aspects of multidisciplinary team work which should be taken into account. One could even argue that these three aspects—multidisciplinary staff, multidisciplinary protocols or pathways and team meetings—are necessary conditions for multidisciplinary team work. Creating a group of health professionals from different professional backgrounds is not sufficient in itself, and neither are multidisciplinary protocols or team meetings. Hence, it may not come as a surprise that one of the reasons why the bundled payment scheme was introduced in the Netherlands was the fact that the multidisciplinary protocols (or care standards back then) alone were not enough to facilitate collaboration between individual professionals (Elissen 2013; Struijs et al. 2012). The bundled payments were created as a financial incentive framework to integrate a multidisciplinary staff consisting of all health professionals involved in the delivery of integrated diabetes care. Moreover, today there are worries about whether the PN has taken over too many tasks from the GP, for which they not be sufficiently qualified (Busetto et al. 2015). One of the causes of this problem can be seen in the fact that the PN provides the care to the diabetes patients relatively independently, instead of consulting with the GP (and other health professionals) during team meetings. In the German case, these team meetings do exist, but the multidisciplinary staff complains about an unclear division of tasks, which can be traced back to the absence of multidisciplinary protocols or pathways. Of course, saying that these aspects are necessary conditions does not mean that they are sufficient, even if all of them are implemented. Other less tangible aspects such as motivation, team culture, common goals, or a tradition of cooperation also play a crucial role (Busetto et al. 2015; Lemieux-Charles and McGuire 2006; Xyrichis and Lowton 2008).

We can also take another step back and look at the connection between the staff mix and skill management strategies discussed earlier and how they relate to the organisation of multidisciplinary team work in practice. For example, if there is a certain mix of qualifications in which a certain staff member holds a certain qualification and corresponding skill set, it may be relatively easy to draft multidisciplinary protocols that specify the tasks and responsibilities of the specific staff members. For example, the division of tasks between internists and specialised nurses can be written down in detail and the respective staff members can follow the procedures defined in the protocols. If an internist is replaced by a different person, the multidisciplinary protocol would not have to be changed, because the new person can be expected to hold a similar skill set as the previous one. The same holds true for a group with a certain mix of disciplines for which the protocols define the division of tasks between, for example, physical therapists and occupational therapists and for which these positions can be held by different persons from the respective discipline. The above is more difficult when skill development and flexibility strategies are applied, as these change the skills and tasks of a staff member beyond their traditional function, role or qualification. This makes it more challenging to formalise task divisions in protocols because the skills, and therefore tasks, of a certain person are likely to evolve and change over time. However, in improving the care for people with chronic conditions we will have to rethink and revise written protocols once in a while and improve them where necessary, which should also be incentivised by new skill management strategies.

It is possible that certain staff mix and skill management strategies are more or less effective when matched with a certain way of organising multidisciplinary team work in practice. For example, balancing junior and senior staff within a group of health professionals is often based on the assumption that senior staff members can teach certain on-the-job skills to the junior members, who in turn have new ideas and ways of doing things that senior staff members can learn from. However, for this effect to take place, it seems necessary that a certain degree of interaction between the two groups takes place, which is unlikely to be achieved where there is a highly sequential organisation of care and in the absence of team meetings as we saw in the Dutch example. On the other hand, once there are a certain number of workers, team meetings become less easy to organise and discussions will likely diminish in efficiency. In those cases, a digital and/or more formalised interaction between team members may be a more worthwhile option. A similar interaction occurs between patients and members of the care team and has to be reflected in skill management strategies as well.

To put the above in an even bigger picture, i.e. healthcare system reform, the WHO perspective on preparing a health workforce for the twenty-first century needs to be taken into account. According to the WHO, a transformation of the workforce is only one component of the more general healthcare system reform that is needed to improve care for patients with chronic conditions. However, transformation in healthcare organisations is impossible without a corresponding transformation in the workforce that provides the care (World Health Organization 2005).

20.5 Conclusions

As is the case for integrated care in general, workforce interventions need to be well planned, implemented and evaluated. The Center for Workforce Intelligence offers three recommendations to support a more systematic consideration of the implications of integrated care for the health workforce (Center for Workforce Intelligence 2013). First, one must realise that there is no universal approach to integration. Instead, different (local) routes to integration exist, and each requires particular workforce interventions and management responses. One such route, as mentioned above, is the multidisciplinary team which requires focussing on specific aspects including the creation of a climate for team building or establishing shared values, legal considerations around the use of information and working protocols, as well as the planning of new roles and responsibilities. Second, one must take appropriate measures to make sure that the right health professionals with the appropriate expertise are in place to deliver tailored integrated care. These may include multidisciplinary training programs or a socialisation of health professionals to consider themselves part of a multidisciplinary team in the service of an autonomous patient in need of care. Finally, one must identify those factors that are critical for the success of workforce changes in integrated care interventions. The impact of integrated care on health outcomes is defined by the interaction of all its components within the healthcare setting as well as with those in the community (Elissen et al. 2012). It goes without saying that many, if not all, of these components have consequences for the healthcare workforce, and vice versa.

The key message for practitioners and policymakers is to take into account the complexity and heterogeneity inherent to integrated care strategies (Calciolari and Ilinca 2011b). When workforce interventions are implemented as part of these strategies, they are not implemented in isolation but in combination with other changes. These may concern changes as diverse as bundled payment systems, shared patient databases or self-management support initiatives. The common denominator remains that for these changes to be implemented and executed effectively, they need to be well-aligned with workforce and staffing changes. A bundled payment system incentivising a care chain will incentivise actions by different health professionals that are linked to each other in a chain of successive treatments, but it will not necessarily support multidisciplinary team work when no regular team meetings are in place. Similarly, implementing shared patient databases and self-management support initiatives requires a workforce with the appropriate skill-set to execute, or at least support, these interventions.

As part of new care models, workforce changes are needed to cope with the risk of a dwindling supply and the necessity of matching knowledge and competences of the workforce with the future needs. In contrast to the growing amount of literature that supports the current drive towards integrated care, little is published about its associated workforce and staffing interventions. Given that the success of integrated care strategies depends to a large extent on the health workforce executing them, it is time for all of us involved to broaden our horizons and start discussing how to address workforce interventions as part of integrated care strategies. For example, attention should increasingly shift to patient perspective on staffing issues and what is needed according to the patients themselves. Moreover, practitioners and policymakers should be aware of the emergence of new stakeholders on the scene who are assuming more important roles in long-term care, including both for-profit and not-for-profit private enterprises (Center for Workforce Intelligence 2013). In particular, practitioners and politicians will need to shift their attention from single-focus solutions to more complex approaches.

The journey to improved health outcomes by means of integrated care is a relatively recent one, but it has demonstrated that workforce changes form an area of attention that is essential for the understanding and success of integrated strategies as a whole. Even if integrated care should be surpassed by a superior approach in the future, workforce changes as part of complex improvement strategies will necessarily remain on the radar of every healthcare system working towards improved population health.

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Financing of and Reimbursement for Integrated Care

21

Ellen Nolte and Lena Woldmann

21.1 Introduction

Problems of care coordination and integration typically arise at the interfaces between primary and secondary care, health and social care, curative and public health services and among specialities and professional groups (Nolte & McKee 2008a). Differences in financing mechanisms and sources and in the allocation and flows of funding, including payment mechanisms, are frequently cited as a major barrier for the implementation of more integrated approaches to service delivery (Calnan et al. 2006; Cameron et al. 2014; Dickinson & Glasby 2010; Hardy et al. 1999).

Leutz (1999) argued that successful integration requires sustained investment in staff and support systems, funding for start-up costs, and flexibility to respond to needs that emerge during implementation. Countries have, directly or indirectly, set aside dedicated resources to support the development and implementation of innovative care models seeking to achieve better service integration, such as through targeted payments or the use of start-up grants (Nolte & Knai 2015; Nolte et al. 2014; Nolte & McKee 2008a). Countries have also increasingly been experimenting with new forms of paying providers in order to incentivize coordination and integration. Examples include bundled payment schemes for a defined package of chronic care such as in the Netherlands (de Bakker et al. 2012; Tsiachristas et al. 2013). This can be seen to form part of a move to what has been referred to as 'value-based payment' more broadly, including mechanisms such as shared savings and global budgets (Hayen et al. 2015; Miller 2009; Cattel &

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Eijkenaar 2019). Such schemes recognize that payment systems that encourage multiple providers with different incentives are unlikely to provide well-coordinated care (Roland & Nolte 2014). Several countries have additionally introduced pay-for-improvement, pay-for-coordination or pay-for-performance schemes in primary care, incentivizing chronic and coordinated care in particular, although the evidence of their benefits remains mixed (Eijkenaar et al. 2013; Scott et al. 2011; Markovitz & Ryan 2017). Furthermore, a number of countries have experimented with different financing mechanisms. Examples include the shifting of responsibility for funding of particular components of service delivery between funding agencies, such as local and regional authorities (Frølich et al. 2015) or health and long-term care insurers (Maarse & Jeurissen 2016), or introducing pooled budgets to integrate health and social care (Mason et al. 2015; Harlock et al. 2020).

This chapter provides an overview of the different ways countries have sought to change financing and payment mechanisms at different levels to enable better coordination among providers in the delivery of health services and between health and social care and thus support integration. The chapter begins with a brief overview of the principles of financing of and payment for services and the advantages and challenges inherent in different approaches. It then reviews examples from different countries that have experimented with innovative approaches to enhance coordination and integration of service delivery and reflects on the evidence of impact of different approaches. It concludes with a set of overarching observations.

21.2 Principles of Financing of and Payment for Services

This section briefly discusses the principles of financing of health and social care and of payment mechanisms for service delivery as they relate to the integration of care. Much of the discussion presented here relates to high-income countries, although it is important to recognize that the challenges arising from different forms of financing and payment systems are universal (World Health Organization 2010).

21.2.1 Financing of Health and Social Care

Health (and social care) financing encompasses a range of functions: the collection of funds for care, the pooling of funds (and therefore risks) across time and across the population and the purchasing of services (Kutzin 2001). It also includes policies that relate to determining the coverage of the population (breadth), of the range of benefits that are being provided (scope) and the proportion of benefit cost covered, that is, user charges (depth) (Busse et al. 2007). Countries differ in the way they carry out these functions and implement related policies. This has implications for important policy goals such as financial protection, equity of access, efficiency of service organization and delivery (Thomson et al. 2009). Choices largely reflect individual countries' institutional, political, social and historical contexts.

Among high-income OECD countries, healthcare is largely financed from public sources, although the extent varies. In 2018, public funding accounted for just under 65% of total health expenditure in Israel up to 85% in Denmark and Norway (OECD 2019). High-income countries use national or local taxation and/or statutory insurance to fund public healthcare, and the majority of countries provide (almost) universal coverage. Residence in the given country is the most common basis for entitlement to healthcare. In the USA, access to health insurance has increased following the 2010 Patient Protection and Affordable Care Act (ACA), but a significant proportion of the population remains underinsured (Collins et al. 2019).

Most high-income countries also provide public support for social or long-term care, although the nature and scope of what is funded vary (Scheil-Adlung 2015; Cylus et al. 2018). Social care is typically financed from (local) taxes; a small number of countries, including the Netherlands, Germany, Japan and France, have introduced mandatory long-term care insurance, and Sweden has established a right to tax-funded social care (Robertson et al. 2014). The term 'social care' does not equally apply to all systems, however. For example, in England, adult social care has been defined as 'the care and support provided by local social services authorities pursuant to their responsibilities towards adults who need extra support' (p. 2) (The Law Commission 2011), essentially capturing those services that are not provided by other organizations under different legislation. Other systems conceptualize social care differently, and for example in Australia, Finland and the Netherlands 'social care' also includes parts of child and youth care (Schweppenstedde et al. 2014). Long-term care may (implicitly) be captured under social care although it is frequently referred to as a separate entity or sector. In Germany, the term 'social care' as an overarching concept does not exist while long-term care forms an established sector (Gerlinger 2018). For ease of comparison, in the following, we will use the notion of social care as a generic term and synonymously with long-term care while recognizing country-specific differences in the nature and scope of this sector.

The main difference between health and social care systems is the nature of entitlement for publicly funded services. In healthcare, entitlement is typically based on residency status as noted above, or in case of insurance systems, contribution or enrolment status. In contrast, in social care, entitlement is typically determined on the basis of need (means tested) with the exception of countries that have introduced insurance or a right to social care (Cylus et al. 2018). This difference in service entitlement can create challenges for collaboration between the health and social care sectors, in particular as these systems are frequently administered separately. Similarly, only a small number of countries provide more integrated health and social care financing at the system level, for example the publicly financed Medicaid system in some states in the USA (Crawford & Houston 2015). Scotland has been moving towards integrated partnerships between health and social care following its 2014 public service reform. From 2016, 31 Integrated Joint Boards (bringing together regional health boards and local authorities) hold an integrated budget for health and social care and have taken over strategic planning functions from the NHS Boards and local authorities (Audit Scotland 2018). A similarly ambitious proposal seeking to integrate healthcare and social welfare services in Finland in 2015 failed although plans are now underway within the 2019–23 reform programme to bring together social and healthcare services organizations into 18 self-governing counties (OECD/European Observatory on Health Systems and Policies 2019). Several countries are experimenting with more integrated financing schemes at regional or local levels, examples of which we will discuss below.

21.2.2 Payment Mechanisms in Healthcare

There are several methods to pay different types of healthcare provider. These methods can be categorized in different ways, for example, whether they are prospective or retrospective, or the extent to which payments bring together ('bundle') components of healthcare services (Charlesworth et al. 2012; Thomson et al. 2009). This is illustrated in Table 21.1, which also discusses some advantages and disadvantages of the four main forms of provider payment. These are block budget, capitation, case-based payment and fee-for-service.

The principal forms of provider payment vary in their ability to support overarching system goals such as preventing health problems, delivering services to effectively address health problems, or responding to the legitimate expectations of the population and contain healthcare costs (Charlesworth et al. 2012; World Health Organization 2000). For example, payment systems based on capitation offer, in principle, the incentive for providers to invest in prevention. However, this is often not translated into practice, due, at least in part, to the often short-term nature of payment contracts, which are not sufficiently long for potential savings to be realized by providers (Marshall et al. 2014). Likewise, fee-for-service payments do not encourage preventive activities, unless these are specifically paid for. Furthermore, different payment systems vary in their ability to support patient choice, with block budgets and capitation providing only limited options in contrast to case-based and fee-for-service payments, which allow for money to follow the patient.

Against this background, systems tend to use several types of payment simultaneously or indeed combine different methods in the form of blended payment to influence provider behaviour (Marshall et al. 2014; Feldhaus & Mathauer 2018). For example, in Europe, primary or ambulatory care providers are typically paid through a combination of capitation and fee-for-service payments while the most common way of paying hospitals is prospectively using case-mix adjusted diagnosis-related groups (DRGs), often complemented with grants or budgets for specific services (Nolte et al. 2014; Thomson et al. 2009) (Table 21.2).

As indicated in Table 21.2, a number of countries have introduced additional payments for providers in primary or ambulatory care. The intent is to incentivize delivery of certain activities and services to enhance accessibility and improve the quality of care, in particular, for those with chronic health problems. We will discuss examples of these in the following section.

Table 21.1 Types of provider payments in healthcare

	Type of payment	Description	Advantages	Disadvantages
Bundled	Block budget/salary	Periodic global lump sum; independent of number of patients	– Low transaction costs – Predictable expenditure/income if budget has fixed cap – Provides flexibility for (cost-neutral or reducing) provider innovation	– Lack of transparency and accountability – Disincentivizes increases in activity – Disincentivizes cost-increasing innovations; innovation may be constrained with limited access to capital – May lead to service rationing or lower quality where demand is high – Does not reward good performance
	Capitation	Periodic lump sum per enrolled patient for a range of services	– Low transaction costs – Supports cost containment and financial control – Incentivizes attracting more patients and possibly improved care quality in selected dimensions of care	– Disincentivizes provision of additional or costlier services – Providers might avoid patients with high levels of needs where payments are not fully risk adjustment – May incentivize shifting of services to other providers where payments cover only part of the care pathway (e.g. primary care)
	Per period	Periodic lump sum per patient diagnosed with a particular condition		
	Per patient pathway	Lump sum for all services required for a defined pathway of care		

(continued)

Table 21.1 (continued)

	Type of payment	Description	Advantages	Disadvantages
	Per	Payment per case based on grouping of patients with similar diagnoses/procedures or resource needs	– Incentivizes reducing costs per episode, which is only advantageous if it improves productivity and does not reduce quality – Incentivizes increasing activity, which is only advantageous if this activity is cost-effective and appropriate	– Transaction costs are higher because of the need for billing and sophisticated costing systems – Incentive to increase activity may encourage unwanted activity (supplier-induced demand) – Challenges financial control where there are no limits on the volume of services provided – Where prices are fixed quality may fall as a result of attempts to increase profit by reducing costs
	Per day	Payment per day of stay in a hospital or other facility		
Unbundled	Fee-for-service	Payment for each item of service and patient contact	– Disincentivizes withholding care and may support quality and comprehensive care – Providers are paid for all services they choose to deliver and may thus promote equity – Supports rapid uptake of innovations that expand or change use or services and technologies that are already reimbursed	– Challenges financial control and likely increases spending through increases in activity (supplier-induced demand) – Does not incentivize improving efficiency or joint working – Does not incentivize investing in prevention efficiency or joint working – Can delay uptake of innovations of services or technologies that are not yet reimbursed and require negotiation for reimbursement

Source Adapted from Charlesworth et al. (2012) and Marshall et al. (2014)

Table 21.2 Selected features of healthcare provider payment in twelve countries in Europe

	Provision of primary/generalist and specialist care outside hospital	General practitioner (GP) gatekeeping	Payment of physicians or practices in primary or ambulatory care	Payment of hospitals (year introduced)
Austria	Office-based primary and specialist care physicians; outpatient clinics	No	Blended system of fee-for-service with capitated element for basic services; determined by payment schemes based on public services or private law and supplemented by bonuses defined by the state	Performance-oriented hospital financing system (LKF) (1997)
Denmark	GPs in private practice	Yes; access to specialist care upon referral only except for ophthalmologists and dentists	A combination of capitation per patient and fee-for-service, in addition to special fees for out-of-hours services, telephone consultations and home visits	Combination of global budget and activity-based funding using DRGs (from 2000)
England	GPs in community-based practices or health centres	Yes	Weighted capitation based on General Medical Services contract, negotiated nationally; plus elements of fee-for-service and performance-related payment	Activity-based ‘Payment by results’ (PbR) using health resource groups for acute services (2003)
Estonia	GPs in independent family practice	Yes; direct access to selected specialties and follow-up consultation for chronic disease	Combination of basic allowance, capitation fee, fee-for-service, with additional compensation for those practising in remote areas; based on national negotiations	Diagnosis-related groups (DRG) (2004), complemented by per diem and fee-for-service payments
France	Office-based primary and specialist care physicians	Voluntary (preferred doctor scheme) with strong financial incentives for service users	Fee-for-service based on nationally set fees; plus pay-for-coordination and pay-for-performance elements; scheme for GPs setting up practice in underserved areas	Diagnosis-related groups (DRGs) (phased in from 2004), supplemented by additional payments for specific areas/services
Germany	Office-based primary and specialist care physicians	No; voluntary scheme in place (GP contracts)	Combination of capitation and fee-for-service based on nationally negotiated fee schedule	German diagnosis-related groups (G-DRG) (phased in from 2003)

(continued)

Table 21.2 (continued)

	Provision of primary/generalist and specialist care outside hospital	General practitioner (GP) gatekeeping	Payment of physicians or practices in primary or ambulatory care	Payment of hospitals (year introduced)
Hungary	Office-based family physician; specialist care in policlinics and dispensaries	Yes, in principle, but wide range of specialist services are accessible without referral	Weighted capitation plus adjustments based on provider characteristics	Diagnosis-related groups (DRGs) (1993); outpatient specialist services on a fee-for-service basis
Italy	Office-based GPs, typically in solo practice; office-based specialists	Yes; direct access to certain specialists, e.g. gynaecologists	Capitation fee plus a share based on participation in public health interventions, based on national contract and regional agreements	Diagnosis-related groups (DRGs) (1995), complemented by capitation and/or grants for selected services
Latvia	Typically GPs in independent practice; health centres	Yes; direct access to certain specialists	Age-weighted capitation plus fees for defined activities, bonus payments and fixed allowances	Case-based payment, per diem plus fee-for-service points
Lithuania	Family physicians in independent practice; specialist outpatient care in health centres	Yes	Age-weighted capitation plus payment for people living in rural areas and incentive payments for certain listed services	Global budgets plus case-based payment
The Netherlands	GPs typically in 2+ practices	Yes; access to specialist care upon referral only	Combination of capitation and consultation fee; bundled payment for selected chronic diseases; additional contracts involving pay-for-performance elements possible	Diagnosis treatment combinations (DBCs) (2005)
Switzerland	Office-based primary and specialist care physicians	No, except for those enrolled in managed care plans	Independent professionals are generally paid on a fee-for-services basis; some managed care plans operate capitation models	Per diem plus diagnosis-related groups (SwissDRG) (from 2009)

Source Adapted from Nolte et al. (2014)
Aadditional sources Mossialos et al. (2017)

21.3 Incentivizing Coordination and Integration of Service Delivery: Examples from Different Countries

This section provides an overview of selected countries' experiences of innovative approaches to enhance coordination and integration of service delivery, focusing on three strategies: committing additional funding, introducing innovative payment schemes and changing financing mechanisms. Where appropriate, it will also reflect on the evidence of impact of different approaches. In the space available, it is not possible to provide a comprehensive inventory of the entirety of initiatives and mechanisms that are being used across countries; instead, the chapter offers insights into a small number of examples for illustrative purposes, building on our previous work (Nolte & Knai 2015; Nolte & McKee 2008b; Nolte et al. 2008). Country case studies in part 6 of this handbook provide details on further examples.

21.3.1 Commitment of Additional Funding

A number of countries have set aside resources to support the development and implementation of innovative care models to achieve better service integration (Nolte & Knai 2015; Nolte & McKee 2008a). The precise mechanisms have varied, reflecting the diverse lines of accountability and responsibility for financing care and allocating resources. Targeted payments have been used where tiers of government have direct control over delivery, while more decentralized systems have tended to use start-up grants to support the development of new approaches, although this distinction is not clear cut.

Examples include provider health networks in France, which were tasked with strengthening the coordination, integration and continuity of healthcare for those with complex needs (Chevreul et al. 2015; Durand-Zaleski & Obrecht 2008). Emerging from the late 1990s, they included disease-specific networks, such as for diabetes, and networks targeting particular population groups, for example older people. Provider networks were supported by the state and the statutory health insurance to finance both infrastructure and operating costs as well as new services, with, for example, a total of €650 million invested between 2000 and 2005 (Durand-Zaleski & Obrecht 2008).

Several countries have used project or start-up grants to support the development of new approaches to care. For example, the federal government in Canada supported provincial reform initiatives through the CA$ 800 million Primary Healthcare Transition Fund (~€560 million in 2006),[1] which operated over a period of six years (2000–2006) (Health Canada 2007; Jiwani & Dubois 2008). Financial support involved direct funding of primary care reform activities in the provinces, many of which were concerned with strengthening collaborative and multidisciplinary

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[1] Source: OANDA. Average exchange rates. https://www.oanda.com/currency/average. Accessed 17 May 2020.

working among primary care providers and enhancing the IT infrastructure to support integration. The fund also supported a range of national initiatives, such as the National Strategy on Collaborative Care. In Denmark, the government allocated a pool of DKK 585 million (~€80 million) over the period 2010–2012 for the development and implementation of regional disease management programmes as well as patient education and self-management, to be shared by regions and municipalities responsible for the organization and financing of health and social care services (see also below) (Frølich et al. 2015). In Austria, the 2005 health reform established a financial pool at the level of the states (reform pool) to promote the coordination of and cooperation between ambulatory and hospital care. Administered by the statutory health insurance funds, the aim was to shift care from the inpatient to the ambulatory care sector, with 1–2% of health expenditure to be set aside for the reform pool to cover the associated costs (Hofmarcher & Quentin 2013). In Germany, reform efforts seeking to strengthen integrated care involved, among other things, enabling statutory health insurance funds to designate a total of 1% of their revenues to develop integrated care contracts with providers from 2004 (Erler et al. 2015). In England, a national programme of 50 new care model 'vanguards', launched in 2015, was supported by just under £390 million over a period of three years (National Audit Office 2018). This included direct financial support to support service redesign locally (about half of the vanguards were designed to develop and test population-based integrated health and social care), as well as funding at national level to support individual vanguards and help spread new care models.

The impacts of these initiatives, where they have been evaluated, have been varied. For example, in France, the financing mechanism to support provider health networks was changed from 2008 to incentivize quality improvement strategies more widely and network funding became less secure (Chevreul et al. 2015). A 2014 assessment noted that attempts to enhance care coordination in primary care in France had led to numerous activities but that these had remained patchy, with networks perceived to be too specialized and to risk duplication of service delivery (Blanchard et al. 2014). In consequence, and in an effort to further improve primary care services and the coordination of care, the 2016 health reform set out a series of measures, including the promotion of coordination support platforms (*plateformes territoriales d'appui, PTAs*) (Legifrance.gouv.fr 2016), a role potentially taken on by provider networks (UNR.Sante 2016). In Germany, the number of integrated care contracts that had been implemented since the introduction of start-up funding in 2004 had remained small, covering, in 2008, around 6% of the population with statutory health insurance (Grothaus 2010). Fewer than half of the contracts had incorporated elements of intersectoral care, and, following the discontinuation of start-up funding, an estimated 20% of contracts were terminated during 2008 and 2009 (Sachverständigenrat zur Begutachtung der Entwicklung im Gesundheitswesen 2009). There is little robust evidence of the overall impacts of integrated care contracts in Germany, with only a small number of exceptions. In an effort to further strengthen intersectoral collaboration, the 2015 healthcare reform committed a total of €300 million per annum for 2016–2019 to further support the implementation of innovative forms of care delivery, with funding to be allocated centrally (Gemeinsamer Bundesausschuss 2016), a commitment recently extended for a further four-year period (2020–2024) at €200 million annually (Deutscher Bundestag 2019). A similar initiative was launched in France in 2018, with the creation of a national health system innovation fund of initially €20 million (Ministère des Solidarités et de la Santé 2018).

21.3.2 Innovative Payment Schemes

21.3.2.1 Financial Incentives

Several countries have used financial incentives to strengthen care coordination through pay-for-improvement or pay-for-performance schemes (Nolte & Knai 2015). These are usually targeted at providers, most often physicians, although payers or purchasers of care have also benefitted from resources earmarked for care coordination (Nolte et al. 2012). Examples of incentive schemes targeting *payers* are disease management programmes (DMPs) in Germany, which were introduced in 2002 in an effort to promote evidence-based, coordinated treatment and care across primary and secondary care (Erler et al. 2015). Their introduction was enabled by an additional payment to statutory health insurance (SHI) funds ('DMP risk adjuster') for each enrolled SHI member joining a DMP. This provided considerable financial incentives for SHI funds to offer such programmes, and it facilitated their rapid nationwide implementation.

Financial incentives targeted at *providers*, most frequently physicians, can involve additional reimbursement for documentation, patient enrolment or regular assessment. Such payments are typically, although not exclusively, used in the context of disease management programmes such as those implemented in Austria (Sönnichsen et al. 2015), Germany (Erler et al. 2015), selected diabetes care programmes in Italy (Ricciardi et al. 2015) and France (Sophia diabetes and asthma care programmes, diabetes provider networks) (Chevreul et al. 2015; L'Assurance Maladie 2016). Incentive payments may also specifically target quality improvement activities aimed at enhanced coordination. Examples include Estonia, which introduced, in 2006, a bonus payment system for GPs to encourage the prevention and management of diabetes type 2 and cardiovascular diseases (Lai & Knai 2015). In Switzerland, physicians participating in the Delta health network in the canton of Geneva, a health maintenance organization formed in the early 1990s, receive a lump sum each time they participate in a quality circle (Peytremann-Bridevaux et al. 2015). This is in addition to their regular reimbursement, which consists of a combination of fee-for-service payments and capitation fee per insured person.

Several countries have additionally introduced specific pay-for-performance (P4P) schemes to incentivize chronic and coordinated care in particular. Such schemes make payment conditional on the achievement of specified targets linked to the provision of evidence-based care and the implementation of (integrated) care pathways. The most prominent examples in Europe include the Quality and Outcomes Framework (QOF) in the UK (Box 21.1) (Doran & Roland 2010; Nolte et al.

2015) and the Remuneration Based on Public Health Objectives (*rémunération sur objectifs de santé publique, ROSP*) scheme in France (Chevreul et al. 2015), along with smaller schemes implemented in some regions in Italy (Ricciardi et al. 2015).

Box 21.1 The Quality and Outcomes Framework in the UK

The UK implemented the Quality and Outcomes Framework (QOF) with the 2004 national GP contract (Nolte et al. 2015). It introduced a new voluntary payment scheme that initially linked up to 25% of GP practice income to performance as part of a wider government programme of initiatives to increase the quality of care delivered by the National Health Service (NHS) (Doran & Roland 2010).

The QOF rewards GP practices for providing quality care through demonstrating that they have met several stages in the management of a given, usually chronic, condition, for a proportion of the relevant population. There have been several updates to the QOF since the original 2004 contract, successively including or redefining a wider range of indicators. For example, in 2009/10, there were over 130 quality indicators in four domains: clinical, organizational, patient experience and additional services (Nolte et al. 2015) while the 2019/20 framework included just under 70 indicators in three domains (clinical, public health and public health/additional services) (BMA and NHS England 2019a). The payment scheme is voluntary for GP practices, and patients join it by virtue of being registered with a given practice participating in the scheme (Nolte et al. 2015). When introduced in 2004, the scheme applied to all four countries of the UK, and most practices had joined. From April 2013, the QOF diverged between England and the devolved administrations; Scotland has now replaced the scheme with a new quality framework (‘Improving together’) (Smith et al. 2017). In England, following review of the scheme in 2018 (NHS England 2018), NHS England, the national NHS lead, agreed a new framework for reforming the GP contract, which included a number of changes to the QOF (BMA and NHS England 2019b).

Notably, while the QOF initially accounted for about 25% of GP practice income, this proportion has fallen over time to less than 10% in 2017/18 (Moberly 2019).

France introduced, in 2009, the *Contrats d’Amélioration des Pratiques Individuelles* (CAPI), a pay-for-performance scheme complementing the prevailing fee-for-service reimbursement in primary care (Chevreul et al. 2015). It comprised voluntary individual contracts between GPs and the statutory health insurance, whereby the GP agreed to meet specific goals including the management of chronic diseases and preventive healthcare. The scheme (renamed ROSP in 2011) was subsequently incorporated into the physicians' collective bargaining agreement with an expanded list of objectives and extended to additional medical specialties. Participation in the ROSP scheme is voluntary for a three-year period and participating GPs receive payments in addition to their regular fee-for-service income, based on the number of patients treated and 29 quality indicators. In 2012, more than 75,000 physicians participated in the programme, receiving an average annual performance-based payment of €3,746 (Chevreul et al. 2015). Pay-for-performance schemes seeking to strengthen coordination across primary care services have also been implemented in Australia (the Practice Incentives Program), New Zealand (the Primary Health Organization (PHO) Performance programme) and in various states in the USA (e.g. the California Integrated Healthcare Association physician incentive programmes) (Cashin et al. 2014).

The evidence of impacts of financial incentives and innovative payment schemes in healthcare is complex. In Germany, the financing mechanism to incentivize roll-out of disease management programmes (DMPs) across statutory insurance (SHI) funds was changed from 2009, with the abolishment of the DMP risk adjuster and the introduction of a morbidity-adjusted risk compensation scheme (Busse & Blümel 2014). This scheme seeks to compensate for differences in healthcare needs of populations enrolled with different SHI funds. The change resulted in lower payments for people joining a DMP as SHI funds now only receive a fixed amount for each enrolled patient to cover programme operating costs. Whether SHI funds continue to benefit from offering DMPs thus depends on whether a given DMP can reduce costs. The impact of this change in financing on DMP enrolment remains difficult to assess. Since their introduction in 2002, the number of patients signing up to DMPs increased steadily but the rate of increase slowed from 2009 (Erler et al. 2015). DMPs have remained the predominant approach to chronic illness care in Germany while the evidence of their impact on health outcomes remains subject to debate.

The evidence of impact of pay-for-performance schemes on health outcomes also remains mixed (Eijkenaar et al. 2013; Gupta & Ayles 2019). Reviews of the impact of the Quality and Outcomes Framework in the UK found that while there was evidence of modest improvements in the quality of care for chronic diseases covered by the QOF, its impacts on costs, professional behaviour and patient experience had remained uncertain (Gillam et al. 2012). Other work noted that the QOF has had limited impact on improving health outcomes, and although there were small mortality reductions for a composite outcome of targeted disorders, the QOF was not associated with significant changes in mortality (Ryan et al. 2016), and its continuation was found to be not cost-effective (Pandya et al. 2018). It has been noted that the impact of pay-for-performance schemes is dependent on the underlying payment mechanisms into which such schemes are introduced. Reviews have pointed to the potential of pay-for-performance to improve the quality of care while also highlighting the risk of unintended consequences related to incentive payments that need to be taken into account when designing such schemes (Roland & Dudley 2015; Markovitz & Ryan 2017).

21.3.2.2 Value-Based Payment Schemes

Decision-makers are increasingly recognizing the limitations of the traditional ways of paying providers in healthcare, which tend to fragment service delivery because of a misalignment of incentives across providers. Countries are, therefore, increasingly experimenting with what has been referred to as 'value-based payment schemes' (VBPs), which seek to link provider reimbursement to a pre-defined set of evidence-based clinical process and/or outcome measures. Examples of VBPs include bundled payments, shared savings and global budgets. Pay-for-performance schemes are frequently also considered under the heading of VBPs, although, as Cattel and Eijkenaar (2019) have cautioned, they tend to apply a relatively narrow definition of value, as do some bundled payments schemes.

Bundled and global payments are disbursed as a single payment in form of a 'lump sum' per period for a specified population (global payment) or per episode or condition per patient (bundled payment) to a collective of providers. By linking payment to clinical, process and outcome measures, providers are incentivized to increase efforts to improve patient care and process efficiency. As the payment is transferred as a single lump sum, regardless of the number of services provided, VBPs are expected to promote care coordination and integration across providers and so reduce wasteful duplication of services and unnecessary hospital use. Bundled payments can be distinguished into episode-based and disease-based payments. Episode-based payments reimburse providers with a single payment for all delivered services for a pre-defined single episode of care. This type is frequently used for surgical procedures such as hip and knee replacements or cardiac surgery and has been experimented with mostly in the USA, within for example, the Bundled Payments for Care Improvement (BPCI) initiative (Centers for Medicare and Medicaid Services 2020a). In contrast, disease-based bundled payments reimburse a package of services on a pre-defined patient pathway; they are paid per patient and cover periods of up to one year. This type of bundled payment is most commonly used for chronic conditions such as type 2 diabetes or cardiovascular conditions (Feldhaus & Mathauer 2018). Examples include the bundled payment schemes that were introduced in the Netherlands from 2007 onwards (de Bakker et al. 2012; Tsiachristas et al. 2013) and related schemes in various states in the USA (Conrad et al. 2015). Further details on the role of bundled payments in integrated care are presented in chapter, which also discusses the example of bundled payment for diabetes in the Netherlands and the BPCI initiative in the USA.

Global payment models include shared savings programmes and comprehensive care payments. Under shared savings programmes, the payer or payers share the risk of rising expenditure with the care provider or providers (Hayen et al. 2015). This means that providers that succeed in lowering their growth in healthcare costs while continuing to meet quality standards will be financially rewarded; savings can be reinvested in the programme. Shared savings programmes are a comparatively recent development; examples include the Medicare Shared Savings Program in the USA (Conrad et al. 2015; Centers for Medicare and Medicaid Services 2020b) and the Healthy Kinzigtal integrated care programme in Germany (Pimperl et al. 2017), with similar initiatives in the Netherlands ongoing (Drewes et al. 2014). Examples of global payment models, which involve fixed payments for the care of a patient during a specified time period, include the Massachusetts Alternative Quality Contract in the USA (Box 21.2) (Song et al. 2014).

Box 21.2 The Alternative Quality Contract in Massachusetts, USA

The Alternative Quality Contract (AQC) is a two-sided contract implemented in 2009 by the non-profit health insurer Blue Cross and Blue Shield of Massachusetts (BCBSMA) (Song et al. 2014). The AQC is a risk-adjusted global budget payment model in which provider organizations agree to accept responsibility for managing care within a specified annual budget, and they share the risk if spending exceeds the budget (or share savings if spending is below budget) (Chernew et al. 2011). The model sought to improve quality and outcomes while moderating healthcare spending growth. The contract includes about 85% of the physicians in the BCBSMA network. Participating organizations receive bonus payments based on 64 process (e.g. preventive screening, medication management), outcome (e.g. high blood pressure control) and patient experience indicators (e.g. access to care, quality of communication), in ambulatory and hospital care. Shared savings (or deficits) are linked to the quality of care delivered, with higher levels of quality implying a larger share of savings and smaller share of deficits to providers. The AQC is among the largest private payment reform initiatives in the USA and seen to provide a model for state and national policy-makers (Blue Cross Blue Shield of Massachusetts 2016).

There is some evidence that innovative payments schemes such as bundled payments and shared savings programmes may be associated with lower spending growth and, possibly, actual savings (Cattel & Eijkenaar 2019; Feldhaus & Mathauer 2018; Vlaanderen et al. 2019). However, effects vary across payment and care models, as do impacts on outcomes as demonstrated by the varied experiences of accountable care organizations in the USA (Kaufman et al. 2019; McWilliams et al. 2018). Assessments of the Alternative Quality Contract in Massachusetts (Box 21.2) found that the population-based payment model was associated with slower growth in medical spending, which resulted in savings, and these were shown to have exceeded incentive payments over time. There was also evidence of improvements in a range of quality measures of processes and outcomes that were greater in the AQC cohorts than in comparable populations elsewhere in the USA (Song et al. 2018).

21.3.3 Changes to Financing Mechanisms

Some countries have also experimented with changing the mechanisms by which health and/or social care are being financed to encourage better coordination across sectors. One example is Denmark, which, in the context of the 2007 structural reform of the administrative system, reallocated responsibilities in the healthcare sector to five newly established regions and 98 municipalities (Olejaz et al. 2012). Specifically, the reform made municipalities responsible for the co-financing (20%) of regional healthcare activities to encourage municipalities to increase preventative services so as to reduce hospitalizations (Frølich et al. 2015).

Others have moved to experimenting with different ways of financing to help integrate health and social care services (Hultberg et al. 2005; Mason et al. 2015). Mason et al. (2015) reviewed the evidence of impact of such approaches in Australia, Canada, England, Scotland, Sweden and the USA. They distinguished different types of financial integration, which can be seen to lie on a continuum. At one end are 'simple' transfer payments, in which purchasers of public social or long-term care services (e.g. municipalities) make financial contributions to health bodies to support specific additional services (and vice versa). At the other end are pooled funds, in which each partner (health and social care) makes contributions to a common fund to pay for agreed projects or services, and structurally integrated budgets, in which responsibilities for health and social care are combined within a single body under single management. However, distinctions are not clear-cut, and schemes tend to use more than one financial integration mechanism. Importantly, the range and scope of services covered under integrated financing schemes vary widely.

The Program of Research to Integrate Services for the Maintenance of Autonomy (PRISMA) model in Quebec, Canada, is an example of an integrated financing scheme in which one partner leads the purchasing of services based on jointly agreed aims (Mason et al. 2015). In this model, all public, private and voluntary health and social service organizations are involved in delivering services for older people in a given area. Each organization retains its own structure but agrees to participate under an umbrella system and to adapt its operations and resources to the agreed requirements and processes. Budgets are negotiated between partner organizations, and a joint governing board, with representatives from all the health and social care organizations and community agencies, decides on the allocation of the resources to the integrated system.

A similar model has been adopted by NHS Highland in Scotland, in which responsibility for adult social care services was transferred to NHS Highland while the local authority (Highland Council) remains accountable for social care. The transaction is delivered through a five-year plan, which is reviewed annually and monitored with regard to the delivery of agreed outcomes. The process also involved the creation of a single budget ('pooled funds') through the transfer of budget lines across the two bodies.

One example of a system involving structural integration is the Integrated Health and Social Care Board in Northern Ireland, which is responsible for the commissioning of services, resource and performance management. Five Health and Social Care Trusts act as local commissioning groups (LCGs) and are responsible for assessing needs and commissioning health and social care for their local populations (Thompson 2016).

An example of pooled funding is the Better Care Fund (BCF) in England (NHS England 2020). Launched in 2015, the BCF requires Clinical Commissioning Groups (CCGs), the purchasers of health services, and local authorities, which are responsible for social care, to establish pooled budgets and develop integrated spending plans. The funds are to be used to pay for services involving both health and social care and examples of activities supported through the BCF include intermediate care, protection of social care such as continued home care, day care, care home placements or care coordination (e.g. case management) (Forder et al. 2018).

As with innovative payment mechanisms described above, the evidence of impact of novel financing mechanisms, where this has been evaluated, remains patchy. There is little robust data on the effects of municipal co-financing in Denmark. One study sought to assess its impact on hospital services but it failed to demonstrate a clear link between local efforts to reduce hospitalizations and the number of hospital admissions among older people during the first three years following the reform (Vrangbæk & Sørensen 2013). At the same time, municipalities were found to have increased investments into public health efforts overall. A review of the evidence of impact of integrating financing for health and social care also failed to establish empirically robust positive effects of such schemes on health outcomes, secondary care use or costs (Mason et al. 2015). There was some anecdotal evidence of unintended consequences such as premature hospital discharge and increased risk of readmission. Identified barriers included difficulties of implementing financial integration, limited control of budget holders over access to services, difficulties in linking different information systems and differences in priorities and governance among those involved. At the same time, most schemes succeeded in improving access to care, with substantial levels of unmet need identified in some, which then led to an increase in total costs. The authors concluded that although the link between integrating funding and better health outcomes and lower costs is likely to be weak, there was also a strong notion that if integration delivers improvements in quality of life, even with additional costs, it may, nonetheless, offer value for money. This conclusion is supported by a recent evaluation of the Better Care Fund in England, which found some evidence that pooled funding has improved integrated working between health and social care as measured by delayed transfers of care from acute hospital care (Forder et al. 2018). While the authors were unable to quantify the impact on outcomes, there is an expectation that the quality of life of those who leave hospital in a timely manner is likely to be improved. At the same time, the evaluation also highlighted that while pooling budgets such as through the BCF can enable closer collaboration between sectors and services, there remain substantial ‘cultural, operational and territorial barriers’ that need to be overcome in order to achieve more integrated working that is effective and sustainable (Harlock et al. 2020).

21.4 Conclusions

Differences in financing sources and mechanisms and in the allocation and flows of financial resources can pose a critical challenge for efforts to better coordinate and integrate across functions, professions and sectors. This chapter has provided an overview of ways in which countries have sought to overcome these challenges. While numerous innovative approaches have been implemented, the evidence of what works best in what contexts and their impacts on outcomes remain elusive.

Importantly, as Leutz (1999) has pointed out when reviewing attempts in the USA and UK to integrate health and social services, there is often a failure to understand that "integration costs before it pays" (p. 89). Indeed, Mason et al. (2015) found, in their review of different ways of financing to help integrate health and social care services in different countries, that some innovative models were associated with an increase in cost, mainly because they uncovered unmet needs. Frequently, there is an expectation that integration initiatives will self-fund from savings arising when a new service is substituted for an existing one. Yet, available evidence suggests that the creation of new coordinating mechanisms will not compensate for lack of resources (Freeman et al. 2007). There may be a temptation to inject one-off extra funding to pay for new services, but this will not necessarily ensure long-term sustainability. Success often depends on the new approaches being incorporated into routine care, and while sustained financing will be a necessary requirement it may not be sufficient, especially where the innovation challenges established ways of working (May 2006).

Finding the right payment mix to support integrated care can be challenging, and countries are increasingly using some form of blended payment through combining different approaches, often involving some form of pay-for-performance element. The right mix will be important, however. Evidence on performance-related pay in particular highlights the need to carefully consider the existing payment structure into which new incentives are introduced and to design the structure of reward schemes to maximize the likelihood of intended outcomes and minimize the likelihood of unintended consequences (Roland & Dudley 2015). Indeed, there is increased recognition of the importance of context and existing infrastructure when implementing a new payment scheme which may help understand slow uptake or variation in outcomes (Feldhaus and Mathauer 2018).

Overall, there is a need to ensure that payment systems encourage rather than discourage coordination. Particular attention needs to be paid to changes in health services which appear likely to further fragment care, such as payment based on activity, which is being used for paying hospitals in the majority of European countries, or the introduction of competition among service providers.

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Reimbursing Integrated Care Through Bundled Payments

22

Patricia Ex

22.1 Introduction

There are no perfect reimbursement instruments. Selecting the most appropriate payment system depends on the intended delivery of care and the incentives set through the payment form (note: payment and reimbursement will be used interchangeably in the following). The variety of traditional reimbursement instruments can be conceptualised as a continuum of delegating risks from payer to provider. Despite their dissemination, traditional forms of paying providers often do not align well with new models of care (Stokes et al. 2018). Especially in the context of pursuing health policy objectives such as improving coordination and patient-relevant health outcomes, inherent disincentives of traditional instruments impede these policy aims and thus may not work very well (OECD 2016). In consequence, many health care systems have had difficulties in improving coordination and cooperation, especially for chronic diseases and for certain acute diagnoses that require attention from inpatient and outpatient care or from acute and rehabilitative care.

Bundled payments were created in response, where payers reimburse a determined amount for an entire episode of care instead of reimbursing individual services. The transfer of risk in the payment forms described above already goes along with a degree of bundling. In the scope of integrated care, however, bundled payments refer to payments that involve various providers within the defined patient pathway. The lump-sum payment thus has to be divided among the providers and facilities involved with delivering the care (Amelung 2019).

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22.2 Reimbursement Instruments

Reimbursement instruments are often subject to conflicting goals. Paying for health care services has a distribution and a steering function. It is supposed to enable innovations, win acceptance and create transparency (Amelung 2019). For some health care systems, it is crucial for the payments to be easily administrable (Ibid.). In consequence, health care systems are increasingly concerned over the design and structure of their payment systems.

There is a firm belief in health economics that higher quality in health care correlates with lower costs (Porter & Teisberg 2006). What may seem counter-intuitive at first is linked to the notion that health care systems work differently from other industries, where paying a higher price is—at least to a certain degree—linked to receiving a higher quality product or service (hotels, cars, shoes, etc.). Instead, low quality in health care often correlates with high prices, such as a poorly managed diabetes patient or an insufficient surgery requiring rehospitalisation or additional treatment, to only name a few. In a similar manner, studies suggest that surgeries of artificial hip replacement that achieve a higher outcome quality are associated with lower long-term costs (Fahlenbrach et al. 2011). Payment systems should thus be designed that they acknowledge performance and quality without incentivising oversupply.

The way of paying for health care can be influenced mainly by three dimensions, (1) the degree of bundling, (2) setting the payment prospectively vs. retrospectively and (3) measuring the performance of the provider through data (Charlesworth et al. 2012). Besides this, every reimbursement system also generates unintended effects (Barnum et al. 1995). Various studies indicate that physicians, hospitals and other health care providers react to the way they are reimbursed for their services. The incentives tend to change the overall behaviour of stakeholders involved, affecting the efficiency, equity and quality of health outcomes as well as the adoption of new technologies (Breyer et al. 2013; Ellis 1998; Ex & Henschke 2019). When assessing the inherent (dis)incentives of a payment system, it may therefore be relevant to consider

- the quality of delivered services,
- the quantity of offered and utilised services,
- the average costs per case,
- the access and number of at-risk population for payer and provider, as well as
- the sharing of risks between payer and provider (Schmid 2020).

The variety of established payment mechanisms can be conceptualised and differentiated along a risk continuum delegated from payer to provider. The risks related to an individual utilising health care services traditionally lie with the payer. In such scenario, health care services are reimbursed through a **fixed salary**. While such a payment serves as an incentive for providers to keep their patients healthy, it may also lead to an inefficient use of resources and long waiting times.

Compared to a salary, reimbursing services through **fee-for-service** slightly increases the risk for the provider, as the reimbursement includes further expenses such as investment and running costs of an office and doctor's needs such as needles. The aim of fee-for-service is to increase productivity and to reimburse performance, even though it may come along with a substantial rise in volumes (Amelung 2019).

A further bundling of the payment is the reimbursement through **diagnosis-related groups** (DRGs) that include all services of one provider related to a defined disease. Besides staff and doctor's needs, this also covers for possible instruments and machines necessary for diagnosis and treatment. DRG systems are often used for inpatient and outpatient hospital care and usually include rehospitalisation for the same diagnosis for a certain time after discharge (Quentin et al. 2013).

In order to also incentivise better quality, concepts such as value-based care (Porter and Teisberg 2006), pay-for-performance and performance-based reimbursement (Forsberg et al. 2001) have been put forward by academia and in policy-making. With the aim to improve the value of care for the money spent on it, **value-based payments** for instance add premiums for top outcomes and/or deductions for outcomes below a defined threshold.

The highest form of risk delegation can be observed in **capitation**, where the entire risk for a defined population is handed to a provider. The group of people for whom services are bundled can vary between all insured of a region or a particular group of insured, such as the patients with the same disease (Schmid 2020). The extent of included services differs, but theoretically can include all services necessary for the care of the insured person, "including preventive and inpatient services as well as annex services" such as laboratory and radiology services or drugs (Amelung 2019). In distinction to capitation, **global budgets** work similarly but are paid independent of the actual volume provided (OECD 2016).

22.3 Reimbursing Integrated Care

Opposed to conventional health care, integrated care focuses on holistic care to improve the person's well-being instead of an isolated illness (Goodwin et al. 2017). Many reimbursement instruments, in contrast, are linked to a particular treatment. Integrated care is often delivered in a team and organised around the patient pathway. The patient pathway is, however, often reverse to the division of health care sectors. Since the different reimbursement systems often only apply to one health care sector or only to medical services, actors are incentivised to focus on their individual element of care delivery instead of a patient-centred process. On a larger scale, this also results in diverging interests between sectors as well as between health and social care (SVR Gesundheit 2018). Furthermore, integrated care often takes place in addition to or besides standard care. This suggests that integrated care becomes necessary due to disincentives of payment systems that allow but do not facilitate cooperation or coordination nor the delivery of services as a team across providers or sectors.

In order to make integrated care work, it thus requires other concepts of reimbursement. Bundled payments—also called episode-based payments—have been developed for integrated care. While many reimbursement systems focus on one narrow specialty or organ system, bundled payments approach it through the medical condition as perceived by the patient and include common comorbidities and related complications (Porter & Kaplan 2015). Also, the treatment with medications can be incorporated into the bundle (Amelung 2019). The aim is to better integrate the care process by improving patient experiences and health outcomes as well as to reduce avoidable ill health and costs, for instance through unnecessary hospitalisation (Charlesworth et al. 2012).

Bundled payments for integrated care are defined as a "single payment to cover the care for the condition or population segment over a specified time period", involving inpatient, outpatient and rehabilitative care (Porter & Kaplan 2015). Being paid for a defined episode of care, this allows providers to jointly assume accountability and deliver health care together. The reimbursement incentive works by paying average costs instead of actual expenses per patient. Providers thus face the risk to be reimbursed less than their expenses or instead can keep surpluses when providing care efficiently (Struijs et al. 2020). In consequence, bundled payments are thought to not lead to unnecessary rise in volumes but instead to incentivise cost-efficient procedures. What must also be considered when designing bundled payments is that usually two purchasing markets exist that influence behaviour, firstly on the level of the care group and secondly on the level of the individual provider (Struijs et al. 2017).

The reimbursement price can be set through various means. It can be based on price negotiations or is fixed. Bundled payments are often determined in advance representing the expected average costs—in this case belonging to so-called prospective payment instruments. Main challenge in this case is to determine the expenses for an episode of care, since health care providers usually do not assess costs from this perspective and may not even have applicable data. Some models therefore use evidence-based guidelines to set the expected consumption of resources and link compensation to these (Amelung 2019; Rosenthal 2008). In some cases, prices are also determined retrospectively, with an upfront fee-for-service payment to individual providers and a retrospective reconciliation period (Struijs et al. 2020).

The large difference among bundled payments is their scope. Bundled payments can include advanced value-based models or instead provide mostly the same health care as in other fields. It is thus most relevant to align the bundled payment to the health care aims. The following table differentiates four hypothetic set-ups of integrated care that demand for quite different reimbursement approaches within bundled payments (Table 22.1).

As this depicts, one aim of an integrated care process may be to yield multi-professional cooperation and coordination, for instance, in the case of a diagnosis such as breast cancer. The bundled payment can thus be closely linked to

Table 22.1 Aligning different types of bundled payments for different types of integrated care

Integrated care	Characteristics	Challenge	Possible form of bundled payment
Regional coalition of providers to integrate health and social care for patients with multi-morbidity	Rural area, many elderly residents	Underdeveloped structures: few health professionals are available	Bundled payment covering entire health care process relating to multi-morbidity
Breast cancer diagnosis that requires a variety of health care professionals	Diagnosis with various health care specialities involved	Little coordination in highly demanding patient situation	Bundled payment defining appropriate health care process and reimburse accordingly
Pilot project of reimbursing digital health application	Innovative technology	No reliable predictions on quantity of use	Outcome-based bundled payment with quantity thresholds
Pilot project of reimbursing adherence programme in addition to drug therapy	Innovative technology	No reliable predictions on quality of use	Risk-sharing contract with tiers based on level of adherence in real-world use

the defined processes and mandate a specific person that assists with the coordination (case management). Similar cases could be stroke, acute cardiac diseases and certain cases of multi-morbidity, for instance, in combination with dementia. Depending on the circumstance, adding a value-based approach to the bundling may be relevant to incentivise investments for a better quality of care.

The bundled payment may look quite differently when piloting an innovative technology in a network of health care professionals, for instance, a digital health application where no reliable predictions exist on the quantity of use. An outcome-based approach seems most important here to evaluate the diffusion of the technology. When the challenge is rather the quality of use, for instance, in an innovative technology aimed at improving adherence, risk-sharing bundled payments may be applicable, where tiers are linked to the level of adherence in real-world use. As this suggests, the variety of bundled payments is large, so that the following will look deeper into the adoption and use of specific bundled payments in practice.

22.4 Bundled Payments in Use

A number of health care systems use some kind of bundled payment to reimburse integrated care. A systematic review on this matter found 32 international examples of reimbursing integrated care, with the majority described in the United States (n = 15), followed by the UK (n = 5), Canada (n = 2), Germany (n = 2), the Netherlands (n = 2) and other European countries (n = 6) (Stokes et al. 2018).

Struijs et al. additionally found initiatives in Taiwan and New Zealand (2020). Most of the initiatives focus on one condition, procedure or treatment (Struijs et al. 2020). Bundled payments have been established mostly for specific disease pathways, such as for the chronic care in diabetes and different forms of cancer as well as the acute episodes of care in stroke, total hip and knee replacement, congestive heart failure and sepsis. They can thus be implemented for a mainly outpatient setting (diabetes care) as well around inpatient and post-acute care (hip replacement).

In addition to these contracts between providers and health care systems, bundled payments are also used in some systems for treatments that patients directly pay for, such as in vitro fertilisation and plastic surgery (Porter & Kaplan 2015). These payments rather resemble other individual purchasing decisions and will thus not be the focus of this paper.

A relevant requirement for bundled payments to work is the availability of data. Most bundled payments are based on a performance and a quality measurement. Despite having been discussed for some time, bundled payments are hence becoming increasingly relevant in times of digitalisation as they are more easily implementable. This can be the case for an easy data exchange between providers through an integrated patient record, through digital billing, through integrated process management and performance measurement. Data is thus a relevant element of executing and operating bundled payments in use.

Two cases of bundled payments will be displayed in more detail in the following (for a more detailed description of the Dutch case, refer to HBIC Vol. 2, Chapters 17 or 18).

22.4.1 Case Study I: Disease Management of Diabetes in the Netherlands

Similar to various industrial countries, the Netherlands is faced with a rising burden of chronic diseases. Four per cent of the Dutch population are diagnosed with diabetes, which is likely to increase in the coming years. With a lack of coordination between different sectors and professional groups, the Dutch health care system was not equipped to take care of chronic patients, especially so with a rising prevalence of multi-morbidity and complex health care needs among the population (Struijs et al. 2017).

In response, the Netherlands Ministry of Health, Welfare and Sport developed the first integrated care programme focussing on diabetes care that was aimed at improving the quality of care, in particular confining quality deviation, and to improve effectiveness while ensuring affordability (Ibid.). A bundled payment was initiated in 2007, first in an experimental design and by 2010 on a more permanent basis, that contracted a single service package with a group of health care providers (the Dutch abbreviation is keten-dbc) (Struijs et al. 2012). These care groups are legal entities that coordinate and execute the care process from diagnosis to after care and contract with health insurers. (Co-)owner of these care groups are often general practitioners, with practice nurses and a variety of health care professionals such as dieticians and podiatrists working as chain partners (Busetto et al. 2015). By 2010, a hundred care groups were operating in diabetes care that covered around 85–90% of all diabetes patients in the Netherlands (Struijs et al. 2012).

The bundled payments were established as packages, where the content and price of the comprehensive package are negotiated. In contrast to bundling downstream after inpatient care by limiting the need of hospital readmissions, the aim here is to focus upstream on improving primary care and thereby not requiring expensive specialist outpatient care and hospitalisation (Amelung 2019, Struijs et al. 2012).

22.4.2 Case Study II: The Bundled Payments for Care Improvement (BPCI) Initiative by Medicare in the United States

Medicare traditionally reimburses providers for each service individually (fee-for-services). As has been described above, it noticed that this can lead to fragmented care with too little coordination, awarding quantity instead of quality (Centres for Medicare and Medicaid Services, CMS 2020a). The Centre for Medicare and Medicaid Innovation was thus established in 2010 to test innovative payment and care delivery models (Micklos et al. 2020).

It developed the Bundled Payments for Care Improvement (BPCI) Initiative in 2013, initially running through September 2018 (CMS 2020b), NEJM Catalyst (2018). In 2015, the Medicare Access and CHIP Reauthorization Act additionally created financial incentives for providers to participate in these advanced payment models. The BPCI offered four models of participation, depending on the area of service delivery. Target prices were set prospectively based on the expected costs of services and items during the episode of care. The models varied in funding the expected costs on the historical performance of the provider, on local or regional spending, or on a combination thereof (CMS 2020a).

However, some models would be considered as regular diagnosis-related groups from international perspective, since the United States does usually not include physician salaries or readmissions in their DRGs, while many other health care systems do (Quentin et al. 2013). Only the most comprehensive Model 2, involving Part A and Part B services for the initial hospital care, all post-acute care and readmissions (Romley and Ginsburg 2018), would be considered as bundled payment in the context of this paper. The model differed in the scope of rehospitalisation, either ending 30, 60 or 90 days after hospital discharge (CMS 2020b). The provider payment in Model 2 was actual expenditures were reconciled retrospectively against the episode's target price (CMS 2020c).

A total of 699 participants were involved in BPCI Model 2 (Centres for Medicare and Medicaid Services 2020b), equivalent to around 85% of the provider groups from all models (Romley and Ginsburg 2018). Of the participants triggering an episode of care in Model 2, almost two thirds were acute care hospitals and one third physician group practices. In contrast to the approach taken in the

Netherlands, the BPCI initiative involved up to 48 different medical and surgical conditions (Chen et al. 2015). Awardees could select the clinical episodes they participated in. Due to the aim of the Innovation Centre to test new models of care, provider groups could try various model definitions that best fit to their institution.

Based on the experiences made above, CMS developed the BPCI advanced, which has been running since January 2018. It involves a single retrospective bundled payment with a 90-day episode duration. Providers receive payments when their total spending for the episode lays below the determined target price. Additionally, prices can be adjusted for quality indicators by 10% (CMS 2020c). There are 29 inpatient and three outpatient clinical episodes that providers can sign up for (CMS 2020b). It has attracted 1299 participating providers as of September 2019.

22.5 Effects of Bundled Payments

The effects and eventually the success of managed care-instruments largely depend on their specific design. Various studies thus investigate in what circumstances bundled payments lead to the intended effects. Three different groups of effects are plausible, firstly yielding better health care delivery including better patient-reported outcomes, secondly improving the work of health care professionals and thirdly to reduce costs. A current meta-analysis found 35 papers empirically analysing the impact of 11 bundled payment initiatives (Struijs et al. 2020). All of these used an observational design, most often with a pre- and post-measurement without control group, some also used a difference-in-difference approach (Ibid.).

Some studies suggest that integrated care with bundled payments was associated with aligning health care delivery along patient pathways and with protocol adherence (Struijs 2017). A first step towards achieving may be a higher transparency of health care quality, which was studied and found by Tol et al. (2013). However, results are mixed mostly between positive effects and no effects when analysing the impact on quality of care as a whole (Struijs et al. 2020). Bundled payments involve the willingness to deliver health care in teams and cooperate with other professions, in particular also new professional roles in the clinical pathway. Ruggeri et al. (2018) found an association between high levels of patient satisfaction and involvement of new professional roles for the case of breast cancer and, in the case of countries with innovative models of health care delivery, also for type 2 diabetes. Overall, patient experiences are rarely measured in empirical studies on bundled payments (Struijs et al. 2020). Struijs et al. (2017) also found increased training of subcontracted providers in the studied integrated care programmes, which was aimed to facilitate protocol-driven work processes.

Literature has confirmed that bundled payments are associated with increased multidisciplinary cooperation (Struijs 2017; Tol et al. 2013). Especially younger generations of physicians have an overall higher expectation in working together in teams, which suits well for integrated care contexts. However, integrated care and bundled payments also have a competitive component included, through transparency on treatment outcomes and being accountable for the own (measured) results. Furthermore, bundled payments may bring a higher efficiency of care, while the defined processes may go along with an increase in administration (Tol et al. 2013). The additional administration and management in integrated care can be addressed through digital tools to connect health professionals in an intelligent way. Studies suggest that implementing interoperability between the patient data banks to allow data exchange and analysis is currently one of the main challenges (Busetto et al. 2015).

Lastly, integrated care has been often connected to the expectation to reduce costs. This can be achieved through reducing unnecessary hospitalisation and readmissions as well as by reducing post-discharge costs. Iorio et al. studied the effects of the Model 2 bundled payment in the US Medicare programme for total joint replacement implemented in a tertiary urban academic medical centre and observed a decrease of discharges to inpatient facilities from 71 to 44% (2016). Navathe et al. studied the same BPCI Model for lower extremity joint replacement in a US health system, finding that average Medicare episode expenditures declined by 20.8% over the 3942 patients treated between 2008 and 2015 (2017). Evaluating the Netherlands, de Bakker et al. found large price variations among care groups that could not be fully explained by the amount of care provided (de Bakker et al. 2012). The Netherlands were the only country in a meta-analysis where medical spending increased in the first two years of implementing the Dutch bundled payment (Struijs et al. 2020). The factors of unnecessary hospitalisation and readmissions have a cost-component as well as a quality of life-component. Busetto et al. (2015) found in their interviews that some payers were mainly interested in costs, while other payers focused on costs in addition to quality of care.

Overall, a clear distinction between the effect caused by the model of integrated care vs. caused by the payment is—in addition to all scientific considerations on causality—barely possible. However, integrated care has often been not very successful when attempted through standard payment instruments. If the bundled payment is considered a requirement or auxiliary for the model of care to work, the described effects are achieved through integrated care paid by bundled payments.

22.6 Discussion

An essential element of making integrated care successful is an appropriate reimbursement instrument, such as bundled payments. They may differ in the scope of bundling (target population, time, sectors), as well as in how the price is set (negotiation, fixed). Yet, they always go along with a specific mindset of taking responsibility for the delivered health care and transparency on the own performance.

The basic notion of integrated care is to define patient pathways along an episode of care. This can be understood as translating evidence-based guidelines into a clinical protocol for the praxis of how to provide health care with a certain diagnosis. The assessment, pondering and negotiation on how to steer patients best through the care remains as important as ever and is a first relevant aspect of integrated care. Having come to an agreement on that, the merit of bundled payments is that they delegate accountability, yet only for the scope of personal and organisational expertise. Too often, it has been attempted to convince providers to follow a defined pathway or protocol through narrow-minded quality management or legal threats. The advantage with bundled payments is that they do not only mandate the content of health care provision, but link this to responsibility and reimbursement. One can understand bundled payments as a response to the disincentives of existing reimbursement systems; overgeneralising, fee-for-service lead to waste, DRGs cause egoisms, and capitation is often too broad. Bundled payments are not perfect, but they do achieve quite well to honorary those who deliver an excellent performance (OECD 2016).

The controversial analyses in how far bundled payments led to the wanted effects when applied suggest that their success largely depends on the specific design. If it is not mandatory to participate in them, one relevant achievement in this context is that providers actually participate, as bundled payments are often an alternative to standard care. Examples in the United States describe that despite establishing bundled payments, some providers perceived many barriers such as administrative burdens and state regulatory uncertainty and thus did not sign in (Ridgely et al. 2014) and facing substantial challenges in implementation, such as the complexity of the particular bundled payments that is built on the existing fee-for-service payment (Hussey et al. 2011). Moreover, what has to be considered is how to correct other fields of health care financing for the bundled payments. This again is especially the case when bundled payments are added on top of other reimbursement instruments.

Despite the relevance of integrated care in health care systems, bundled payments have not been broadly adopted. One central reason may be the current payment mechanisms that do not incite providers to change and act in more uncertainty. Patients may be interested, but there are often large information deficits, especially when patients are not used to being addressed to enter into different model of care. Main interest of integrated care lies with the payer, while the incentive to save expenditures promptly may sometimes be in the way to develop integrated care. Therefore, the main question that remains is how to incentivise health care systems to foster integrated care. It may thus make sense as health system to consider bundled payments as sole payment for specific public health relevant diagnoses.

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Strategic Management and Integrated Care in a Competitive Environment

23

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23.1 Integrated Care as a Strategic Option: Preliminary Remarks

Few integrated care-related issues depend on health system design as much as the question of integrated care as a strategic option. This chapter focuses on how integrated care can be considered as a strategy of differentiation for any stakeholder in the system. A local hospital has to decide whether it wants to invest in ambulatory care services, rehabilitation or home care as a means to expand their value chain along the patient journey.

The question is whether integrated care is a suitable competitive positioning strategy in a competition-oriented healthcare system. For example, a hospital, an insurance company, a pharmacy or a physician network can consider whether it should expand into upstream and/or downstream service sectors in order to improve its strategic position. In addition to improving patient care, other potential targets of

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focus may include the growth of market share, the creation of barriers to entry for competitors, capacity utilization, the use of synergy potentials, product line expansion, risk diversification and entry into more profitable market segments. These are mainly the same topics that managers in other industries are facing too.

In a national healthcare system, integrated care is viewed as an overall policy for the respective healthcare system. The focus is not on the various players' strategies, but on the extent to which integrated care is a strategy that benefits the entire system. The ultimate goal is to provide a population the best possible health care while taking both cost and quality considerations into account. However, even within national healthcare systems such as in the UK, there is a significant degree of competition that exists amongst contractees seeking to work together to provide health and social care services e.g. between independent GP practices, semi-autonomous hospital trusts, social enterprises and the third sector). Hence, even with the most regulated health and care systems, competitive behaviours within system remain. This is a challenge for planners and purchasers of care seeking more integrated solutions since there is a need to broker mutual gain across partners in care with competing interests.

Differentiation is very important because it explains behavioural patterns and can generate a need for regulation. In a competitive environment, an organization's goal will be to be better than the others. Accordingly, the objective cannot be that all players must necessarily be involved. Moreover, where competition exists there are often incentives to obscure information on one's own success factors or withhold them with others (patent protection, e.g., is an essential aspect of competition). There is a need for regulatory action because the compatibility of these strategies with the core values of many healthcare systems is limited.

Competition exists in every healthcare system, as different interests and interest groups are competing for scarce resources (e.g. nurses vs. physicians, hospitals vs. ambulatory care). Important tools needed to implement the competitive strategies described in detail on the following pages are not available or are only partially available to stakeholders in healthcare systems. Pricing, for example, is an instrument that is unavailable, or only partially available, in nearly all healthcare systems. Therefore, if a hospital's healthcare system has a diagnosis-related group-based payment system, it cannot implement any type of pricing strategy—i.e. raise or lower its prices. Similar is the situation for most ambulatory care services. Pricing in this case is more or less under state control (administrated) and therefore cannot be used as a strategic tool. In product design, there is a similar situation, leaving most healthcare systems very little room to manoeuvre. State regulations (forbidding hospitals in Germany to fully diversify into outpatient care, for example) and demand and volume planning—the predominant strategies in most healthcare systems—are the underlying causes. Consequently, many healthcare players basically have a monopoly that is legitimized by the state. There is almost no other sector where the level of regulation is as extensive as in health care. This by no means exhaustive list of restrictions on our strategic positioning options clearly shows that the healthcare system is in this respect fundamentally different from other markets, and that strategic options must be considered in the regulatory framework of each country.

Also worth considering is that health care is characterized by a high degree of complexity and change. Unlike many other sectors, its value chains are not clearly definable but are often iterative processes. In many indications, treatment is not a clearly structured process (outpatient inpatient rehabilitation), but a series of long-term pathways characterized by the individual patient's comorbidities and courses of treatment. This considerably limits the possibilities for standardization despite the existence of guidelines. What is more, because medical knowledge changes very rapidly (e.g. via the potentials of personalized medicine, technology, patient demands), the system's structures must be designed to be flexible.

In the following sections, we will mainly focus on the first variant, which is competition-oriented, and will explain what is generally meant by the term "competitive strategy", how they are developed, and which strategic options are available. Rather than concentrating on the strategy development process in general, we will focus specifically on how to utilize integrated care as a strategic management option (e.g. instead of or in addition to concentrating on a focus) and on what factors must be considered when doing so.

23.2 Strategic Management: Definition and Differentiation

In the general management discussion, strategic management is a topic characterized by scores of definitions. Some of these definitions are only minimally different from others, and new definitions are constantly being added. Nevertheless, some cornerstones for understanding strategic management exist that are generally accepted, at least in the scientific discourse. Decisions are considered strategic if they affect the basic direction of company development and are thus intended to have sustained effect. The aim is to ensure a firm's long-term success and to secure its position in relevant markets. In this case, market positioning and the necessary resource endowments are considered to be at least partially influenceable. The decisive factor is that the focus is on a higher-level perspective, and it is crucial to consider the overall perspective and that of the individual entities.

In the following section, we will start by defining key terms and will then describe various instruments used for aforementioned purpose.

23.2.1 Strategy

The term "strategy" is a greatly over-used term today. It is derived from the Greek word "strategos", which means the art of war. Von Clausewitz (1976, p. 84) defined strategy as "the use of engagements for the object of war". The important thing is that in this concept of strategy the means of achieving the goal rather than the goal itself is an element of the definition. Transferred to the context of integrated care, the goal could be to provide comprehensive care to a given population with a given budget. Integrated care concepts are then implemented in order to achieve this goal. Mintzberg (1979) defined strategy as "a pattern in a stream of decisions". His well-known "Five Ps for Strategy" (Mintzberg 1992) framework differentiates five definitions of strategy—strategy as plan, pattern, position, perspective and ploy. First, he describes strategy as a plan—a course of action to achieve a desired state or condition. This is based on a number of individual decisions that can be intentional or simply emerge (strategy as pattern). Strategy as position comprises recognizing attractive positions and striving to get there. Due to the higher layer, he also describes strategy as a perspective. Strategy as a ploy refers to the fact that tactics are used in the game of outwitting competitors.

23.2.2 Basics of Management Theory

The term "management" can be defined as the organization of processes and structures. General distinctions can be made between different management functions, institutions and levels. Management functions and responsibilities, depending on the respective definition, may include planning and organization, leadership and supervision, as well as personnel placement (see the respective chapters). The institution of management refers to the hierarchy level of an organization. The functions associated with management vary considerably by country and cultural region. Normative, strategic and operational management levels can be distinguished. Normative management defines the self-image of a company or organization and thus sets the foundations for its legitimation. It finds expression in corporate governance and corporate culture. The importance of strategic management, which is effectively positioned between normative and operational management, was already discussed. Operative management is the level involved with converting strategic concepts into concrete measures. Some of the most prominent among the health management thinkers are Henry Mintzberg, Stephen Shortell, Peter Drucker and Michael Porter.

23.3 The Strategic Planning Process

In strategic planning, organizations decide which markets they want compete in and with which products and at what prices, and how they wish to position themselves in the competition. Strategic planning thus addresses:

- An organization's range of services and the values of the players involved,
- An organization's relationship to other market players or stakeholders and
- Assessment of developments in the markets and one's own organization.

Traditionally, this workflow starts by performing a strategic analysis and then formulating and implementing a strategy derived from it. The two basic types of strategic analyses are internal analysis and external analysis. This will be explained later in terms of a Strengths-Weaknesses-Opportunities-Threats (SWOT) analysis. Based on the knowledge gained from the analysis, the company identifies the available strategic options and chooses one, which it then implements and, by necessity, monitors continuously. Since this course of action involves constantly recurring tasks, it can be characterized as an iterative process. It does not need to be a formalized process, but can also occur implicitly by people taking an appropriate course of action.

Methodologically speaking, the basic strategic process is fundamentally the same in health care as in other industries. However, a number of players in the healthcare sector place less emphasis on strategic planning and generally tend to focus on fulfilling healthcare contracts. Nevertheless, the question of how a healthcare organization wishes to position itself becomes more and more important as the level of competitiveness in which it must operate increases. In contrast to other branches of business, healthcare companies generally have less room to manoeuvre (e.g. due to healthcare contracts), and it takes much longer to implement changes.

23.4 Instruments for Strategic Planning

A range of instruments are used for strategic planning in practice. Two essential concepts will be discussed in detail below: the classic SWOT analysis, which differentiates strengths and weaknesses and opportunities and threats, and Porter‘s analysis of competitive environments, which is much more strategically oriented and analyses five competitive forces.

23.4.1 SWOT Analysis

In order to decide on a strategy, one must first collect and analyse all relevant information. This has become increasingly difficult in the age of “information overload.” The Strengths-Weaknesses-Opportunities-Threats (SWOT) matrix, developed at Harvard Business School in the 1960s, is a simple analytical framework for operationalizing the indispensable strategic position assessments (Kotler et al. 2010, p. 30). The collected information is divided into four quadrants: the Strengths (*S*) and Weaknesses (*W*) of internal factors, and the Opportunities (*O*) and Threats (*T*) of external factors. The strategy to be formulated is, therefore, the result of opportunities and threats arising from the changing economic and political environment in which a company operates as well as the strengths and weaknesses of the company. The most difficult step of SWOT analysis is to identify the strengths and weaknesses of a company’s internal factors and link them to the

External factors Internal factors	Opportunities • New business segments • Reforms	Threats • New competitors • Market saturation
Strengths • Know-how • Market position	SO strategies	ST strategies
Weaknesses • Growing costs • Poor brand recognition	WO strategies	WT strategies

Fig. 23.1 SWOT analysis [original illustration based on Kohlöffel (2000), p. 155)]

opportunities and threats of its external factors in a meaningful manner. For example, a company looks for ways to utilize its strengths so as to avoid potential risks (David 2011, p. 210). The elements of a SWOT matrix and examples of the four dimensions are shown in Fig. 23.1. The different types of strategies resulting from combining the dimensions are explained below.

The four basic types of strategies delineated by SWOT analysis are SO, ST, WO and WT. SO strategies use a business's internal strengths to take advantage of external opportunities. This represents the ideal case. WO, WT and ST strategies are aimed at getting the company in a position to be able to use SO strategies (David 2011, p. 210). In health care, for instance, a hospital could exploit its above-average knowledge about the treatment of a given disease in the outpatient setting. Rigid sectoral boundaries have prevented this until now, but integrated care provides opportunities to overcome this.

WO strategies involve utilizing changes in the business environment (e.g. new legislation) as an opportunity to convert internal improvement potentials into strengths to ultimately be able to use a SO strategy. In many cases, great external opportunities exist, but internal weaknesses prevent a company from exploiting them. One possible WO strategy is to acquire human capital in order to obtain the necessary skills in the area of opportunity. Even if, for instance, a service provider has weaknesses in communication and IT, it can use a government-supported e-Health initiative as an opportunity to invest in its IT capabilities. It can do this either by hiring external IT service providers or by educating and training its existing personnel. Another WO strategy is to form technology partnerships with competitors. Such partnerships can be established within the framework of an integrated care concept (Kohlöffel 2000, p. 156; David 2011, p. 210).

In ST strategies, a company uses existing strengths to ward off impending external threats. The goal is to avoid or at least mitigate risks (Kohlöffel 2000, p. 156). If, for instance, the corporate success of a financially well-situated hospital or physician network is threatened by an intensely competitive environment, they could use its strength (money) to acquire a competitor. In addition to mitigating the competitive situation, this would allow them to benefit from the economies of scale. Integrated care also provides opportunities for approaches in this regard. Intense competition for patients can be lessened by embedding the hospital or physician network in a network. This also serves to secure patient streams.

WT strategies are defensive tactics that aim to overcome internal weaknesses and avoid external risks. Here, the greatest changes must be made and innovative solutions found to ensure the viability of a company or division. If too many weaknesses and risks collide, options such as the divestment of business units, mergers or workforce reductions must be considered as well (David 2011, p. 211). To illustrate a possible WT scenario, take, for example, a networked healthcare provider with a small, low-profit gym who is looking for a way out of that highly competitive segment. Divestment of this business unit is a possible WT strategy.

Many important points must be considered when performing a SWOT analysis. Strengths and weaknesses should be portrayed in purely descriptive terms without interpretation. If, for example, a given characteristic cannot be clearly defined as a weakness/risk or strength/opportunity, it should be included in both categories in order to avoid interpretation. The information-gathering process should purposefully focus on collecting data for the external analysis, which takes much more time and effort. Conversely, it is relatively easy to obtain information on a company's internal strengths and weaknesses, for example, via controlling and benchmarking.

It is also important to mention that a SWOT analysis should attempt to be as abstract and descriptive as possible. Since it does not make recommendations or set priorities, a SWOT analysis can only serve as a starting point for determining a company's strategic direction (Kotler et al. 2010, pp. 30–33). Still, it is a very useful tool for visualizing a company's current situation. Nevertheless, SWOT analyses are just one out of numerous strategic management tools.

23.4.2 Analysis of Value Chains and Competitive Environments

Porter's value chain (Porter 1999) is another potential analysis model used to analyse a business's relative competitive position. This analytical tool systematically tries to explain the causes of competitive advantages based on all of a company's activities. A value chain is a set of activities that a business must perform in order to produce and sell a product or service. In addition to a company's own value chain, the upstream and downstream value chains of its suppliers and customers play an important role (Porter 1999, pp. 67–68).

The value chain itself can be defined as the sum total of the value-added yields of the individual value activities and the profit margin. The profit margin is defined as the difference between the added value and cost of all activities (Porter 1999, p. 68). There are two basic types of activities in the value chain: primary activities and support activities (Fig. 23.2). *Primary activities* can be divided into five categories and are responsible for the primary production and sale of a product. *Support activities* serve to support the primary activities.

As shown in the illustration, the value chain activities are geared towards the traditional operational functions of logistics, production and sales. The novel aspect

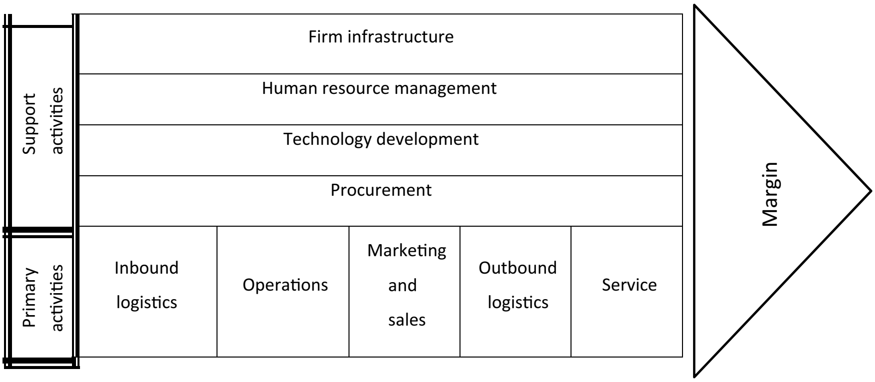


Fig. 23.2 Porter's value chain (Porter 1999, p. 66)

of Porter's concept is that all parts of the value chain are regarded as sources of costs and differentiation advantages and, thus, of competitive advantages. However, Porter's model does not directly show how to achieve strategic advantages within a given value activity. Porter explicitly states that the value chains of suppliers and distribution channels (Fig. 23.3) or, more generally, of players operating downstream or upstream also contribute to the margin. They are part of the total costs to the customers and, thus, are factors affecting a company's strategic competitive advantages (Porter 1999, p. 68).

In health care, the integration of upstream and downstream players could also improve a hospital's competitive position by helping it to better control its profit margins. An integrated value chain system in health care is illustrated below based on the concepts in Fig. 23.4.

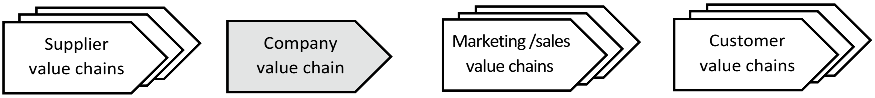


Fig. 23.3 Porter's value chain (Porter 1999, p. 64)

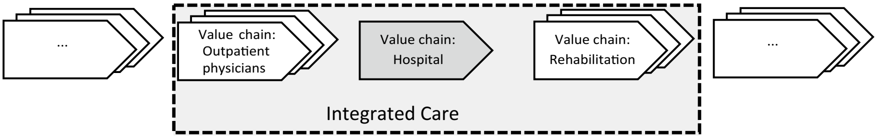


Fig. 23.4 Integrated value chain (VC) system in health care (original illustration)

In order to formulate a competitive strategy, a company must be in a relationship with its environment (Porter 2013, p. 37). Because the external factors in Porter's value chains only exist in the form of upstream and downstream value systems, Porter developed another instrument that specifically addresses the competitive environment: The Five Forces model. The intensity of competition within an industry is the central factor that shapes the industry structure and business environment in which a company operates. Porter identified five competitive forces that determine the intensity of competition. Porter's Five Forces model (Fig. 23.5) defines the five forces driving industry competition as rivalry among existing firms, the bargaining power of suppliers, the bargaining power of buyers, the threat of substitute products or services, and potential entrants or competitors (Swayne et al. 2008, pp. 94–95; Porter 2013, p. 37). The higher the collective strength of these competitive forces, the lower the profit potential in the respective industry (Kotler et al. 2010, p. 47).

Due to high barriers to entry, the threat of new competitors is much lower in health care than in other industries, e.g. hospital planning considerations, licensing requirements for outpatient clinics, and a large number of regulations prevent free market access. This is complicated by the fact that there are relatively rigid restrictions on the range of products that can be offered in health care, and alternative products cannot be introduced to the healthcare market as easily as in other industries (Swayne et al. 2008, pp. 95–98). An integrated care concept can allow for exceptions in some circumstances, standard care models with sharp sector boundaries can be replaced, at least in part, by implementing a networked integrated care

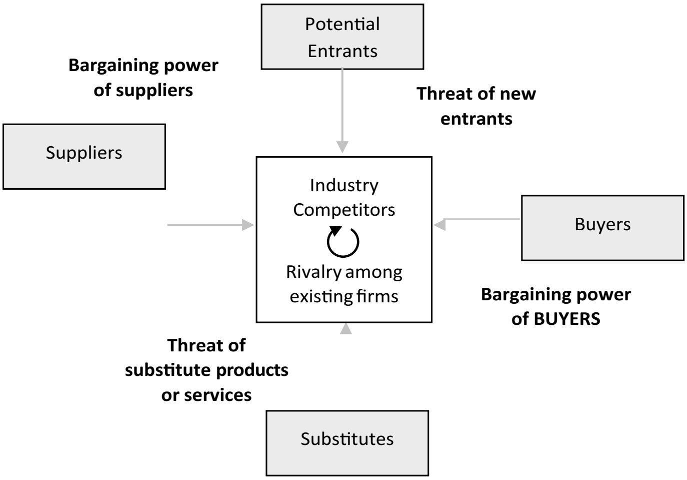


Fig. 23.5 Porter's Five Forces model for analysis of the competitive environment (Porter 2013, p. 38)

system. Moreover, integrated care can provide companies in the healthcare industry a competitive advantage because integrated care systems give them the potential to internalize suppliers and buyers and thus decrease their bargaining power.

23.5 Options for Strategic Positioning

A range of different strategic concepts are used in practice. Two basic concepts will be discussed in detail below: Ansoff's Product/Market Matrix from the 1960s focuses on the fundamental question of which products should be supplied in which markets. Porter, on the other hand, focuses on uniqueness as perceived by the customer and the scope of a company's strategy.

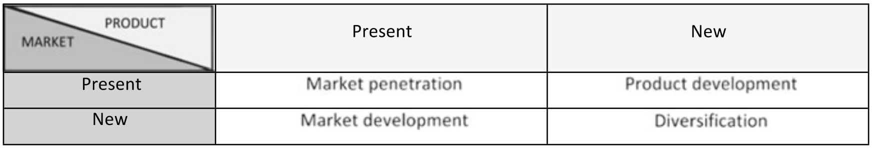
23.5.1 Ansoff's Product/Market Matrix

Ansoff's product/market matrix (Ansoff 1966; Fig. 23.6) is a tool for analysing corporate growth potential that divides the corporate environment into four possible product/market combinations characterized by the dimensions "existing" and "new" to delineate four different growth strategies that can be used by firms or hospitals: market penetration, product development, market development and diversification (Ansoff 1966, pp. 131–132).

23.5.1.1 Market Penetration

Market penetration is a growth strategy intended to increase a firm's market share in a current market segment. The firm can usually accomplish this by increasing its market share by using various marketing instruments or by expanding its market volume. The main goal is to increase the market share of products (increased number of cases), and the fastest way to do so is through mergers and acquisitions.

Whereas companies outside the healthcare sector are usually relatively free to determine what goes into their marketing mix, companies in the healthcare sector are often very limited in their choice of marketing instruments. Communications policy is the only marketing tool available because the fixed standard care catalogue and fixed fee per case rules do not allow for independent product and pricing policies; moreover, distribution policy is hardly relevant in patient-related services.



PRODUCT MARKET	Present	New
Present	Market penetration	Product development
New	Market development	Diversification

Fig. 23.6 Ansoff's product/market matrix (Ansoff 1966, p. 132)

Opportunities for action via communication policy are also extremely limited due to statutory provisions (e.g. Laws on Advertising in the Health Care System) designed to protect the patient. Integrated care provides an additional option because patient flows are easier to steer through a networked regional system. This creates opportunities for service providers to increase their market share.

Increasing the market volume can also lead to increased market penetration and thus growth. From a business perspective, the aim is to increase the volume of utilization and to arouse latent needs in the population, i.e. to acquire customers who did not use a given service before. If a service provider chooses to generate growth this way, it must first determine whether there is objective evidence of such a need in the population. This task is much more difficult for an independent service provider than for a member of a supply network because members can selectively refer patients to the services offered by other members of the network.

23.5.1.2 Product Development

Product development is a growth strategy that aims at introducing new or more or less extensively modified products into existing markets (Ansoff 1966, pp. 132–136). Despite major restrictions in health care, providers of care still have different opportunities for product development. They can, for example, supplement existing healthcare services by adding certain characteristics and thus marginally alter the services such that they offer (seemingly) greater benefit to the patient. Another product development option is to use an innovative technology or treatment method that is markedly superior to the existing technology or method in order to generate additional revenues in an existing market. Potentials for growth through product development can also be exploited by offering related services in areas where needs have not yet been satisfied, but the existing care contract of the respective service provider must be taken into account. For example, a hospital could set up a cardiac catheter laboratory to meet the additional needs of its existing cardiac patients and thus generate more revenue. A second possibility is to develop and provide specific prevention services for an existing customer segment. If, for instance, a care provider treats a lot of overweight patients, they could offer their patients additional services such as sports or cooking classes. Integrated care gives product developers in health care the opportunity to place truly new products on the market through the integration of other service providers. Integrated care can generate potentials for growth in this industry where product development opportunities are greatly limited.

23.5.1.3 Market Development

The third potential area of growth is market development. According to Ansoff's Product/Market Matrix, market development consists of introducing virtually unchanged services into a new market segments. The new market segment could be either a customer group that the company has not addressed fully or a segment where the company is not yet regionally present. Mergers or takeovers are effective external growth strategies in the latter case. However, they have the disadvantage of being either very expensive or associated with the partial abandonment of corporate sovereignty. An integrated care contract can help to avoid these disadvantages. For example, the creation of a network can enable a hospital to address customer groups in yet untapped regions as thus reap the benefits of broader regional distribution through network partners.

23.5.1.4 Diversification

Diversification is the last of the four growth strategies in Ansoff's Product/Market Matrix (Ansoff 1966, pp. 131–139). The aim of diversification is to achieve corporate growth by increasing the number of branches of industry in which a business is involved (Alberts and Segall 2003, p. 31). Diversification can be accomplished by creating new products and services or related products and services that expand the existing portfolio and offering them on untapped markets to generate additional revenue. Diversification strategies can be classified as horizontal, vertical and lateral. In horizontal diversification, a provider adds new services that are technically or commercially related to current provider services and offers them in a new market segment. Vertical diversification in the healthcare sector is a growth strategy along the healthcare value chain that integrates upstream and downstream services into the range of services provided by other providers. This can, for example, enable a hospital to enter the outpatient, rehabilitation or nursing market. Integrated care provides many opportunities for vertical diversification. In an integrated care system, all players along the healthcare value chain have the possibility to tap upstream and downstream markets. Lateral diversification gives care providers almost unlimited possibilities for growth because it allows the provider to market new products or services that are technically or commercially unrelated to the original hospital services.

23.5.2 Porter's Competitive Strategies

Whereas Porter's Five Forces model tries to explain business success based on the attractiveness of an industry, Porter's generic competitive strategies deal with strategic considerations. Porter developed this concept to more deeply analyse strategies that will result in sustainable competitive advantages over direct competitors within an industry. According to Porter, the number of strategic opportunities to gain long-term competitive advantage over a competitor, or competitors, is very limited. Although other strategies may be successful for companies operating in less competitive markets, it is generally very useful to follow Porter's recommendations in most industries. As a rule, a company must be fully committed to a given strategy to ensure that it is executed effectively. The basic types of strategic options, which will be described in detail below, arise from two levels: *competitive advantage* and *target scope* (Fig. 23.7). The two basic types of competitive advantage according to Porter are low cost and differentiation. These advantages arise when a company's strengths allow it to deal with the five competitive forces better than its competitors. Market scope, or the width of the competitive field, is the second level of this strategy matrix. Porter states that companies operate either

Fig. 23.7 Porter's generic strategies to sustain a competitive advantage (Porter 1999, p. 38, Porter 1985)

in the overall market (industry-wide) or focus on a narrow niche market (particular segment only). This yields the four ideal types of generic strategies illustrated below (Porter 1999, pp. 37–38).

Hybrid strategies, Porter maintains, are possible but are only successful in exceptional cases, for example, when there is low-level competition.

23.5.2.1 Cost Leadership

Cost leadership is a competitive strategy in which a firm strives to gain a cost advantage over its competitors in a number of industry segments via a number of measures (Porter 1999, p. 74). Many of these measures are based on exploiting economies of scale and scope. Relevant instruments for this include increasing the number of products, establishing an efficient corporate size, selectively exploiting experience in cost reduction, and minimizing costs in all business units. The ultimate goal of this strategy is to become the industry's absolute lowest cost producer. This protects a company from the competitive forces in the industry because the cost advantages resulting from the economies of scale create barriers to entry for competitors. Secondly, the cost leader's earnings remain higher than those of its competitors, even in highly competitive markets. Cost leadership also strengthens a company's negotiating position against its customers and suppliers (Porter 2013, pp. 74–75). Integrated care also gives healthcare players opportunities for cost leadership. Cost reductions can be achieved through better integration of upstream and downstream service providers along the value chain.

23.5.2.2 Differentiation

Differentiation is a competitive strategy in which a company strives to modify a product based on existing or latent consumer needs to the extent that the product will be perceived as unique within the industry and can be sold at a higher price because of its uniqueness (Porter 1999, pp. 40–41). Unlike cost leadership, differentiation focuses on the supply side rather than the resource side. Offering additional services, creating noticeable quality differences, and establishing a "brand experience" are examples of differentiation strategies. The uniqueness of its product protects a company from competitive forces and can increase profitability.

23.5.2.3 Low Cost and Differentiation Focus Strategies

The two focus strategies, which are also called *niche strategies*, follow the competitive advantages of cost leadership and differentiation. The difference, however, is that the company then only addresses a certain segment of the market. Focus strategies are based on the assumption that a very narrow strategic focus leads to advantages over competitors within a given niche. Cost leadership and uniqueness can be achieved more efficiently in a small market segment than in the entire market (Porter 2013, pp. 77–79, Porter 2014).

23.5.2.4 "Stuck in the Middle"

Another scenario by Porter is called "stuck in the middle". This occurs when a company does not succeed in focussing on only one of the discussed strategies, but is virtually stuck between the two. The company then has no competitive advantages and will have under-average performance over the long term because other companies striving to achieve cost leadership, differentiation or focus will achieve a better competitive position in each segment. The way out of this situation is for the company to make a conscious decision for one of these strategies (Porter 1999, p. 44).

23.6 Integrated Care as a Quality Improvement Strategy

It should be emphasized that integrated care is a means to an end, not an end in itself. It serves merely as a strategy aimed at providing better services for patients and populations. The aim of integrated care is to improve quality, not to reduce costs. As illustrated throughout this book, an integrated care strategy may be implemented on different levels, but in order to be sustainable and effective, it must permeate all tiers of the healthcare value chain—from the system level to the individual level. When healthcare managers accept these basic principles, they can learn a lot from classic management literature and practical experience in other sectors (Perri et al. 2006).

The management side of health care has long been neglected because many care providers consider it to be a necessary part of business, but not of health care. However, due to the manifold and often stated challenges of the twenty-first century and the slow speed of development new forms of care delivery, such as integrated care, the need for more strategic thinking, planning, management and implementation approaches has become evident. As described in this chapter, strategic management requires not only a clear vision and common goals shared by all stakeholders involved, but also a thorough understanding of one's partners, providers and "clients", i.e. patients. This is essential for implementing changes in the process of transitioning to integrated care as well as for realizing sustainable integrated care solutions. The following chapters will go more into detail on these and other key elements of integrated care design, implementation and management.

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Part III
Tools and Instruments

Disease Management

24

Ellen Nolte

24.1 Introduction

Structured disease management has been suggested as a potential means to improve the quality and reduce the cost of health care, and to enhance health outcomes for people with chronic conditions. Health professionals, policymakers and institutions in many countries in Europe and elsewhere have begun introducing some form of disease management programme and similar approaches in order to address the rising burden of chronic disease. However, attempts to do so have varied and the nature and scope of programmes and care models differ (Nolte et al. 2008, 2014). Some, such as Germany and the Netherlands, along with Denmark, France and Italy, have introduced large-scale, population-based structured disease management programmes while others are experimenting with smaller-scale care approaches, although this is changing (Nolte and Knai 2015).

As approaches to chronic disease management vary, so does the evidence about their effectiveness, about the value of different approaches, and about what works in what contexts and for what populations (Nolte and McKee 2008a). It has been noted that this is in part because of the variety of terms and concepts that are used to describe efforts to improve chronic illness care and its components. Coleman et al. (2009) have further highlighted the relative lack of scientific rigour in evaluating these approaches and the reporting of the results of such interventions, which tend to be complex in nature and scope, with several interrelated components often acting at different levels of service delivery (Craig et al. 2008).

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In this chapter, we explore the nature of disease management as a tool or strategy for integrated care. We examine the evidence base for disease management and identify requirements for advancing the debate, building on and updating our earlier work around chronic disease management and integrated care (Nolte and McKee 2008b; Nolte and Pitchforth 2014). We close with some overarching observations.

24.2 What is Disease Management?

One of the key challenges to describing disease management as a strategy is that definitions of this concept vary widely (Krumholz et al. 2006; Schrijvers 2009). Disease management, by definition, traditionally targets patient groups with a specific condition, such as diabetes, and focuses on addressing the clinical needs of those affected (Nolte and McKee 2008b). However, more recent definitions are explicitly adopting a population-based approach that may also consider the needs that arise from multiple chronic conditions (Care Continuum Alliance 2010).

Disease management was first mentioned as a concept in the USA in the 1980s. It was initially used mainly by pharmaceutical companies offering educational programmes to employers and managed care organisations to promote medication adherence and behaviour change among people with chronic conditions such as diabetes, asthma and coronary artery disease (Bodenheimer 1999; The Boston Consulting Group 2006). From the mid-1990s, disease management strategies were adopted more widely across the private and public sectors in the USA (Krumholz et al. 2006), and, subsequently, in several European countries (Nolte and Knai 2015; Rijken et al. 2012), Australia (Glasgow et al. 2008; Hamar et al. 2015), Israel (Goldfracht et al. 2011) and Singapore (Tan et al. 2014), among others. This occurred in parallel with an emerging body of evidence, which pointed to the potential for disease management to improve care quality and lead to cost savings.

However, approaches vary widely in focus, nature and scope of interventions, and populations covered. For example, in the USA, descriptions range from ‘discrete programs directed at reducing costs and improving outcomes for patients with particular conditions’ (Rothman & Wagner 2003, p. 257) to ‘a population-based systematic approach that identifies persons at risk, intervenes, measures the outcomes, and provides continuous quality improvement’ (Epstein & Sherwood 1996, p. 832). Ellrodt et al. (1997, p. 1687) defined disease management as ‘an approach to patient care that coordinates medical resources for patients across the entire delivery system’. The Population Health Alliance (previously Care Continuum Alliance and, before that, Disease Management Association of America) defined disease management as ‘a system of coordinated health care interventions and communications for populations with conditions in which patient self-care efforts are significant’ (Care Continuum Alliance 2010, p. 55). The definition provided by the Population Health Alliance further stipulates for full-service disease management programmes to include six components: population identification processes; evidence-based practice guidelines; collaborative practice models to include physician and support-service providers; patient self-management education; process and outcomes measurement, evaluation, and management; and routine reporting or feedback loop. Approaches that use fewer than these six components are to be considered disease management support services only.

Although authors have increasingly adopted the definition proposed by the Population Health Alliance, variation in what is referred to as disease management has remained (Coelho et al. 2014; Coleman et al. 2009; Lemmens et al. 2009; Martinez-Gonzalez et al. 2014; Peytremann-Bridevaux et al. 2015; Pimouguet et al. 2011). Norris et al. (2003) observed that programmes tend to vary 'in breadth, in focus or purpose … [they] may also vary with the writer's perspective (economic, research, clinical) and the delivery system to which the term is being applied (e.g. primary care, specialty-based services contracted to another delivery system, pharmacy services)' (pp. 478–479). This appears to have changed little since Norris and colleagues published their observations in 2003, as we shall see below. While variation may be necessary to focus a given programme to the needs of a given population, it poses challenges for comparison and the assessment of effect in particular. Furthermore, in many settings, the focus continues to be on single diseases, albeit with some adjustment to consider comorbidity (Fullerton et al. 2011), and there remain concerns overall about the suitability of current approaches to disease management to address the complex needs of those with multiple disease processes (Aspin et al. 2010; Nolte et al. 2012a; Rijken et al. 2012).

24.3 What are the Impacts of Disease Management?

As noted in the introduction to this chapter, structured disease management has been proposed as a means to improve the quality and reduce the cost of health care, and ultimately improve health outcomes for the chronically ill. However, the evidence on the ability of such approaches to achieve this varies by type of approach and target group. What is known is mainly based on small studies of high-risk patients, often undertaken in academic settings (Mattke et al. 2007). Evidence of the impact of large-scale, population-wide programmes is slowly becoming available, such as from Australia (Hamar et al. 2015), Denmark (Smidth et al. 2013), Germany (Fuchs et al. 2014; Jacob et al. 2015; Mehring et al. 2014) and the Netherlands (de Bakker et al. 2013; Elissen et al. 2012; Tsiachristas et al. 2015).

There is now a wide range of systematic reviews, reviews of reviews and meta-analyses of the evidence on (chronic disease)-specific interventions and disease management programmes. However, reflecting the variation in the interpretation and use of the term 'disease management', it remains challenging to arrive at an overarching conclusion. This is particularly the case where terms such as disease management are being used interchangeably with 'collaborative care', 'case management', or, indeed, 'integrated care', reflecting the challenges that have been discussed in the context of assessing the evidence base for the impacts of integrated care, as reported in Chap. 3. For example, Ouwens et al. (2005) presented a review of systematic reviews of approaches seeking to improve the care for people with chronic conditions. While broadly referring to 'integrated care' programmes, of the 13 systematic reviews considered, 8 were reviews of disease management interventions, each employing a distinct definition of disease management. The remainder reviewed some form of care or case management (two reviews), multidisciplinary teams/structures (two), and more generally management of patients with chronic health problems (one). Similarly, Martinez-Gonzalez et al. (2014) provided a meta-review of integrated care programmes for adults with chronic conditions, of which the majority reported on disease management interventions.

As we noted elsewhere in this book (see Chap. 3), this issue is not only of academic relevance but has important implications for practice. Empirical evidence of approaches that can be subsumed under the above terms is often difficult to compare because of a lack of clarity in defining and describing the approach being studied. This challenge was also highlighted by Ouwens et al. (2005). They concluded, on the basis of their review of reviews, although there was considerable heterogeneity in interventions, patient populations, and processes and outcomes of care, programmes under review appeared to have led to improvements in the quality of care. Yet, they noted that the variation in definitions and components of care, and failure to recognise these variations, could lead to inappropriate conclusions about programme effectiveness and the application of findings in practice.

Building on the work by Ouwens et al. (2005), this section updates and amends an earlier rapid review of the evidence base for chronic disease management (Nolte and Pitchforth 2014). Our earlier work assessed the evidence identified in 15 systematic reviews and meta-analyses that were published between 2004 and 2012. We complemented these with an additional eight systematic reviews, which we identified from a separate search of PubMed (NCBI 2016) carried out to inform Chap. 3. The review presented here is not intended to be exhaustive. Instead, we sought to provide an overview of the nature of evidence that has been published since the work by Ouwens et al. (2005) and to examine the extent to which recent evidence has provided more certainty around the impacts of disease management on service and health outcomes, and the implications of these findings in the context of integrated care. Table 24.1 provides a summary overview of the main observations of the 23 systematic reviews considered here.

Conditions most frequently considered in reviews were heart failure (Drewes et al. 2012; Gonseth et al. 2004; Roccaforte et al. 2005, 2006; Takeda et al. 2012; Whellan et al. 2005; Yu et al. 2006), diabetes (Egginton et al. 2012; Elissen et al. 2013a; Knight et al. 2005; Pimouguet et al. 2011), asthma or chronic obstructive pulmonary disease (COPD) (Adams et al. 2007; Boland et al. 2013; Kruis et al. 2013; Lemmens et al. 2011; Niesink et al. 2007; Peytremann-Bridevaux et al. 2008, 2015), depression (Archer et al. 2012; Ekers et al. 2013; Neumeyer-Gromen et al. 2004; Thota et al. 2012), or a combination of these (de Bruin et al. 2011; Ofman et al. 2004; Tsai et al. 2005). Definitions of disease management varied among studies, although all adopted a fairly comprehensive conceptualisation. Earlier

Table 24.1 Evidence of effect of disease management programmes as reported in 23 systematic reviews

	Number studies reviewed	Condition/s targeted	Definition disease management	Functional status, clinical outcomes	Hospitalisation	Quality of life	Patient satisfaction	Mortality	Process	Cost
Chronic heart failure										
Gonseth et al. (2004)	54 studies: 27 RCT, 27 non-RCT	Heart failure (ages 65+)	An intervention designed to manage heart failure and reduce hospital readmissions using a systematic approach to care and potentially employing multiple treatment modalities (adapted from Weingarten et al. (2002), who used the definition by Ellrodt et al. (1997))		⇓					(⇓)
Roccaforte et al. (2005)	33 RCT	Heart failure	None specified; description of DMP characteristics of included studies: multidisciplinary approach, use of specialist nurse or case manager, (patient) education, planned home/outpatient clinic visits, regular phone contacts		⇓	?		⇓	+	
Whellan et al. (2005)	19 RCT	Heart failure	None specified; focus on postdischarge interventions		⇓			(⇓)		(⇓)
Göhler et al. (2006)	36 RCT	Heart failure	None specified; considered interventions ranging from patient education on self-monitoring and knowledge of disease to		⇓			⇓		

(continued)

Table 24.1 (continued)

	Number studies reviewed	Condition/s targeted	Definition disease management	Functional status, clinical outcomes	Hospitalisation	Quality of life	Patient satisfaction	Mortality	Process	Cost
			electronic home monitoring; all had to have scheduled interventions after discharge							
Yu et al. (2006)	21 RCT	Heart failure (ages 60+)	A programme that uses multiple interventions in a systematic manner to manage heart failure across different healthcare delivery systems (adapted from Ellrodt et al. (1997) and Weingarten et al. (2002))		⇓	(+)		(⇓)		(⇓)
Drewes et al. (2012)	46 studies: 32 RCT, 4 CT, 9 before/after, 1 chart review §	Heart failure (adults)	Interventions that contained 2 or more elements of the Chronic Care Model (healthcare system, community resources and policies, self-management support, delivery system design, decision support, clinical information system) (Wagner 1998)		⇓	+		⇓		
Takeda et al. (2012)	25 RCT (of which 2 represented disease management)	Heart failure (adults)	Used broad conceptualisation of 'clinical services interventions', which included case management, clinic models and multidisciplinary interventions, including		⇓**	(+)*		(⇓)*		

(continued)

Table 24.1 (continued)

	Number studies reviewed	Condition/s targeted	Definition disease management	Functional status, clinical outcomes	Hospitalisation	Quality of life	Patient satisfaction	Mortality	Process	Cost
			disease management, which was defined as ‘a system of coordinated healthcare interventions and communications for populations with long-term conditions in which patient self-care is significant’ (adapted from Royal College of Physicians (2004))							
Diabetes										
Knight et al. (2005)	24: 19 RCT; 5 non-RCT	Diabetes (adult patients)	Programmes that use a systematic approach to care and include more than 1 intervention component. A systematic approach to care was defined as inclusion of any of the following components: guidelines, protocols, algorithms, care plans, or systematic patient or provider education programmes	+ / (+)	(⇓)	(+)	(+)		(+)	
Pimouguet et al. (2011)	41 RCT	Diabetes type 1 or type 2	Ongoing and proactive follow-up of patients that includes at least 2 of 5 components: patient education; coaching;	+				=		

(continued)

Table 24.1 (continued)

	Number studies reviewed	Condition/s targeted	Definition disease management	Functional status, clinical outcomes	Hospitalisation	Quality of life	Patient satisfaction	Mortality	Process	Cost
			treatment adjustment; monitoring; care coordination							
Egginton et al. (2012)	52 studies: 45 RCT, 7 non-RCT	Diabetes type 2	Not defined; uses the term ‘care management’, distinguished delivery mode (office (interaction or chart review in outpatient setting), web (interaction using computer/Internet) and telephone (interaction using telephone/pager)) and leader type (physician, other (e.g. multidisciplinary team, nurse))	+		(+)			(+)	?
Elissen et al. (2013a)	61 studies: 41 RCT, 6 CT, 4 before/after, 10 observational studies §	Diabetes mellitus (adult patients)	Interventions that included at least 2 components of the Chronic Care Model (Wagner 1998)	+					+	
Asthma and/or chronic obstructive pulmonary disease (COPD)										
Lemmens et al. (2009)	36 studies: 28 RCT, 8 controlled before/after	Asthma or COPD (adults aged 16+)	Multiple interventions in the context of disease management targeting the patient (e.g. patient education, self-management support), professional practice (e.g. professional education, audit, feedback)	=	⇓	+	(+)		(+)	

(continued)

Table 24.1 (continued)

	Number studies reviewed	Condition/s targeted	Definition disease management	Functional status, clinical outcomes	Hospitalisation	Quality of life	Patient satisfaction	Mortality	Process	Cost
			or organisational structure (e.g. role redesign, follow-up)							
Peytremann-Bridevaux et al. (2015)	20 RCT	Asthma (adults aged 16+)	Interventions that met five criteria: at least one organisational component (i.e. elements that interfere with the care process or that aim to improve continuity of care) targeting patients; at least one organisational component targeting healthcare professionals (e.g. physicians, nurses, etc.), the healthcare system, or both; presence of a patient education or self-management support component, or both; active involvement of two or more healthcare professionals; and minimum duration of three months	+/(+)	?	+				
Adams et al. (2007)	32 studies: 20 RCT; 5 CT; 7 before/after	COPD	Interventions that contained at least 1 element of the Chronic Care Model (self-management support, delivery system design,	+/(+)	⇓	?		=		(⇓)

(continued)

Table 24.1 (continued)

	Number studies reviewed	Condition/s targeted	Definition disease management	Functional status, clinical outcomes	Hospitalisation	Quality of life	Patient satisfaction	Mortality	Process	Cost
			decision support, clinical information system) (Wagner 1998)							
Niesink et al. (2007)	10 RCT	COPD	Programmes that contained at least one of the following components: (1) multidisciplinary care team, (2) clinical pathway, (3) clinical follow-up, (4) case management, or (5) self-management or patient education	(+)		(+)				
Peytremann-Bridevaux et al. (2008)	13 studies: 9 RCT; 1 CT; 3 before/after	COPD	Interventions included 2 or more different components (e.g. physical exercise, self-management, structured follow-up), active involvement of 2 or more health care professionals in patient care; consideration of patient education; at least 1 component of the intervention lasted a minimum of 12 months	+/(+)	⇓	(+)		=		
Boland et al. (2013)	11 studies: 7 RCT, 2 before/after, 2 case–control	COPD	Interventions that contained 2 or more elements of the Chronic Care Model (Wagner et al. 2001):		⇓	+		⇓		⇓

(continued)

Table 24.1 (continued)

	Number studies reviewed	Condition/s targeted	Definition disease management	Functional status, clinical outcomes	Hospitalisation	Quality of life	Patient satisfaction	Mortality	Process	Cost
			organisational support, community resources and policies, self-management support, delivery system design, decision support, clinical information system; programme had minimum duration of 12 months							
Kruis et al. (2013)	26 RCT	COPD	Integrated disease management intervention which includes at least 2 of the following components: Education/self-management; exercise; psychosocial; smoking cessation; medication; nutrition; follow-up and/or communication; multidisciplinary team; financial intervention, and which includes active involvement of at least two different categories of healthcare providers; minimum duration of three months	+/(+)	⇓	+/(+)	*n/r*	=	*n/r*	*n/r*

(continued)

Table 24.1 (continued)

	Number studies reviewed	Condition/s targeted	Definition disease management	Functional status, clinical outcomes	Hospitalisation	Quality of life	Patient satisfaction	Mortality	Process	Cost
Depression										
Neymeyer-Gromen et al. (2004)	10 RCT	Depression (adults aged 18 +)	'Complete DMP' comprising use of evidence-based guidelines, patient self-management education, provider education, collaborative care, reminder systems, monitoring (*detailed definition not provided, inferred from the text*)	+		+	+		+	?
Archer et al. (2012)	79 RCT	Depression or anxiety (any age)	Collaborative care intervention that included (i) multi-professional approach to patient care, (ii) structured management plan, (iii) scheduled patient follow-up, and (iv) enhanced interprofessional communication	+ (adults)		+ (adults)	+ (adults)		+ (adults)	
Thota et al. (2012)	32 studies: 28 RCT, 5 quasi-experimental	Major depression, minor depression, dysthymia	Collaborative care intervention that included at least a case manager, primary care provider, and mental health specialist with collaboration among these roles	+		+	+		+	

(continued)

Table 24.1 (continued)

	Number studies reviewed	Condition/s targeted	Definition disease management	Functional status, clinical outcomes	Hospitalisation	Quality of life	Patient satisfaction	Mortality	Process	Cost
Ekers et al. (2013)	14 RCT	Depression plus one or more physical health problems (adults aged 16+)	Nurse-delivered collaborative care with at least two of the following components: proactive follow-up of participants, assessment of patient adherence to psychological and pharmacological treatments, monitoring of patient progress using validated measure, provision of psychological support, regular communication and supervision with mental health specialists and/or primary care physician	+						
Combined										
Ofman et al. (2004) ¥	102 experimental or quasi-experimental	Asthma (9 studies), back pain (6), COPD (6), chronic pain (2), heart failure (9), coronary artery disease (6), depression (20), diabetes (22), hyperlipidaemia (6), hypertension (7), rheumatoid arthritis (9)	An intervention designed to manage or prevent a chronic disease using a systematic approach to care and potentially employing multiple treatment modalities (adapted from Ellrodt et al. (1997))	+/(+)	(⇓)	(+)	+	(⇓)	+/(+)	(⇓)

(continued)

Table 24.1 (continued)

	Number studies reviewed	Condition/s targeted	Definition disease management	Functional status, clinical outcomes	Hospitalisation	Quality of life	Patient satisfaction	Mortality	Process	Cost
Tsai et al. (2005)	112 randomised and nonrandomised trials	Asthma (27 studies), chronic heart failure (21), depression (33), diabetes (31)	Interventions that included at least one of the 6 elements deemed to be essential for providing high-quality care to patients with chronic illnesses: delivery system design, self-management support, decision support, clinical information systems, community resources, and healthcare organisation (adapted from Wagner et al. (1999))	**+**		+/(+)			+/(+)	
De Bruin et al. (2011)	31 studies: 18 RCT, 3 quasi-experimental, 3 cross-sectional, 2 descriptive, 2 before/after, 2 prospective observational, 1 longitudinal analysis of paid claims	Diabetes (14 studies), depression (4), heart failure (8), COPD (5)	Interventions that contained 2 or more elements of the Chronic Care Model (healthcare system, community resources and policies, self-management support, delivery system design, decision support, clinical information system) (Wagner 1998)							(⇓)

Note Symbols in bold indicate a significant finding: **⇓**, significant reduction in more than half of studies reviewed or as demonstrated in meta-analysis; (⇓) some evidence of reduction; **+** significant improvement in more than half of studies reviewed or as demonstrated in meta-analysis; (+) some evidence of improvement; + /(+) significant improvement in some outcomes; = no significant change in outcome concerned;? evidence inconclusive

*Considered two RCTs of disease management only

§ Study also reviewed 15 systematic reviews which were not included in the meta-analysis

¥ Assessed percentage of statistically significant comparisons per outcome (number of statistically significant comparisons for selected outcomes favouring treatment/total number of comparisons) studies tended to draw on the definition by Ellrodt et al. (1997), which we described earlier in this chapter as 'an approach to patient care that coordinates medical resources for patients across the entire delivery system' (p. 1687), while more recent reviews built on the Chronic Care Model (CCM) proposed by Wagner (1998), which considers six elements as essential for improving chronic illness care. Several reviews analysed primary studies that included a minimum of two discrete interventions considered beneficial for chronic illness care, such as patient self-management, provider feedback, structured follow-up, or role re-design (Boland et al. 2013; de Bruin et al. 2011; Drewes et al. 2012; Knight et al. 2005; Kruis et al. 2013; Lemmens et al. 2009; Peytremann-Bridevaux et al. 2008, 2015) or a variation of this conceptualisation (Egginton et al. 2012; Göhler et al. 2006; Gonseth et al. 2004; Neumeyer-Gromen et al. 2004; Roccaforte et al. 2005; Tsai et al. 2005). Three reviews focusing on depression explicitly used the concept of 'collaborative care', considered to include a multiprofessional approach to patient care and care or case management (Archer et al. 2012; Ekers et al. 2013; Thota et al. 2012). Typically, at least half of primary studies covered by reviews were set in the USA, followed by Australia, the UK, Canada, Sweden and the Netherlands. Two reviews focused on studies set in the USA only (Egginton et al. 2012; Neumeyer-Gromen et al. 2004).

Studies reported on a diverse set of outcomes, reflecting the condition being targeted. In brief, available reviews provided fairly consistent evidence of a positive impact of disease management interventions targeting those with depression. For example, a meta-analysis of 102 experimental or quasi-experimental studies targeting 11 conditions by Ofman et al. (2004) found that disease management interventions for those with depression had the highest proportion of studies demonstrating substantial improvements in patient care (48% statistically significant), which was supported by evidence of significant improvements of disease management programmes for depression severity (Neumeyer-Gromen et al. 2004). Subsequent reviews focused on the impacts of disease management conceptualised as 'collaborative care', and these demonstrated significant improvements in depression symptoms, patient adherence to treatment, response to treatment and satisfaction with care, among other outcomes (Archer et al. 2012; Ekers et al. 2013; Neumeyer-Gromen et al. 2004; Thota et al. 2012).

A similar consistency was found for disease management interventions targeting heart failure. These showed, for example, statistically significant reductions in the frequency of disease-specific and all-cause hospitalisations of at least 15% up to 30% and more (Drewes et al. 2012; Gonseth et al. 2004; Roccaforte et al. 2005; Whellan et al. 2005; Yu et al. 2006), with a significant reduction in all-cause mortality demonstrated in three of the seven reviews considered (Drewes et al. 2012; Göhler et al. 2006; Roccaforte et al. 2005). A 2012 meta-review of meta-analyses of heart failure disease management programmes noted that out of a total 13 reviews that reported on all-cause mortality, 6 had identified statistically significant improvements, with effect sizes varying from 3 to 25%, mostly clustering around 15–20% (Savard et al. 2011). Drewes et al. (2012) highlighted the substantial heterogeneity among findings of primary studies included in their review, which they were unable to explain by the quality of studies, the length of follow-up, or the number of components considered beneficial in chronic care. Two reviews reported evidence that programmes which had incorporated a multidisciplinary team approach had a stronger impact on outcome measures (Göhler et al. 2006; Roccaforte et al. 2005).

Evidence for the impact of disease management on diabetes also tended to show beneficial effects overall, with significantly improved glycaemic control among diabetes disease management populations compared to usual care, along with improvements in the quality of care as measured through, for example, adherence to treatment guidelines (Elissen et al. 2013a; Knight et al. 2005; Pimouguet et al. 2011). The overall clinical significance of observed improvements in glycaemic control remains uncertain, although there was evidence that disease management may be more effective for patients with poor control (Pimouguet et al. 2011). Elissen et al. (2013a) noted that the most promising results were attained in studies with limited follow-up (<1 year) and by programmes that included more than two chronic care components. The review by Knight et al. (2005) further showed that observed effects were larger for studies conducted in the USA, although the number of trials outside the USA considered in their review was small. Overall there was considerable variation across studies included in individual reviews in terms of intervention delivery methods, duration and populations covered, leading Egginton et al. (2012) to conclude that findings from their review would not allow for recommendations for a particular type of intervention to be more effective than another one.

Such variation was also observed in studies that examined the evidence base for disease management targeted at people with asthma or COPD. Among these, there was consistent evidence of significantly reduced hospitalisations among those receiving disease management for COPD (Adams et al. 2007; Boland et al. 2013; Lemmens et al. 2009; Peytremann-Bridevaux et al. 2008), and, possibly, asthma (Lemmens et al. 2009). There was evidence that patients who received three or more chronic care interventions in disease management programmes for COPD had lower rates of hospitalisations (Boland et al. 2013). Impacts on health outcomes were mixed across reviews, with evidence of significant improvements in some outcomes, such as exercise capacity in COPD patients (Peytremann-Bridevaux et al. 2008), and measures of quality of life among patients with asthma (Lemmens et al. 2009; Pimouguet et al. 2011) or with COPD (Boland et al. 2013; Niesink et al. 2007; Peytremann-Bridevaux et al. 2008). Evidence of impact on mortality was more difficult to interpret. For example, Peytremann-Bridevaux et al. (2008) estimated, on the basis of ten studies, a trend for reduced mortality, while Boland et al. (2013), based on the findings of six primary studies, found a small but significant reduction in all-cause mortality (0.70, 95% CI 0.51–0.97). However, similar to reviews of disease management targeting diabetes or heart failure, findings of primary studies included in reviews of COPD interventions were heterogeneous, varying by study-, intervention- and disease-characteristics, and it remains unclear which specific components of interventions have the greatest benefit.

Few studies explicitly considered costs, and where they did, the evidence tended to be inconsistent (Egginton et al. 2012; Neumeyer-Gromen et al. 2004; Ofman et al. 2004). De Bruin et al. (2011) reviewed the impact of disease management programmes on healthcare expenditures for patients with diabetes, depression, heart failure or COPD. Of 31 studies reviewed, 21 reported incremental healthcare costs per patient per year, and of these, 13 demonstrated evidence of cost savings but observed effects were typically not statistically significant or not tested for statistical significance. Conversely, Boland et al. (2013), in a review of the economic impact of disease management programmes targeting COPD specifically, found these to lead to hospitalisation savings of 1060 € (95% CI: 80–2040 €) per patient per year and savings in total healthcare utilisation of 898 € (95% CI: 231–1566 €). The review further demonstrated indicative evidence that COPD disease management led to greater savings in studies of patients with severe COPD or those with a history of exacerbations. However, heterogeneity of studies included in either review remains a considerable challenge, with variation in the intervention (content and type) and study design. De Bruin et al. (2011) highlighted variation in the economic evaluative approach chosen, the type of direct health care costs and cost categories considered, alongside lack of reporting on reliability of estimates as a particular challenge to deriving comparative estimates. This highlights the need for higher-quality studies.

24.4 Interpreting the Existing Evidence Base

The interpretation of evaluation findings such as those presented here will have to be placed in the context of programme implementation specifically and issues around evaluation more broadly (Nolte et al. 2012b). For example, where an evaluation finds improvements in process indicators (suggesting improved quality of care) but not in outcomes, this might be because the length of evaluation was not sufficient to demonstrate health improvements. Likewise, an evaluation might find that a given intervention improved outcomes for a subgroup of participants only; this might indicate that the intervention was suboptimal or not sufficiently targeted at those who would benefit most. Also, intervention effect will differ by disease type.

This is reflected in the overarching findings of our review. We found fairly consistent evidence that disease management can have beneficial impacts on outcomes for those with depression, in terms of both disease severity and treatment response. Similarly, for those with heart failure, existing evidence points to beneficial effects of disease management on measures of utilisation (reduced hospital use) and outcomes (reduced mortality). Evidence of the impact of disease management on diabetes outcomes remains less certain, however. While some interventions are frequently found to have statistically significant impacts on glycaemic control, which typically forms the primary outcome, the clinical importance of observed reductions remains questionable. Likewise, for COPD, the impact of disease management on outcomes tends to be less consistent, with the possible exception of exercise capacity and quality of life. However, available evidence does consistently demonstrate reduced hospitalisation, which has been shown to lead to actual savings in one review (Boland et al. 2013).

The majority of studies reviewed here echo the concerns reported by Ouwens et al. (2005), confirmed by a recent review of the same topic (Martinez-Gonzalez et al. 2014). Thus, it remains challenging to interpret the evidence from existing primary studies, which tend to be characterised by heterogeneity in the definition and description of the intervention and components of care under study. In this respect, the conclusions by Ouwens et al. (2005) still seem to hold, namely that variation in definitions and components of care, and failure to recognise these variations, might lead to inappropriate conclusions about programme effectiveness and the application of findings. While this further underlines the continued need for the use of consistent definitions and of better description of the content of interventions to enable comparison, evidence presented here does allow for some observations suitable to inform the further development of approaches to more effectively address chronic conditions.

Thus, available evidence points to the value of multifaceted approaches to enhance outcomes of those with chronic disease. For example, reviews that examined the impact of different care components highlighted an association between the format or ‘modality’ of the intervention and reported outcomes (Elissen et al. 2013a; Göhler et al. 2006; Roccaforte et al. 2005). Evidence from collaborative care models for the management of depressive disorders suggests that interventions were more effective when based in the community or that involved nurses as case managers (Thota et al. 2012). Further, Ekers et al. (2013) found that nurse-delivered treatment based on a collaborative care approach was effective in the treatment of depression in patients who also had at least one physical health problem, such as arthritis, cancer, coronary heart disease or stroke. Similarly, for persons with heart failure, the impact on outcomes was found to be stronger for those interventions that incorporated a multidisciplinary team approach (Göhler et al. 2006; Roccaforte et al. 2005), while disease management interventions that had a multimodal format according to the Chronic Care Model resulted in lower hospitalisation rates among patients with COPD compared with control groups (Adams et al. 2007; Boland et al. 2013), which in turn was linked to cost savings (Boland et al. 2013).

Other evidence points to the need to develop approaches that more specifically target those who are most likely to benefit. For example, Pimouguet et al. (2011) showed how diabetes disease management may be more effective for patients with poor glycaemic control. Similar findings were reported for a large population-based diabetes care intervention in the Netherlands (Elissen et al. 2012), although requiring further confirmation (Elissen et al. 2013b).

It is notable that in selected studies reviewed here the reported evidence tended to be stronger for primary studies undertaken in the USA compared to elsewhere. This was the case for disease management for diabetes (Knight et al. 2005) and collaborative care programmes for depression (Ekers et al. 2013). Given that much of the available evidence tends to originate from the USA, these findings highlight a need for caution when considering transferring models across countries with different health systems, and for developing a more robust evidence base to demonstrate that relevant models are effective outside the US context (Nolte and McKee 2008b; Ekers et al. 2013).

24.5 Conclusions

This chapter has reviewed the recent evidence base on the effectiveness of disease management strategies and programmes. We show that, overall, disease management holds promise to improve processes and outcomes of care but evidence that is available tends to be limited to a small set of conditions only. Arguably, by restricting the review reported here on published systematic reviews we will have missed more recent evidence from primary studies that have investigated the impact of disease management on a broader range of conditions.

There is emerging evidence that provides important insights into how disease management approaches that employ a multifaceted strategy and target those most likely to benefit are more likely to enhance outcomes of those with chronic disease. However, one fundamental issue remains, which is related to the need to develop a system-wide model of care for patients with chronic disease. Disease-specific approaches such as disease management programmes are ill-suited to meet the needs of the typical patient in primary care who frequently has multiple health problems with complex needs (Nolte and McKee 2008b). The rapid rise of those with multiple care needs is of particular concern to all health systems. The nature of multiple chronic conditions creates a challenging spectrum of health care needs in itself, with further complexity added to in cases of increasing frailty at old age in particular, involving physical, developmental, or cognitive disabilities. This complexity of health and care needs requires the development of delivery systems that bring together a range of professionals and skills from both the cure (healthcare) and care (long-term and social care) sectors (Nolte and McKee 2008a). More generalist approaches such as integrated care models that are being implemented in a range of European countries and elsewhere are potentially better equipped to respond to more complex patient needs, while disease management can form an important instrument within integrated care strategies. There remains a need for more systematic evaluation of new models of care as a means to inform the development of efficient and effective interventions to address the growing burden of chronic conditions globally.

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Case Managers and Integrated Care

25

Guus Schrijvers and Dominique Somme

This chapter on case management starts with a case story about Julia, a person with dementia, and her case manager, John (Sect. 25.1). It shows six innovations which are necessary to introduce case managers. Julia and John live in the year 2025, in a rich western country with a health system that supports integrated care by means of adequate financing and digitalization of care. Section 25.2 introduces a definition of the concept of case management and discusses important terms in it. Then (Sect. 25.3), two specific competences of case managers are discussed: (1) the assessments of care and social needs and (2) empowering interviewing of clients. The chapter continues (Sect. 25.4) with the comparison of the "ideal world" in the case story in 2025 with the real world in 2015 by focusing on case management practices in the Netherlands and France. The chapter ends (Sect. 25.5) by offering theories to support the implementation of the case manager. The chapter emphasizes that case managers not only are for clients with dementia but are relevant as an approach to support other people with health, educational and financial problems; clients with developmental disorders; patients with severe mental illness; patients with cancer and metastases; and persons with more than one chronic condition. In this chapter, the words clients, patients and persons are used as synonyms occurring in different care contexts.

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25.1 The Story of Julia and John in 2025

In the story below, an added asterix means: This kind of services generally does not exist in 2016, neither in the Netherlands nor in France. However, they exist in small innovative, experimental projects. They are necessary for an implementation of case managers in the year 2025. They are summarized (Box 25.2) and discussed in Sect. 25.4.

It is 2025. Julia is 84 years old. She lives with her husband Peter, also 84, in a small old apartment in a lower middle class neighbourhood in a city. They own this apartment, which is mortgage-free. In previous years she was a school teacher. Peter was a machine operator. Several years earlier, he had a foot amputated after an accident and now he is in constant pain. The couple has a modest pension. They have one son, living with his family 20 km away.

Julia suffers from dementia, periodical heart rhythm disorder and chronic itch. If an itch attack occurs, she does not stop scratching. She is not able to do her skin care by herself. She takes five different medications, three times each day. Julia cannot be alone and must always be supervised. Peter is somewhat healthy, except for the pain, but frail. He is unable to supervise his wife 24 h a day. Much of their health care is provided by non-profit care providers and financed by their social insurance companies and the municipality where they live. However, the insurance and municipal payment for the services is not enough. Julia and Peter pay hundreds of euros per month out of pocket.

John, a case manager, came into the picture a year ago after Julia fell in her home; she tripped over a small table in the living room and hurt herself. Julia's general practitioner Carla was called and did a home visit. She introduced Julia and Peter to John. He is a nurse specialist with an academic background specializing in care for persons with dementia*. He works for the group practice in which Carla is one of the five GP's*. After being introduced, John did a couple of things. He introduced himself as the first contact person and care coordinator for Julia. He left his business card under a magnetic button on the fridge door. Then he did a care assessment of both Julia and Peter. Peter, Julia and John made a live/care plan for the next 6 months*.*

Later, John organized a "non-professional potential caregivers conference," to which he and Peter invited members of the family, neighbours, friends and old colleagues. They were asked to be a buddy for Julia and Peter and to offer respite care (to relieve Peter), transportation services, technical help and social support for Julia and Peter. Because this conference did not yield enough buddies, John mobilized voluntary organisations to send volunteers a couple of mornings and afternoons during the week. He also asked the local pharmacist to review Julia's medication* and to introduce some technical devices to improve Julia's medication therapy adherence. John also involved the fall prevention service from the department of geriatrics at the local hospital*. They sent a nurse, advised the couple to take some vitamins and inspected the apartment. She further advised them to remove small tables and to install a stair lift and extra railings in the bathrooms,* *toilet and hallway. Peter and Julia complied, although they had to pay the cost out of their own pocket. This meant that they had to take out a small mortgage on their apartment. John also found that Julia was undernourished because of dental complaints. She was reluctant to go for a consult but he convinced Julia to visit a local dentist, although that meant additional expenses.*

John also showed Peter and Julia how to use an Internet connected tablet PC to have contact with him, Carla, their son and other buddies. A simple screen with big buttons, a 2-h course and a helpdesk were enough to introduce the telecare. Peter and Julia bought a new Internet connected tablet PC and a better and faster modem. This was an option because in the last 10 years the bandwidth was much enlarged in the city where they live. Peter was less stressed with caregiving and John convinced him to ask Carla for a referral to a pain specialist.*

John was consulted during Julia's next heavy itch attack. He organized a short stay in an assisted living facility in the neighbourhood. There he visited Julia daily, sometimes accompanied by Carla, the GP. Care assistants helped Julia with bathing, skin care and clothing. John encouraged Peter to visit his wife daily. The short stay was partly paid from a personal budget from the insurance company*; Peter, being the mentor of Julia, could decide how to spend the funds.*

As Julia's dementia progressed, John arranged for Julia to sleep at the assisted living facility to give Peter a good night's rest. During the days, she was at her own apartment. After a year and a half, Julia died sitting in her chair with Peter nearby. After her death John visited Peter several times to provide comfort and to help him start a new life as a single person.*

25.2 The Definition of Case Manager

This section introduces a definition of case manager as used in the Netherlands and in France. The concepts used in the definition are explained in the order of their place in the definition. At the end of the section, broader definitions receive attention as well as the arguments why these are rejected. Box 25.1 shows the definition of a case manager.

Box 25.1 the Denition of a Case Manager

A case manager is a professional who:

1. *has regular contact with persons in complex situations*,*
2. *evaluates all of their care and social needs*,*
3. *cooperate with physicians and other professionals**
4. *makes a life/care plan* for the health and social domain,*
5. *organizes the formal and informal care* of the client*
6. *works within a program,**

7. *use all communication means including digital information and communication technology**
8. *works only for persons who are not able to organize their life/care plan and are without a sufficient network of relatives to assist with this.**

The words with an asterix are explained in Sect. 4.2.

This definition is based on definitions used in France[1] and in the Netherlands (Mahler et al. 2013). It is also in accordance with the definition of the Case Management Society of America (CMSA).[2] The definition is broad, as illustrated by the story of Julia and John. Case managers are involved in the health and social domain, in formal and informal care and in financial and non-financial affairs. Such a broad array of responsibilities for a case manager is rare at the present time.

25.2.1 Complex Situations

The first words with an asterix in the definition in Box 25.1 are *complex situations*. As a concept, complexity can be related to instability, unpredictably and intensity.[3] Persons in complex situations will probably experience some disruptions in the evolution of their situation (instability), some of which are not anticipated even by professionals (unpredictability), and the disruptions are frequently severe (intensity). Clinicians and case managers, even when they cannot say very clearly why a situation is complex, are often skilled in detecting complexity. Usually, a complex situation requires collaboration between clients, clinicians, case managers and informal carers to be properly handled. A difference has to be underlined between persons in complex situations and frail persons, for example, frail elderly, frail families and frail persons with severe mental illness. Frail persons have a high risk to become persons in a complex situation. However, they do not belong to that group. Case managers could work for frail persons without complex situations. This has the advantage that the relation between them and the client already exists. They are able to help with preventive measures such as mobilizing other relatives to extend the time during which the partner of the patient can provide care. They could inform clients about opportunities and the possible (dis)advantages of options and coach the clients in their choices. Nevertheless, extending the target population to

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[1] Décret n° 2011–1210, 29 Sept 2011, implementing the houses for autonomy and integrated care for people suffering from Alzheimer's disease and related disorder. Journal Officiel de la République Franc¸aise JORF n° 0227, p. 16,463, text 30 and Arrêté 16 Nov 2012, fixing the activities and skills repository for case managers in houses for autonomy and integrated care for people suffering from Alzheimer's disease and related disorder. Journal Officiel de la République Franc¸aise JORF n° 0271, p. 18,343, text 22.

[2] https://www.cmsa.org, consulted on September 29, 2015.

[3] A National Interprofessional Competency Framework Canadian Interprofessional Health Collaborative, Fev 2010. See: https://www.cihc.ca/files/CIHC_IPCompetencies_Feb1210.pdf.

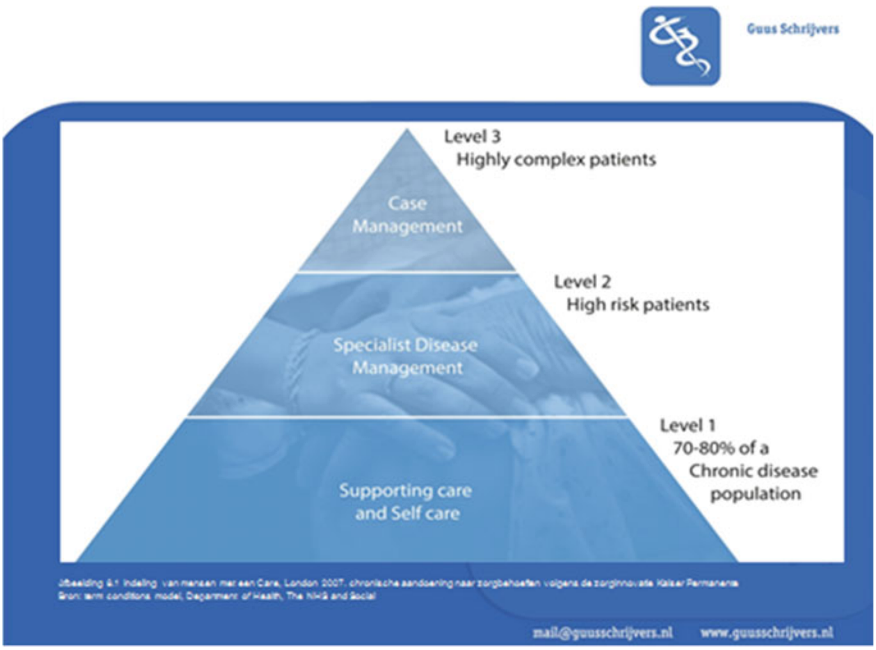

Fig. 25.1 Three-level Kaiser triangle

“frail” people obviously and dramatically increases the societal need for case managers. This increases their caseloads with a risk of decreasing the quality of the intervention for people in complex situations. Kaiser Permanente, a healthcare organization in California, introduced the three-level Kaiser triangle (see Fig. 25.1). Most patients with a chronic condition deal with their diseases with support of primary care as usual. This is the first level. At the second level, they are in need of a disease management program. Only in the case of complexity (level 3) are they in need of a case manager.

25.2.2 All the Needs

The second set of words in Box 25.1 with an asterix is *evaluates all of their care and social needs*. Case managers have to be careful about all possible expressions of needs, preference and priorities. In fact, even when people say that they cannot express an opinion, this is rarely the case for all the dimensions of the situation. Understanding one aspect frequently helps a lot in understanding the other. The point is that case management is related to person-centered care. The coaching abilities of the case managers are thus crucial (Corvol et al. 2016; Balard et al. 2013). This in important whether the classification of the client is a family with many problems, a person with dementia, a person with psychiatric disorders or a person with cancer.

25.2.3 Physicians' Cooperation

In the definition of Box 25.1, the third set of words with an asterix is: The case manager cooperates with physicians and other professionals. In our case story, the case manager cooperates with a general practitioner and is part of the primary healthcare team of which the GP is also a member. This is only one of the options. Case managers also work in a setting with geriatricians, treating Alzheimer patients at home and in nursing homes. If case managers work for cancer patients, they could cooperate with oncologists working in a hospital. In all these settings, the physician is responsible for diagnosis, therapy, prognosis and the prescription of medication. However, case managers are responsible for the continuity of care and other services and for the making of the life/care plan. They can also coach clients or patients to raise questions to physicians and other professionals, to express their preferences and to ask to improve the quality of their care (Parrish et al. 2009; Coleman et al. 2004; Parry et al. 2008).

25.2.4 The Life/Care Plan

This life/care plan, the fourth concept in the definition in Box 25.1 with an asterix, describes five elements: (1) the health and social needs of the person in the complex situation; (2) the support of the informal carers to satisfy these needs; (3) the supply of care and services by professionals; (4) the allocation of tasks and responsibilities to informal carers and professionals; and (5) the time scheduling of informal and formal carers. The plan also has formal aspects showing who is the case manager; who is the first contact person (the client or a relative) within the informal carers; and who is the first responsible physician. It has also a validity period depending on the stability of the situation: 6 weeks? 6 months? A year?

A life/care plan contains a crisis section. This describes what the client and their informal carer have to do in case of a calamity, for example, illness of informal carer, failure of nursing or medical equipment or sudden worsening of the complex situation. In the story of Julia and Peter, the crisis paragraph describes what to do when Peter himself becomes ill, when the stair lift does not function and who to consult in case of a severe itch attack. Sometimes, the case manager or even the whole professional team is convinced that something is required to prevent a crisis. However, the client refuses it. It is important that the relationship is not severed by this refusal. On the contrary, the risk assessments of crises on one side and patient's rights on the other side have to be very carefully weighted. That is an important role of case managers.

Does a case manager make a life/care plan for an individual person or for a household? In the Netherlands, families exist with multiple problems at the same time with all members as clients or patients. For example, the father is unemployed, the mother has breast cancer and the kids do not function in the school and neighborhood. For this kind of family, the professional mantra is: *One family, one plan and one case manager*. In the Netherlands, the concept of a life care plan is under scientific discussion and not crystallized in a new paradigm.[4] A debate exist in scientific, professional and financial circles about the content and other aspects of such plans, since in 2015 it is mandatory to develop one under the new Act of Long-Term Care.[5,6]

Finally, the plan can entitle an individual to use public or insurance paid resources to assist the client. This position of advocacy for the client and gate-keeping of some scarce resources can put case managers in ethical dilemmas for which they must be trained (Corvol et al. 2013). A professional or policy maker other than the case manager could do this job. However, it seems less bureaucratic that one and the same case manager decides about payments based on life/care plan within financial guidelines. If case managers have the power to allocate resources, their decisions are faster made than in a context with a back office deciding about that.

25.2.5 Informal Care and the Case Manager

Informal care (the fifth set of words with an asterix mentioned in the definition of Box 25.1) is divided into care by relatives (or family care) and by volunteers. The latter are united in an organization, for example, a church or a charity. Often they provide supportive services such as friendly visiting, transport, garden maintenance or small jobs like repairing a wall plug. Care such as washing patients or helping to go to the toilet is mostly done by relatives or eventually by professionals; that is too intimate for volunteers. Within the group of family carers, a central person (the partner, a son or daughter) often offers most of the informal care. Often this person is healthy but frail. It is not simple for a case manager to define who the primary informal carer is, because sometimes appearances are misleading; for example, a partner who lives with the person could be less involved in the informal care than a daughter living elsewhere. The assessment of the informal care network is one of the most important skills that a case manager has to possess.

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[4] Inventarisatie individuele zorgplannen. https://www.vilans.nl/Pub/Home/Ons-aanbod/Producten/Inventarisatie-Individuele-zorgplannen.html.

[5] https://www.rijksoverheid.nl/documenten-en-publicaties/kamerstukken/2014/03/10/wetsvoorstel-wet-langdurige-zorg.html.

[6] https://www.rijksoverheid.nl/documenten-en-publicaties/kamerstukken/2014/03/10/memorie-van-toelichting-wet-langdurige-zorg.html.

25.2.6 Within a Program

The case manager works within a program is the sixth phrase with an asterix in the definition of Box 25.1. Such a program could be the chronic care model of Wagner (Wagner et al. 1996; Coleman et al. 2009), an integrated care program in Dutch style or German style. Such a program defines multidisciplinary professional pathways, decision trees, referral guidelines and treatment options. The program is also the link between case management and integrated care. The relation between case management and integrated care is not simple. Per se, the addition in a health and social services of a new service (the case managers) is at risk of increasing the fragmentation of the system (with new interfaces with this professional and the organization hiring them etc. In fact, case managers can participate in the integrated care movement only if their action is "translated" by a dedicated professional in organizational transformation leading to a more integrated health and social services system (Somme et al. 2014a).

25.2.7 Target Population

The last phrase in the definition with an asterix is *about persons who are not able to organize their care/life plan and are without a sufficient network of relatives.* A representative survey in the Netherlands of persons between 57 and 77 years of age showed four types of profiles of potential clients and patients (Doekhie et al. 2014). The first group (46%) lives proactively and wants to make decisions about their own life and care delivery. The second group (28%) could plan their own life but like to be cared for. This type of person does not like self-service in a restaurant and wants to be served. The third group (10%) asks professionals to make decisions and accepts advice as an order. The fourth and last group (16%) is unable to express their needs and to think on a longer term. Persons in this group often live alone, have a lack of money and have a low education and quality of life. In social services and in the public health domain, persons in the last two groups are eligible for case managers. For the second group, there seems to be a market for commercial case managers who organize for them care and services if complex situations arise.

25.2.8 Rejected Broader Definitions

Although the definition in Box 25.1 is broad, emotional support could also be included but is not mentioned. This is included in the task of case managers: It strengthens their relation with the clients. However, they may offer tissues for the tears and listening ears for the complaints, but they do not take over the feelings of the clients. They do not give them hugs. In the Netherlands, this professional attitude is called detached commitment.

The definition could also be extended to include continuous supervision if a patient or client cannot be alone. However, this is not a special task for case managers.

Generally, they have a caseload of 30–40 clients of the same target group: persons with dementia, cancer patients at home with metastases or multiproblem families. They help during a longer period and not only during transfers from one facility to another. Sometimes, case managers work for a group of patients living in an assisted living house for persons of the same target group. But even in that case, they have to keep confidential the personal relationship they have with each individual. All clients have to be assessed in a one-to-one exchange (and not as a part of a whole group) about their own needs.

The third extension could be that a case manager is also involved with treatment, for instance, giving injections to cancer patients. In the Netherlands, case managers for cancer patients do this. However, in youth health and in care for persons with dementia, it is unusual. That is why inclusion of therapeutic interventions is not necessary to be a case manager.

25.2.9 Competencies and Skills of Case Managers

The qualifications of case managers are given in their definition. They have competencies (knowledge and skills) about health and social needs, the functioning of informal networks, the local supply of professionals and the mechanisms of cooperating with them. They know a lot about the regulations and financial limitations. Two competencies, communication skills and integrity, are discussed in more detail here.

Case managers must be able to apply different communication styles. Evidence seems to be in favor of an empowering style offering different options for life and care in a neutral way. However, sometimes case managers have to persuade clients/patients that their demands for help are unrealistic or too expensive for the municipality or social insurance agency. Case managers have professional autonomy: They are not waiters serving whatever the client demands. They have empathy for the clients or patients but also have to keep a professional distance.

The second competency, integrity, is in danger if case managers are on the payroll of suppliers of care and services. Then, they could be pushed or seduced to create work for the supplying organization. If they are on the payroll of a municipality or a social insurance, integrity is in danger because of cost control goals of these organizations. It should be recommended to adopt an independent position. How to realize this is not easy to answer and is under discussion in the Netherlands. Above that, a professional organization for case managers is necessary to resolve ethical questions and with its own disciplinary rules.

Case managers have responsibility for the continuity of care for the clients. Here, a tension may exist with clinicians. If patients are hospitalized and their case managers judge that there is an issue at home, they have almost no authority to contradict hospital clinicians even if they have more information on the home arrangements. Another source of tension occurs in conflicts between clinicians about the best therapy for a patient. Such a conflict causes delays in the start of treatment and makes clients unsure. Then, case managers do not typically have the power to insist that the two come to consensus. In the Dutch oncological world, a dog metaphor exists: A case manager should be a kind labrador for the patients and a pit bull for arguing doctors. It is not easy for nurses to combine both characteristics.

25.3 Specific Tools for Case Managers

This section discusses the contribution of scientists to make case managers more professional with their own scientific tools: (1) to evaluate health and social needs and (2) to empower patients and clients. Not discussed are here other necessary skills of case managers such as negotiation skills, coordination and management skills, interprofessional and interdisciplinary working and patient and family support. Neither is discussed the role of the case manager as caregiver, and so the need for advanced nursing skills. All these skills are necessary for all professionals working in an integrated setting. They are discussed elsewhere in this book.

25.3.1 Evaluating Health and Social Needs

Case managers have to assess all the social and healthcare needs of their clients, and also living arrangement needs and psychological needs. They have to assess these needs with a formal assessment process. Otherwise, arbitrariness and personal preferences of the case manager could play a role.

There is no international assessment tool approved by the authorities for the assessment task. In Canada, some parts of France and parts of Australia case managers use the FAMS or derivations of it (Somme et al. 2014b; Nugue et al. 2012). FAMS means Functional Autonomy Measurement System. It was developed by the Prisma Program originating from the province of Quebec (Stewart et al. 2013). It allows the classification of personal situations in 14 groups with very similar care or social needs. Germany uses a three-level assessment model to evaluate health and social needs. Its focus is on nursing needs. A debate is going on to broaden the assessment and to include also communicative and cognitive limitations (Büscher 2011). In 2003, the Netherlands introduced an assessment system based on the International Classification of Functioning, Disabilities and Health (World Health Organization 2001). This system facilitated assessment of health, limitations and disorders without mentioning what kind of professional care should be offered. Based on this system, the Netherlands uses now six kinds of care needs: (1) personal care on the body like washing; (2) technical nursing care (e.g., wound cleaning); (3) supporting and supervising (if the client cannot be alone);

(4) psychological treatment; (5) special conditions for housing (for instance, bars in the bath room); and (6) short stay in a nursing home (e.g., after a hospital admission).

In Scandinavian countries, no assessment instruments exist. It is up to the professional to make an assessment. In the UK and the USA, local instruments are that are not necessarily based on scientific research. In the rehabilitation sector in France, Canada and the Netherlands, the Resident Assessment Instrument (RAI) (Morris et al. 1990) and the Barthel Index (Mahoney & Barthel 1965) are popular: Case managers here measure the mobility of persons and clients and the need for support if it is limited.

Until now, a universal assessment instrument covering all health and social needs is not available. In the Netherlands, there is hesitation to make better (and longer) questionnaires to assess the client and patient needs. The latest strategy is that a case manager goes immediately to the experienced problems of the client without analyzing the interaction between different needs. This is popular in youth health and is known as solution-focused therapy (Molnar et al. 1987; Visser 2012). However, clients' situations have to be assessed on all their dimensions and not only the "obviously problematic" ones. This is because it permits preventive action on dimensions that are unstable but not overly problematic and because it allows examination of all the causes of the situation and thus finding the best solution (Somme 2014). Another new development is the structured dialogue between case manager and client or patient. Here, case managers assess health needs, for example, limited mobility within the house. If there is a problem, they assess immediately what solutions the client or the partners have. They offer a professional solution only if there is absolutely no informal one.

In 2012, the Skidelskys, a father and son who are an economist and a philosopher, respectively, wrote a bestseller with the title *How much is enough?* (Skidelsky & Skidelsky 2012). Their book is interesting for case managers working in the field of supporting clients' quality of life within financial limitations. They studied the theories of Keynes, Aristotle, Rawls, Sen and Nussbaum. Based on their publications, they formulated seven basic needs of human beings: (1) health; (2) a safe and trusted environment; (3) respect from others; (4) personal autonomy; (5) harmony with nature; (6) friendships and other affective relations; and (7) free time for pleasant activities. They put these seven needs on the same level. This is in contradiction with Maslow's pyramid showing a hierarchy in which physical needs are more basic than, for example, free time for pleasant activities (Maslow 1943).

In most countries, case managers work with assessment systems in which health needs and physical needs are more important than the Skidelskys' social needs (numbers 3–7). To our knowledge, only in Sweden do professional personal assistants exist. They are assigned to a client by case managers. Together with the client, they decide whether they spend their time fulfilling the client's physical needs or they drink friendly coffee as to build affective relations.[7] In the Bible, the competition between physical and social needs is also discussed. In the parable of

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[7] https://www.independentliving.org/docs5/jag.html visited on September 27, 2015.

the two sisters, Maria and Martha provide housing and care to the Lord, who appears as a traveler. Martha starts immediately with washing the feet of the Lord and preparing a meal, for her physical needs were most important. Maria started with a conversation with the Lord about his trip. For her, social needs like attention and love come first. The Lord appreciated Maria more than Martha. We, as authors of this chapter, do not follow the Bible or the Beatles with their song *All you need is love*. We prefer the Swedish model where clients and professionals share decisions about priorities between physical and social needs.

25.3.2 Empowering Interviewing of Patients, Clients and Relatives

Stimulating self-management by client, patient or relatives is called patient empowerment or patient activation. There are four types of self-management (Heijmans et al. 2012): (1) medical self-care, e.g., the intake of drugs; (2) dealing with professionals, e.g., making appointments with a professional; (3) coping with the effects of the disease or limitation, e.g., coping with pain; and (4) adapting the lifestyle, e.g., doing physical exercises. Empirical Dutch research teaches that persons with chronic conditions have the most problems with self-management of the third and fourth type. English studies show that it is not enough to educate them on these domains by giving information and instructions in a leaflet or on a Web site (Kennedy et al. 2013; De Jong et al. 2014; Bardsley et al. 2013). Three other aspects are also necessary.

First, it is important to measure current self-management before introducing new forms. The patient activation measure (PAM) is an example of a measurement tool for this (Hibbard et al. 2004). The designers of this instrument distinguish four phases of self-management: (1) belief that the patient's role is important; (2) self-confidence and know-how to apply self-management; (3) the self-management action; and (4) self-management in stressful periods.

Second, an educational theory is necessary to check that information is understood and applied. Educational theories are the triangle (from knowing to doing) of Miller (1990) and the learning style theory of Kolb (1984).

The third necessary aspect is the use of the motivational interviewing designed by Miller et al. (2012). He distinguishes four phases in his interview technique:

(1) Creating a relationship of trust between professional and client/patient;
(2) Focusing on behavioral change goals in the client or patient;
(3) Enforcing these goals; and
(4) Making a plan with practical steps to implement the goals.

Patient empowering interviewing is a crucial role for case managers. Their skills are distinguishing different types of self-care, applying the PAM instrument, using an educational theory and motivational interviewing. Although case managers are focused on clients and patients, they also have to activate the relatives. Behaviors to be activated are: (1) perseverance of supporting of their loved patients or clients;

(2) assertiveness (how to say no to a patient without feeling guilty); and (3) physical support (how to lift your partner from bed into a chair?). Courses for relatives seem to be cost effective (Livingston et al. 2013; Knapp et al. 2013; Long et al. 2014).

25.4 The Real World and the Ideal World of the Case Story

Section 25.1 contains the story Julia and Peter. Six types of services are mentioned with an asterix. They do not exist nationwide, neither in France nor in the Netherlands. However, they exist in small experiments and innovations, mostly not officially published in scientific journals. These six types of services are summarized in Box 25.2.

Box 25.2 Services of Case Managers with Do Not Exist in 2016

1. *Advanced nursing specialist working as case manager in primary health care for target groups as persons with dementia, multimorbidity, cancer or families with many problems*
2. *Making a care-life plan for a period of e.g. a year*
3. *a pharmacist reviewing the medication of patients with many shifts a day*
4. *an outreaching fall prevention service within primary health care*
5. *an IT expert helping patients and their relatives using their Tablet PC to communicate with their formal and informal care providers*
6. *Providing comfort and relaunch tips for informal carers with a deceased partner.*

The six show the differences between the ideal world of the authors and the reality in their countries. The reality exists in the Netherlands because of a lack of consensus about the aims of the Dutch healthcare policy. The most important stakeholders, government, professional organizations, healthcare providers, labor unions and patient organizations disagree about the triple aim of improving health, enhancing quality of care and controlling costs as formulated by Berwick and colleagues in 2008 (Berwick et al. 2008) and Bisognano in 2012 (Bisognano et al. 2012). First, there is a difference in the time frame of the policy aims. Broadly speaking, scientific advisory institutes and professional organizations think in terms of 8–12 years or more. The government and its agencies think in periods of 4 years until the next election. Commercial firms and innovations subsidizing charities have a time horizon of 2 years. Second, the aims of the stakeholders are different. For the government, all policy was focused on healthcare cost control and decentralization of power to municipalities. Case managers and continuity of care were low on the policy agenda. Contrary to this, research and professional institutes for health services embrace these two policy aims. Third, if there are case managers and integrated care programs within which they have to work, they are not supported by an adequate health information technology (IT) system and financing system.

In France, there has been a shift toward more case managers, especially in care for persons with dementia. However, case managers are not recognized as a profession. Instead, it is mandatory to have a professional qualification before being hired as a case manager. There is no case management professional organization (order or syndicate). There is no specialized journal. Nevertheless, the "professional field" is defined in a regulation. Case managers have to fulfill four conditions:

- They have to be hired by a local leader in charge of a local integrated care project.
- They have to be a professional from a limited list of professions which are authorized to make "in-home" assessments of a person's entire situation. These professions are: social services workers (with a certain level of responsibility corresponding to a license level at least), medical auxiliary (a group of professionals in which there are nurses, occupational therapists, physiotherapists and so on) or clinical psychologist (with a master's degree).
- They have to have professional experience with in-home care arrangement for people with loss of autonomy and in complex situations.
- They have to take a 100 h university training program with a minimum of 20 days of practical course with a licensed case manager during the first 3 years of the contract.

Case management for clients with dementia was implemented in France as one part of a vast program for improving the integration of social and healthcare systems. It was not the only means of improving integration but just one part.

25.5 Implementation Strategies to Disseminate the Function of Case Managers

This chapter started with an ideal case story in the year 2025. It has been mentioned above that best practices exist in the Netherlands and France and also in other countries. Or said in a slogan: The future is already invented in best practices. The problem is how to disseminate the best practices. Evidence does not support (de Stampa et al. 2010) a top-down, big bang introduction of case managers in a state or a nation. That creates only chaos and makes case managers unpopular in the population and within professional groups. Our rejection is based on bad experiences in the period from 2009 to 2014 with the introduction of case managers within family centers for Dutch families with multiple problems. On the other hand, it is probably inefficient to "wait" for integrated care, because professionals and

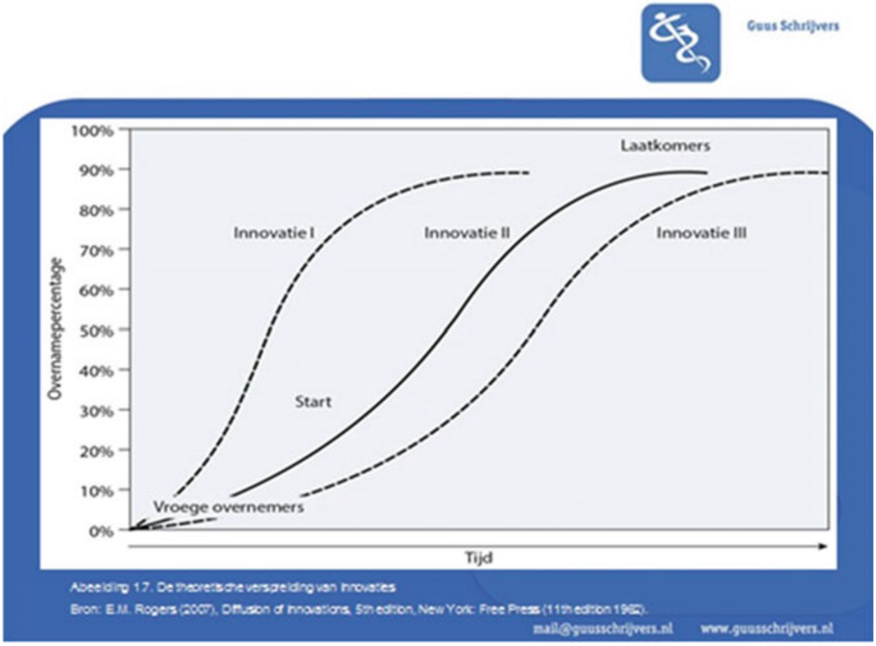

Fig. 25.2 Rogers model (Rogers 2003)

organizations have no direct interest in working in an integrated (often more complex) way. Thus, what is needed from the top down is not to define “how” to do what is to be done but why and when to do that and to help the change happen rather than making it or letting it happen. The fact is that without political will, integrated care never appears “naturally,” but without sufficient margins at an operational level, integration will always be rejected (Greenhalgh et al. 2004).

Instead of the top-down approach, the model by Rogers (2003) to gradually disseminate case managers in a country is interesting. Figure 25.2 shows the Rogers model. In it, innovation 1 is disseminated faster than innovations 2 and 3. The three innovations have comparable introduction phases. In the first phase, only early adopters use the innovation. The innovation is relatively slowly implemented. Then, the curve goes up fast: The early and late majority takes over the innovation. In the last phase, only laggards remain, explaining why the implementation speed is again low.

Rogers shows five conditions that decrease the implementation speed. One of these is the complexity of the innovation. A monodisciplinary guideline is implementably faster than the new role of case manager. The latter changes the roles of many professionals, redefines the relations with physicians and changes access to health and social services.

For the introduction of complex innovations, another scientist, Christensen, has a theory (Christensen et al. 2009). He is the author of the bestseller *The Innovator's Prescription.* Christensen emphasizes the simultaneous innovation of care, the payment system and the health information system. Let us explain this theory with the innovation of the broad case manager as an example. If professionals have designed this care innovation, it only has a chance for implementation if simultaneously a fee and payment system for the new function is introduced. Otherwise, there is no business case for this innovation. Alongside that, the IT system has to be changed or else the case manager (often a nurse) cannot communicate with physicians, nurses and social workers in the social domain.

Are the models of Rogers and Christensen enough to design an implementation strategy for the introduction of case managers in a country? We think that these are necessary but not enough. On a micro-level, the case manager integrates health and social services. On the macro-level, there should be a sense of urgency to stimulate this by means of adaptation of current regulation. In the UK, the legislation for the health services and social services was already integrated. In the Netherlands, this is the case for long-term care. In France, this integration on a national level is being prepared for clients with dementia.

If the implementation of the function of case manager is simultaneously supported on micro- and macro-levels from professional, financial and digital sides, in 2025 the case story of Julia and John would become a reality.

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Discharge and Transition Management in Integrated Care

26

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26.1 Introduction

A key part of integrated care is to ensure a continuous pathway for a patient when being transferred from one healthcare sector to another. Discharge planning and management tries to achieve exactly that. The discharge process demonstrates excellently the need for integrated care. In almost no other part within the care process, one can see a clearer clash of different (a) settings and capacities, (b) personal resources and professional cultures, (c) reimbursement and payment schemes, (d) care and medication procedures, (e) usage of (information) technologies, (f) professional cultures and (g) interests. The importance of each of these aspects depends significantly on the degree of pressure each entity within the healthcare system and their sub-systems has to face. For example, the higher the pressure in the hospital sector, the more likely hospitals will optimize their part in the value chain according to their specific interests. This is not necessarily in the best interest of the entire healthcare system—or even the patient.

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The following chapter describes what discharge management entails, why it is needed in healthcare systems and in what different ways it can be organized. In conclusion, discharge management is an essential part of providing integrated care in all health systems, but there is still a long way to go to guarantee adequate transitions for patients in most (if not all) health systems.

26.2 What Is Discharge Management?

Despite its importance, there is no universal definition of the concept of discharge management. Instead, various descriptions can be found in the literature. Taking a very broad perspective, discharge and/or transition management encompasses any transfer of patients between sectors of care delivery, between care givers or providers, or from one setting to another (Chenoweth et al. 2015). It not only describes the planning and guaranteeing of continuity of care (Wong et al. 2011), it also entails "the transfer of professional responsibility and accountability for some or all aspects of care for a patient, […], to another person or professional group, on a temporary or permanent basis" (Toccafondi et al. 2012, p. i58), including the transfer of budgetary responsibility (Wong et al. 2011).

In the following, we focus on a more narrow scope and use the term discharge management to describe the process of patients leaving the temporary in-patient care setting and entering the out-patient care setting, which can be either the patient's home or long-term care institution. The in-patient setting does not only refer to an acute hospital, but also include in-patient rehabilitation settings (Müller and Deimel 2013).

26.3 Why Discharge Management?

Discharge management appears to be almost an inevitable component of (health) care delivery in modern healthcare systems. The desire to enhance patient empowerment and their satisfaction in order to improve medical outcomes, save costs and meet the demographic challenges supports the need for organizing and optimizing the discharge process. The relevance of well-organized and planned discharge processes arises from the fact that patients who are discharged from hospitals experience higher mortality and morbidity risks which are not only related to medical factors, but may also be linked to social and health service backgrounds (Escobar et al. 2015; Yiu et al. 2013). Patients are especially vulnerable in the period during or directly after discharge (Philibert and Barach 2012). Therefore, the need for discharge planning results from several different factors interacting with each other. The following trends within healthcare systems contribute to the growing importance of managing the interface between out- and in-patient care adequately.

26.3.1 Demographic Challenges

The starting point is—as in many other respects—the demographic challenge as one of the main drivers for the need of discharge management. First of all, there is a simple numeric effect: with an increased average life expectancy, the risk of being hospitalized once or more often in life also rises. Hospitalized patients often suffer from worse health and are on average older than those treated in out-patient settings (Abad-Corpa et al. 2013; Mohr 2009). For example, older people make up only 13% of the US population and 14% of the Canadian population, but they are responsible for 45% (USA), respectively 50% (Canada) of the hospital costs (Fox et al. 2013). In older age, not only chronic illnesses are more common, also multi-morbidity becomes more likely. This means that in many societies the share of people who are dependent on repeated in-patient medical care which needs to be coordinated with long-term and social care is increasing.

Besides the simple effect of higher age, changes in lifestyles and family situations play a role when it comes to discharge management. In many Western societies, an increasing number of people—especially the elderly—lives alone without the support of families or communities readily available. This is why the patient’s living situation and social network needs to be considered at the point of discharge and when planning follow-up care. For example, the type and amount of care needed by an old patient with a hip fracture who lives with family members in a house with a ground floor will differ from the care needed by a patient with the same age and condition who lives alone in an apartment on the fifth floor with no elevator (Wehmeier and Scha¨fer 2013). Transition planning is particularly necessary as the treatment process and its outcome within the in-patient sector are mutually interconnected with the medical, but also the social and nursing situation of a patient. Not only do patient factors impact whether and how a patient needs to be treated in hospital. A patient’s mobility, quality of life, need for care and nursing, and ability for social inclusion may all be changed as a consequence of hospitalization (Deimel 2013). Patients may (at least temporarily) lose their independence-especially if they are older (Bender 2013).

26.3.2 Rising Costs and Financial Pressure

Financial pressure has increased dramatically in almost every health system due to constantly rising costs. This, however, increases the tendency of single providers or sectors to act in their own interests which may not necessarily be in the best interest of the entire healthcare system—and most likely even less in the interest of the patient. One result of the ongoing budget constraints in the in-patient sector is the trend of shifting procedures from the in-patient setting into the out-patient setting. However, in the long run this may lead to higher total costs. In the USA, almost 20% of elderly patients are readmitted to a hospital within one month after discharge (Shu et al. 2011). This does not only lead to rising costs, and it also leads to increased suffering by the patients. Studies have shown that discharge management can reduce readmission and mortality rates (Shu et al. 2011). The financial incentives for effective discharge planning are considerable and relate to reduced readmissions, keeping patients in their homes and out of residential care (Chenoweth et al. 2015) or freeing up acute beds (Atwal et al. 2002). It is assumed that approximately 30% of discharges in the USA are delayed due to non-medical reasons, including inadequate assessment of the patient and lacking knowledge of a patient's social environment, problems in the organization of follow-up care, delays in the ordering of transportation means for the patient (to their homes, etc.) and poor communication between hospitals and out-patient service providers (Shepperd et al. 2013). More and more reimbursement systems focus on some kind of guarantees which have to be met by the hospitals. For example in the German DRG system, insurance companies will not reimburse the hospitals for patients with certain defined indications if they had been readmitted within a defined period of time after discharge.

26.3.3 Declining Length of Stay

The average length of hospital stay has declined in many countries over the past years (see Fig. 26.1, also Eurostat 2015). In the EU member states, it dropped from 9.6 to 7.8 days between 2000 and 2012 (OECD 2014). Even though these numbers do not say much about the quality of care as such, they do imply that the process of entering and leaving the hospital setting needs to be optimized to guarantee the same quality of care in a shorter period of in-patient time. It also means that patients leave the hospital more vulnerable than they used to. They often still require intensive and specific care-which should preferably be closely coordinated with the care received in the in-patient setting. However, it may be challenging for the out-patient setting to maintain the intensity of care provided in the in-patient unit

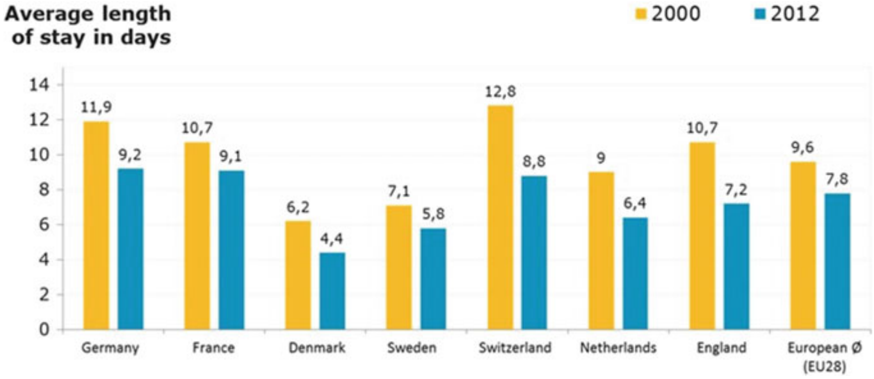

Fig. 26.1 Average length of stay in hospitals for all causes, 2002 and 2012 (or nearest year). *Source* OECD Health Statistics (2014), own diagram

(Deimel 2013). In Germany, for example, hospitals have access to more expensive medications. The continuous treatment with the same products can therefore cause financial problems for ambulatory care providers due to their more restrictive budgets. A decline in the length of stay further implies an increase in interfaces as patients have more care needs and thus more providers need to be involved and coordinated. Given this context, it is particularly important that the transition between hospitals, general practitioners (GPs), social care and other providers works well.

26.3.4 Financing and Reimbursement Systems

As mentioned before, there is a variety of financing systems and responsibilities involved in the process of discharge management and they usually co-exist without cooperation between systems. Discharge management is especially needed in systems that are still organized in silo-structures. The silo-analogy refers to the coexistence of structures which are not interacting with each other. For example, in Germany both the in- and the out-patient sector have strictly separate budgets, and the health and social care sectors are even financed by a different insurance system. The Diagnosis-Related Groups (DRG) systems, and other comparable systems which are used for reimbursement in the hospital sector in many countries, provide a fixed payment per patient based on the average costs of patients with a comparable condition. The less the patient costs, i.e. the shorter the stay of the patient, the more the hospital can profit. Increasing competition between hospitals adds to the pressure hospital providers face nowadays. These factors lead to a strong focus on economic efficiency and cost reductions. In the example of Germany, the introduction of the DRG system has brought about some important changes, highlighting the importance of discharge management. Previously, the financing system allowed the hospital to take into consideration the individual situation of a patient and even postpone the discharge if there was nobody to care for the patient in the out-patient setting. This became less common (and financially unbearable) under the DRG system (Mohr 2009). The revolving-door effect mentioned in this context refers to a situation where patients are discharged “too early” and re-enter the in-patient setting within a few days after discharge. Reasons for this include a lack of or inappropriate provision of care in the out-patient setting. Numbers from the USA underline this vividly: approximately one-fifth of Medicare beneficiaries who are discharged from the hospital re-enter the in-patient setting within 30 days of discharge. Half of them had no contact to a GP during the out-patient time (Hennessey and Suter 2011).

Organizing care in a coherent and coordinated way is particularly difficult in the context of economic pressure that most or many health systems face today. This, together with the divided financing and reimbursement systems, does not foster but work against integration and cooperation. Services that focus on organizing and managing the transition of patients are oftentimes not or not sufficiently remunerated as each sector calculates their costs separately. This means that shifting cost from the in-patient to the out-patient sector by discharging as early as possible appears rational from the perspective of the in-patient sector but may in the long run lead to higher costs for the health system—and to a poorer medical outcome for the patient. However, this does not mean that discharging patients early is never an optimal choice. Looking at COPD patients for example, finding alternative ways to treat patients outside of hospitals is an important factor for minimizing cost. The key is well-designed discharge planning to make early discharge a fruitful way for all actors, including the patients (Escarrabill 2009).

26.3.5 The Need to Manage Complexity

Discharging a patient from the hospital into the out-patient sector or the long-term care sector is a process involving many different actors and systems. According to Deimel et al. (2013), there are six main areas that the discharge process potentially has to cover: medicine, rehabilitation, nursing care, medical aids, social care and relatives (see Table 26.1). Usually, more than one of these areas or actors has to be involved in the discharge process. It is important to note again that the process does not only involve professional actors, but also the social environment of a person. Discharge management is thus a multidisciplinary process focusing on many aspects of a patient's life.

Given a high degree of specialization of hospitals, the complexity and the number of actors that have to be coordinated increase. Instead of one regional

Table 26.1 Sectors and actors involved in follow-up care

Follow-up care sectors	
Medicine	*Nursing care*
Physician and specialist care	Ambulatory care services
Diagnostics	Care consultation services
Therapy in another hospital	Partial in-patient and in-patient care services
Wound management	
Nutrition therapy	
Drug management	
Rehabilitation	*Aids*
In- and out-patient rehabilitation	Movement
Physiotherapy	Home support
Ergotherapy	Medical devices
Speech therapy	
Social	*Relatives*
Housing and financing matters	Out-patient assistance/support
Psychosocial services	In-patient care services
Severe disability	Short-term nursing

Source Adapted from Deimel et al. (2013)

hospital, there are often many specialized clinics treating patients. In many countries, the general practitioner (GP) takes a large share of the responsibility in guaranteeing the follow-up treatment but is often not sufficiently informed about the treatment the patient received in the hospital (Hesselink et al. 2014; Harbord 2009). The fact that various independently operating actors—such as social care institutions, specialists and therapists, nursing providers or pharmacists—may be responsible for the same patient further adds to the challenge of providing continuous care. To guarantee seamless care, sectors must communicate and exchange information (Mohr 2009). This does not only require the exchange of medical or social information but also the clarification of responsibilities between actors. The latter is often unclear, especially when multi-morbid patients leave the hospital setting, needing services of different specialized providers (Hennessey and Suter 2011). Gaps in the delivery of care may particularly result from patients being discharged on weekends, when the GP or a follow-up care specialist are not available, or adequate medication, medical aids or else cannot be provided in time. Furthermore, many communication systems are not compatible between sectors or providers. These factors may lead to patients receiving wrong or inappropriate treatment and increase the risk of adverse effects such as a longer length of stay or a higher proportion of readmissions. This, in turn, may cause patient dissatisfaction and increased healthcare expenditure (Drachsler et al. 2012). To guarantee seamless delivery of care, professional discharge and transition management is key (Harbord 2009), and implementing it successfully requires a clearly defined regulatory and legal framework.

26.4 How to Put Discharge Management into Practice

> Effective discharge planning requires capacity planning, performance review, hospital discharge policies, and healthcare providers/stakeholders agreements. There is clear evidence and wide agreement among healthcare providers/stakeholders that a standardized and policy-driven protocol [is] important to an effective discharge planning. (Wong et al. 2011, p. 9)

To date, many different attempts and models to organize the discharge and transition process exist. They vary not only across but also within health systems. However, this diversity has not yet led to a clear "best-practice" model. Instead, discharge management processes in general leave a lot of room for improvement to guarantee optimal care for the patients, but also their relatives, the caring institutions and other partners (Deimel 2013).

Overall, research draws a rather negative picture of the situation of discharge management, pinpointing to a lack of effectiveness in daily practice, a lack of clear strategies and challenges in evaluating interventions (Hesselink et al. 2014). Among others, the difficulty of changing behaviours of providers is being widely emphazized and discussed. Inefficiencies caused by poor information exchange, poor coordination of care and poor communication between the various providers as well as between providers and patients lead to—oftentimes preventable—readmissions

(Hesselink et al. 2014). The HANDOVER project which was initiated in 2008 and funded by the European Union's Seventh Framework Programme aimed at investigating and defining how to best improve the discharge process. In this project, researches from Italy, the Netherlands, Poland, UK, Spain and Sweden as well as from the USA and Australia worked together (Philibert and Barach 2012). The research group identified among other things barriers to transitions, which include "time constraints and low prioritisation of discharge communication, pressure on available hospital beds, and variability in patient and family member involvement in discharge planning" (Philibert and Barach 2012, p. i1).

The diversity in discharge practice is reflected in the various categorizations of discharge management that can be found in the literature. For example, interventions or models can be categorized based on the time of care they focus on. Tang et al. (2014) suggest a categorization into pre-discharge, post-discharge and bridging interventions (see Fig. 26.2).

For each of these three phases of discharge management, various different models of integrating health care and organizing discharge management can be further identified and applied. Burns and Pauly (2002, p. 136ff), for example, suggest four models of integrated health care within hospitals, which can be also applied to models of organizing discharge management:

1. Customized integration and disease management, describing the tailored integration around diseases or individuals (case management and disease management), oftentimes covered by public health insurance programs.
2. Co-location of care, describing joint-venture collaborations including the relocation of personnel to foster interaction and integration.

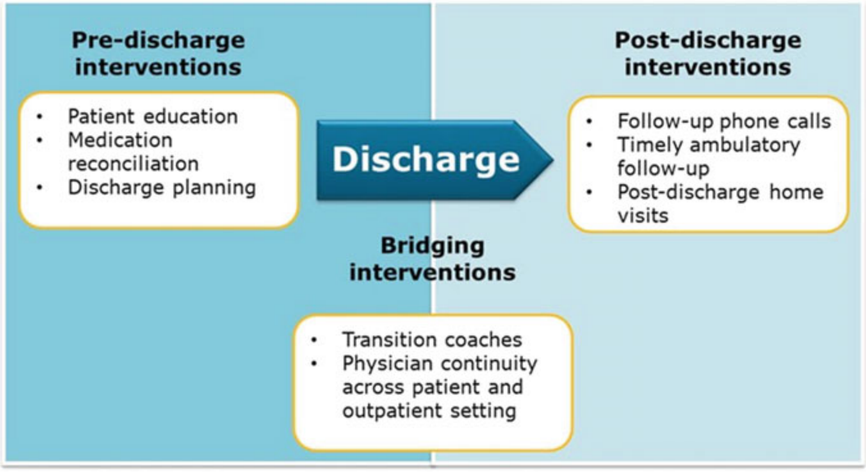

Fig. 26.2 Discharge interventions according to Tang et al. (2014)

3. IT-integrated health care, describing the integration through technologies such as electronic health records, automated drug dispensing, remote patient monitoring, etc.
4. Patient-integrated health care, empowering the individuals as gatekeepers of their own health.

If the out-patient and social care sector would be added, the list would likely grow longer. Nevertheless, these four models show clearly how many different ways exist to put discharge management into practice. No matter which phase of the discharge process and which model is chosen, it is important to take a professional approach.

26.4.1 Professionalization of Discharge Planning

Discharge management, if primarily understood as the process of leaving the in-patient setting, is to a large extent seen as the responsibility of the hospitals. Even though the process is multi-professional and multi-dimensional, it is (or should be) initiated in the hospital—some argue as soon as the patient enters the hospital (Deimel 2013; Müller and Deimel 2013). Planning and managing the discharge process of patients is, as should be evident by now, a very complex task. Therefore, it is quite surprising that a recent survey of hospital managers in the UK found that case managers responsible for discharges seldomly had certifications or long-time experiences in discharge planning (Chenoweth et al. 2015).

Effective discharge management needs the cooperation of various actors within a complex setting: the hospitals with their doctors, social services, nursing services, the specialists and practitioners in the out-patient setting, pharmacies, and rehabilitation or care institutions (Pilgrim and Kittlick 2013). In this context, the call for a professional and qualified discharge manager who is responsible for navigating the patient through this complex system is not surprising (Deimel et al. 2013; Harbord 2009; Hennessey and Suter 2011; Wong et al. 2011). Communication among the various actors needs to be organized and professionalized since they are not used to interact in their regular day-to-day work (Mohr 2009). Defining a responsible person in charge of this process has proven to be helpful to achieve successful communication (Wong et al. 2011). In Germany, the responsibility for discharge management was for the longest time with the social services, but over time has been shifted to the nursing services of the hospital. The responsible departments guarantee that the patients receive all services they are entitled to, manage the initiation of nursing care, help with financial as well as housing questions, and initiate psychosocial interventions if needed. However, the degree to which these agencies are responsible and capable varies from hospital to hospital. In the Anglo-American healthcare systems, it is common to find a “discharge planner” who is responsible for the adequate discharge of the patients. In these systems, discharge management also includes the empowerment and active involvement of the patients (Müller and Deimel 2013). Still, the work initiated in the hospital is often not adequately continued once the patient leaves the in-patient setting (Pilgrim and Kittlick 2013).

Frequently, GPs take the lead and responsibility for coordinating the patient's care. However, it was found that they are often very challenged by these tasks, especially due to a lack of communication and information. They further do not feel sufficiently rewarded for this work (Philibert and Barach 2012). Short-notice releases of patients from the hospital that do not allow enough time to initiate follow-up care add to the challenge (Müller 2013). Not only the out-patient doctors see the inter-sectoral cooperation as being problematic at times; the in-patient doctors also voice concerns. They complain, for example, about the resistance of GPs to continue or at least take into account the care provided in the in-patient setting (Dienst 2013). The out-patient doctors, in contrast, point out delays in receiving discharge documents from the hospital or receiving incomplete documentations. Information technology may help improving this process in the future.

26.4.2 Integrating Various Components

Evidence seems to suggest that only discharge programs including various interventions are successful in improving care and reducing hospital readmissions. "In a recent systematic review, no single intervention was found to be associated with a reduced risk for 30-day readmissions" (Tang et al. 2014, p. 1513).

Even though many tools currently in use have been evaluated, there is a lack of clear evidence of their effectiveness. Limited evidence exists for the effectiveness of discharge planning reminders, financial incentives and penalties. The effects of including discharge management in the medical curriculum and of feedback forms and other ways to trigger provider reflections are also not clear (Hesselink et al. 2014). A systematic review of literature assessing post-discharge telephone calls and their impacts found no clear evidence of their effects on readmission, emergency department use, patient satisfaction and well-being as well as follow-ups (Bahr et al. 2014).

However, evidence regarding models that integrate various components into the discharge process seems to be more conclusive. In the USA, for example, an integrated post-discharge transitional care program entailing a disease-specific care plan, follow-up phone calls, hotline counselling and referrals to hospital-run clinics significantly decreased readmissions within 30 days after discharge (Shu et al. 2011).

The finding that integrated approaches are more fruitful is not surprising when keeping in mind that inefficiencies are rooted in various factors. These can be divided into those related to attitudes and behaviours, to processes (such as missing guidelines), to technical problems (such as lacking electronic information exchanges) or patients (Hesselink et al. 2014). Addressing just one factor is unlikely to have a strong impact given the complex context. Effective tools need to go hand in hand with training, reimbursement, policies and enabling organizational structures. Further they must include the patient's preferences (Drachsler et al. 2012; Hesselink et al. 2014).

26.4.3 Patient Involvement

Patients who experience discharge management are more satisfied with the care they received in and outside the hospital than those who did not receive this service (Abad-Corpa et al. 2013; Shepperd et al. 2013). This introduces another important actor of the discharge process, who is often not sufficiently included as an active participant in the care process: the patient. The mostly passive role of the patient to date is slowly changing in many aspects of the healthcare system, but particularly in successful discharge management. The patient is an important, if not the most important, actor in the process of care after treatment. This is also reflected in the shift of responsibilities: Patients are becoming increasingly responsible for their own health and wellbeing. One crucial component needed for patients to assume a more active role is information and education which they increasingly demand and wish for (Mohr 2009). Research shows that the patient's involvement is positively influenced when she or he is provided with information regarding the discharge—written or verbal—and when she or he is given guidance, for example via counselling, follow-up calls or home visits (Hesselink et al. 2014). If not informed and integrated appropriately, patients may not be able to meet the expectations of being responsible actors in this process (Philibert and Barach 2012). Discharge management should not only aim at improving coordination of care, but also at including the patients into decision-making processes (Abad-Corpa et al. 2013).

Bender (2013) summarizes the findings of various studies highlighting the main problems patients and their relatives experience during the discharge process. These problems can be encountered pre-discharge, inside the hospital setting during the discharge process and post-discharge, in the out-patient setting (see Fig. 26.3).

Besides the patients themselves, their relatives are important actors to be involved in discharge management. Relatives often bear a large share of the responsibility of providing and guaranteeing immediate follow-up care after patients are discharged (Pilgrim and Kittlick 2013). Informing them in a timely manner about the various challenges, changes and needs will lead to better care for the patients.

26.4.4 Information Exchange and Technology

Another common challenge related to planning discharge processes is connecting the various actors. Technology can help improve this process by, for example, enabling care providers to communicate via a common electronic patient record (Pilgrim and Kittlick 2013). In many countries, such records are already being

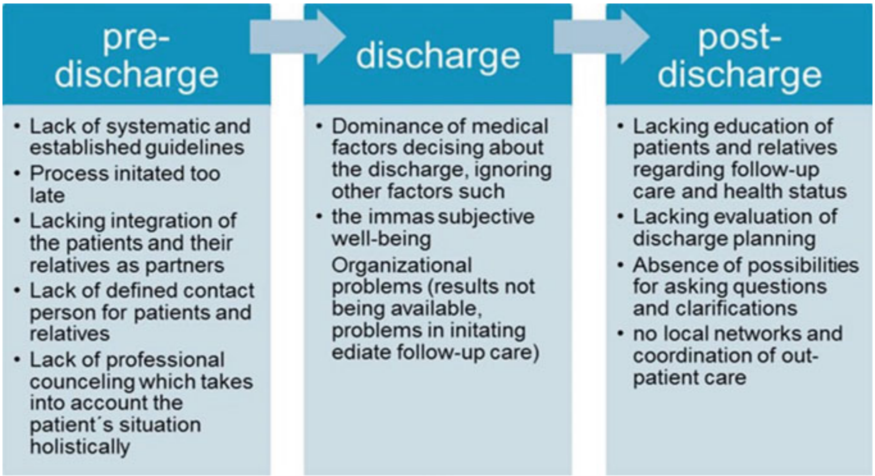

Fig. 26.3 Problems experienced with discharge management by patients and relatives. *Source* Adapted from Bender (2013)

widely used. Other countries, such as Germany, are far behind—especially due to restrictive data protection policies (Amelung et al. 2016).

For successful discharge planning, it is crucial that relevant information is exchanged between care providers and that it is available for the follow-up care givers as soon as possible. This also includes the need for complete, accurate and understandable documents as well as the adequate transmission of information which can be via the patient or electronic means (Hesselink et al. 2014). The review by Hesselink et al. (2014) finds that using standardized procedures such as discharge letter templates, planning guidelines, or medication reconciliation checklists has proven to be an effective tool.

26.4.5 Early Initiation and Predictive Models for Discharge Management

Besides coordinated communication, the importance of an early initiation of the discharge process is emphasized, so that the various actors involved can be contacted and coordinated as needed (Harbord 2009). This should also include early screening of high-risk patients upon admission (Wong et al. 2011; Müller and Deimel 2013). Early initiation of discharge processes has been shown to lead to a significant reduction in re-admission rates one and twelve months after discharge from the hospital compared to standard care (Fox et al. 2013). Early initiation of discharge management was defined as initiation during the acute phase of the medical condition. If patients were readmitted, early discharge management reduced the average hospital stay by 2 1/2 days. Mortality, however, did not vary between the treatment and the control group. Not just early discharge management, but any discharge management has been shown to have a positive effect on the length of hospital stay, especially for elderly patients, and re-admission rates (Shepperd et al. 2013; Rennke et al. 2013).

Models that predict the likelihood of readmission and the occurrence of health problems are a useful tool to support early initiation of the discharge process. Such models can be used to guide discharge planning before the patient gets discharged. Administrative data are fed into the system. However, Escobar et al. (2015) found such models to rarely incorporate clinical and patient-reported data. In the USA, organizations such as Kaiser Permanente are increasingly using information from electronic medical records (EMR) for predictive models to generate scores indicating the severity of illness and longitudinal comorbidity (Escobar et al. 2015). Using the information and infrastructure available, Escobar et al. (2015) developed a predictive model that calculates a 7- and 30-day risk estimate to inform in-patient care givers as well as case managers outside the hospital setting to help preparing service delivery.

26.5 Conclusion

Discharge management is an essential—if not the essential—part of providing integrated care in all health systems. However, there is still a long journey towards guaranteeing adequate transitions for patients in most (if not all) health systems. Discharge management is one of the traditional managed care approaches which potentially leads to both—higher quality and reduced costs. The major challenge for its success is the existence of conflicting interests within the different sectors of the healthcare provision which come together in this process. If hospitals are not integrated in a larger system with a single financial responsibility for a defined population they will continue to optimize their individual value chain. Therefore, an adequate reimbursement system such as bundled payments is essential to enable a functioning discharge management system. Secondly, the different professional cultures in the various sectors need to be addressed adequately to be of value to the patient and not a barrier to optimal treatment. It must be in the interest of all parties to internalize the discharge management interfaces within a network of providers.

One factor is important to keep in mind: organizing and sustaining successful discharge management requires resources and comes at a cost (Shepperd et al. 2013). However, in the long run discharge management has high potential for increasing the efficiency of health systems. It has been shown that professionalizing discharge management can lead to reduced costs for healthcare provision (Shepperd et al. 2013). Nevertheless, coherent and reliable evidence is still missing.

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Polypharmacy and Integrated Care

27

Alpana Mair and Albert Alonso

27.1 Introduction

It has been estimated that the global population aged over 65 years will double from 8% in 2010 to 16% in 2050 (WHO 2011). In 2015, approximately 5% of the population in OECD countries were aged 80 years and above, a percentage that is expected to rise to more than double by 2050 (OECD 2017).

In Europe, advances in healthcare, education and socio-economic circumstance mean that in most countries people can now expect to live beyond the age of 80. However, evidence shows that the average healthy life years (HLY) for EU citizens is only 61 years meaning that many people are living for around twenty years in sub-optimal health. First, the global population faces a demographic shift with the proportion of older population groups on the rise

Multimorbidity is defined by the World Health Organization as the co-occurrence of two or more chronic medical conditions in one person (WHO 2008). Patients with multimorbidity may require medicines to treat each condition, which can lead to polypharmacy. Currently around 50 million EU citizens are estimated to have multimorbidity. Most of them are 65 years and over, and this number is expected to

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continue to increase (OECD 2017). Epidemiological data indicates that multimorbidity increases markedly with age. In a Scottish study, multimorbidity was prevalent in 81.5% of individuals aged 85 years and over, with a mean number of 3.62 morbidities (Barnett et al. 2012). Ornstein et al. found that the most prevalent chronic conditions in primary care were hypertension (33.5%), hyperlipidemia (33.0%) and depression (18.7%) (Ornstein et al. 2013). The presence of multiple morbidities is associated with multiple symptoms, impairments and disabilities. Multimorbidity may result in a combined negative effect on physical and mental health, and can have a major impact on a person's quality of life, limiting daily activities and reducing mobility (Boyd and Fortin 2012; Wister et al. 2016). The need to take multiple medications can be just as problematic, resulting in frequent healthcare contacts and an increase in the likelihood of medication-related harm (Doos et al. 2014). Furthermore, it imposes a large economic burden due to patients' complexity of healthcare needs and frequent interaction with health services, which may be fragmented, ineffective and incomplete (Picco et al. 2016).

Population-level data also shows that multimorbidity and polypharmacy affect adults up to ten years earlier in deprived communities (Barnett et al. 2012). The burden of multiple diseases in areas of deprivation can have a combined effect on physical health, the quality of day-to-day living and mental health.

27.1.1 What Is Polypharmacy?

Polypharmacy is the concurrent use of multiple medications, and while polypharmacy is often defined as routinely taking a minimum of five medicines, it is being more frequently suggested that the emphasis should be on evidenced-based practice (Scottish Government Polypharmacy Model of Care Group 2015; Masnoon 2017). All medications that a patient is taking should be considered including traditional medications as well as herbal preparations and those purchased by the patient, over the counter.

27.1.2 Why Is It Important to Address Polypharmacy?

The rise in the prevalence of multimorbidity (the co-occurrence of two or more chronic medical conditions in an individual person) in ageing societies is one of the greatest challenges now faced by health services internationally (WHO 2008). Despite this, most medical research, guidelines and contractual agreements (such as pay-for-performance initiatives) are focused on the management of single disease states (Barnett et al. 2012; Ornestein et al. 2013). In these patients, individually treating each condition inevitably leads to the use of multiple medications (polypharmacy), without proper consideration of the risks and benefits of which are largely unproven and often unpredictable.

It is important to note that polypharmacy is not inappropriate per se (see below), and it is often appropriate (Scottish Government Polypharmacy Model of Care

Group 2018). For example, effective secondary prevention of myocardial infarction requires the use of at least four different classes of drugs (antiplatelets, statins, angiotensin-converting enzyme inhibitors and beta blockers). However, polypharmacy becomes inappropriate when the risks of multiple medications begin to outweigh their potential benefits for an individual patient (Scottish Government Polypharmacy Model of Care Group 2015).

Appropriate polypharmacy is present, when: (a) all drugs are prescribed for the purpose of achieving specific therapeutic objectives that have been agreed with the patient; (b) therapeutic objectives are actually being achieved or there is a reasonable chance they will be achieved in the future; (c) drug therapy has been optimised to minimise the risk of adverse drug reactions (ADRs) and, (d) the patient is motivated and able to take all medicines as intended.

Inappropriate polypharmacy is present, when one or more drugs are prescribed that are not or no longer needed, either because: (a) there is no evidence based indication, the indication has expired or the dose is unnecessarily high; (b) one or more medicines fail to achieve the therapeutic objectives they are intended to achieve; (c) one, or the combination of several drugs cause inacceptable adverse drug reactions (ADRs), or put the patient at an unacceptably high risk of such ADRs, or because (d) the patient is not willing or able to take one or more medicines as intended.

Therefore, appropriate polypharmacy should be considered at every point of initiation of a new treatment for the patient, and when the patient moves across different healthcare settings.

The risk of harm is generally higher in older people with multimorbidity than in younger patients due to their reduced ability to clear drugs (e.g. due to renal and/or hepatic impairment) and increased vulnerability to drugs' adverse effects (due to general frailty and drug–drug and drug–disease interactions) and medication burden (Köberlein et al. 2013; Shippee et al. 2012). However, the increased risk of harm is not always offset by increased benefits, and for many preventive medicines, such benefits may never be realised due to a shortened life expectancy.

There is mounting evidence that polypharmacy is a public health threat and a major source of unnecessary harm, greater use of health services, hospitalisation, reduced quality of life and substantial financial cost to healthcare systems (Köblerlein and Jürges 2013; Duerden 2013). In 2012, the US Institute for Healthcare Informatics estimated that inappropriate polypharmacy contributes to 4% of the avoidable costs of health care, equating to an expenditure of $18 billion worldwide, and one recommendation was to support pharmacist collaboration with physicians for medication reviews (IMS 2012). Up to 11% of unplanned hospital admissions in the UK are attributable to mostly avoidable harm from medicines, and of these, over 70% are in elderly patients on multiple medicines. There are,

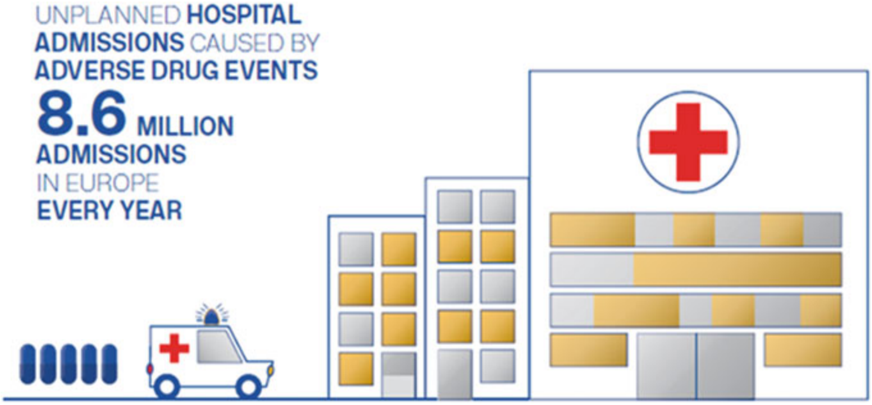


Fig. 27.1 Unplanned hospital admissions caused by adverse drug events across the EU each year. *Source* (Mair et al. 2017)

therefore, significant opportunities to reduce this burden by timely and effective interventions (Kongkaew et al. 2013). If this was extrapolated across the EU, this would result in 8.6 M admissions due to adverse drug effects (Fig. 27.1).

In view of this evidence, the World Health Organization (WHO) has recognised polypharmacy as a global challenge and has included it as part of the third global patient safety challenge, Medication Without Harm (WHO 2017; Mair 2019).

27.2 Polypharmacy Management

Polypharmacy management is a whole system approach which optimises the care of multimorbid patients through maximising benefit while reducing the risks of inappropriate polypharmacy.

27.2.1 Prevalence of Polypharmacy

Polypharmacy is a growing public health issue occurring within all healthcare settings worldwide and affects low-, middle- and high-income countries. A recent report has summarised some of the recent data (Mair 2019; WHO 2019). However, the difficultly is that, globally, different operational definitions of polypharmacy are adopted, with variation in the structure of health and care delivery systems and variation in data collection methods, thus making country comparisons difficult.

The burden of multiple treatments can be just as problematic, causing frequent healthcare contacts and an increased likelihood of medicine side effects, adverse drug reactions and interactions. As well as the burden of treatment, medication adherence is an important factor to consider. This might be intentional (where the patient will make a decision not to take the medication due to concerns they may have) or unintentional non-adherence (where the individual wants to follow the directions but is unable to do so because of practical barriers).

Non-adherence to prescribed medicines is a major public health issue, intricately related to multimorbidity and polypharmacy. Research suggests that between 50 and 80% of patients with chronic conditions may be non-adherent, depending on the clinical condition being studied. Non-adherence has been estimated to be responsible for 48% of asthma deaths, an 80% increased risk of death in diabetes and a 3.8-fold increased risk of death following a heart attack (Elliot 2009). It has been estimated that non-adherence to medicines costs the European Union EU 125 billion annually (PGEU 2008).

The European Innovation Partnership on Active and Healthy Ageing had a target to increase the average healthy lifespan of citizens by two years by 2020 (European Commission 2009). The partnership sought to identify and share good practice and drive research and innovation. One of the partnership's action groups, "Prescribing and Adherence to Medical Plans", includes a focus on multimorbidity, polypharmacy and adherence.

27.2.2 Appropriate Polypharmacy and Integrated Care

The impact of inappropriate polypharmacy on health and economic outcomes is well established, but addressing it remains a challenge.

Polypharmacy management seems to be well aligned with current trends in health care: it adopts a patient-centric perspective, and it assumes a multidisciplinary holistic approach. But these characteristics alone seem to be insufficient to ensure incorporation in routine practices at large scale. In this regard, a review done in the context of the EU-funded project Stimulating Innovation in the Management of Polypharmacy and Adherence in the Elderly (SIMPATHY), exploring existing polypharmacy initiatives, could not find developed activities in nearly half of the cases (Mair et al. 2017).

However, the review also threw some light on the apparent contradiction of having established evidence, good alignment but limited adoption. In those cases where polypharmacy initiatives existed, the review noted a disparity of settings (community pharmacies, primary, intermediate and hospital care) and significant variability in the role and involvement of professionals (independent pharmacist prescribers, physician in collaboration with pharmacist, multidisciplinary teams). But, more importantly, the polypharmacy management initiatives identified presented the common characteristic of having been developed within the context of larger initiatives. These initiatives could have had different origins and motivations: an increased focus on older, more complex patients, medication safety or workforce development; but all of them provided a context for polypharmacy activities to happen.

The above-mentioned particularities around the deployment of polypharmacy initiatives point to the fact that polypharmacy management must be understood as a complex intervention (Craig et al. 2006). Therefore, it might be probably wrong to address it in isolation. Rather, we need to consider it in the context of other complex, system-level approaches and, in particular, the framework provided by Rainbow Model of Integrated Care (RMIC) (Valentijn et al. 2013). RMIC was originally designed to address multimorbidity in old people. It represents the needs of integration at the system, organisation, professional and clinical levels to achieve optimal clinical outcomes. Each of the levels shows overlaps with topics that were well identified in the SIMPATHY review: professional integration, the value of health professional training, a focus on collaboration and teams, and the importance of developing the professional roles of different providers.

Therefore, it seems reasonable to consider integrated care as an appropriate lever to facilitate the deployment and transferability of polypharmacy management initiatives.

27.2.3 How to Undertake a Polypharmacy Review

When undertaking a polypharmacy review, a recommended way to assess the appropriateness of a prescription is to take a holistic review of the medication in discussion with the patient or carer so that the patient's life priorities are considered.

Case Study

Mrs. MP is an 80-year-old woman with a history of cardiovascular disease (hypertension, angina and type 2 diabetes). She also has osteoporosis, walks with a walking aide (a walking stick) and suffers from chronic back pain. She experiences a period where she is unable to move, and GP wonders if it might be polymyalgia rheumatica and prescribes a long course of steroids. However, with these the lady feels breathlessness and says that she has fluid retention around her stomach and feeling uncomfortable. She then reduces her steroid dosage by herself which she felt had no impact on her mobility. However, she is cautioned by her GP for taking this action.

One such example is the 7-step process which addresses all the dimensions of quality in health care, and this should also be applied at point of initiation of treatment and undertaken when a patient moves across care transitions. The steps have been developed on processes to consider medication appropriateness, such as medication appropriateness index (MAI) and the Pirmohamed study (2004) and tools such as BEERs and STOPP/START that identift medicines that should betargeted to prioritse for review.

These 7 steps are described below (Fig. 27.2):

The 7 steps are described below:

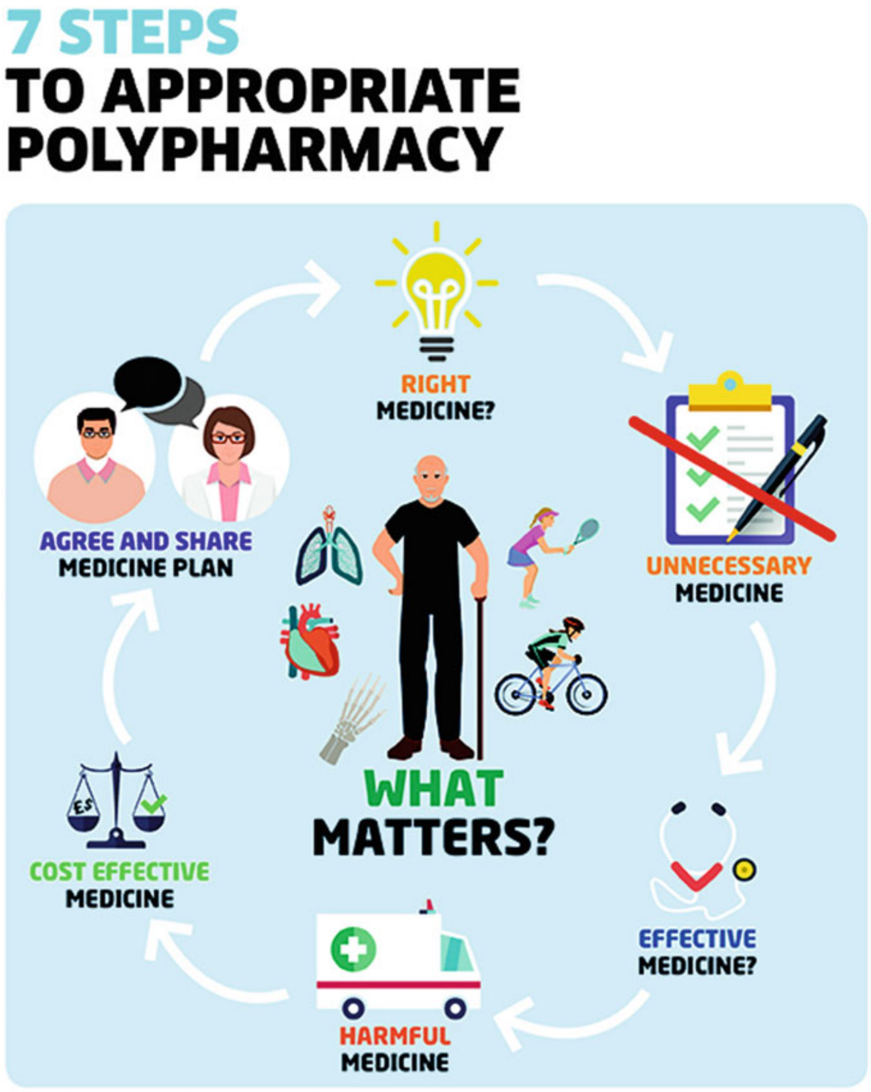


Fig. 27.2 Seven steps to appropriate polypharmacy. *Source* Scottish Polypharmacy Guidance, 2018

Step 1: What matters to the patient
The initial step is to find out "what matters to the patient" and assess medication need.

Step 2: Unnecessary medication
It is important here to consider which medicines are essential for the patient, e.g. thyroxine or those that are needed to prevent symptom decline such as diuretics in heart failure.

Step 3: Necessary medication

Those medicines that would be considered to be non-essential where there is no longer an evidence base for continued use, time-limited (e.g. proton pump inhibitor) or where there is marginal benefit or questionable benefit (e.g. preventative treatment in those with questionable benefit; for example, preventative treatment in those with short life expectancy). Therefore, in order to aide decision-making it is helpful to look the numbers needed to treat for the medications that are commonly prescribed and how they were derived.

Assessing risks and benefits

To facilitate the medication review, prescribers need practical tools and information to help with decision-making on the safety and effectiveness of medicines and the appropriateness of initiating or continuing long-term medications (Mair et al. 2017). One useful measure which helps prescribers to understand the probable clinical efficacy of a medicine is the number needed to treat (NNT).

The **number needed to treat (NNT)** is a measure used in assessing the effectiveness of a particular intervention. The NNT is the *average* number of patients who require to be treated for one to benefit compared with a control in a clinical trial. It can be expressed as the reciprocal of the absolute risk reduction.

The ideal NNT is 1, where everyone improves with treatment: the higher the NNT, the less effective is the treatment in terms of the trial outcome and timescale.

So if treatment with a medicine reduces the death rate over 5 years from 5 to 1% (very effective), the absolute risk reduction is 4% (5 minus 1), and the NNT is 100/4, (25).

The NNT is only a statistical estimate of the average benefit of treatment, usually calculated based on clinical trials. It is rarely possible to know precisely the likely benefit for a particular patient. However, NNT still remains a universal concept to assess the efficacy of medicine. Several tables and further information are available on NNT, which can support prescribers in decision-making and aid discussions with patients regarding the potential benefits of their treatment (Scottish Government Model of Care Polypharmacy Working Group 2015, 2018; NNT group 2018).

Similarly to NNT, another measure used in decision-making is the number needed to harm (NNH). The NNH is the average number of people taking a medication over a time period in order for one adverse event to occur. This concept is not as widely used as the NNT. Combined with NNT, the overall benefit-to-risk ratio (NNT/NNH) should be considered for individual patients during the decision-making process. In polypharmacy, this ratio may vary considerably between patients (Eff Prescr. Ther 2019). For several commonly used medications, there are some NNT and NNH estimates for older people available.

Ideally, such information on risks and benefits is made accessible and comprehensible for the public, in order to include patients in the decision-making process. For example, a Scottish polypharmacy guidance tool helps healthcare professionals work in partnership with patients. This resource is available as a combined mobile application and website that outlines the process for initiation and the review of treatments (Eff Prescr. Ther 2019).

Step 4: Optimising medication effectiveness

In order to minimise the harm from medication, there are factors that should be considered. This can be factors such as the health status, multiple morbidity that the individual has as well as high-risk medications, and these are dealt with below.

What are the patient risk factors for adverse reactions?

There are several factors that will increase the vulnerability of a multimorbid or frail patient to drugs. These factors include age-related changes in drug clearance (due to renal or hepatic impairment or drug–drug interactions) and volume of distribution (due to reduced body water and serum albumin concentration), which can lead to drug accumulation reaching toxic levels and acute renal failure (Rawlins 1977). Heart failure may further compromise kidney and liver function (Dumbreck et al. 2015; Lindblad et al. 2006; Taber et al. 2014; Hayward et al. 2016; Chang et al. 2012; Sutaria et al. 2016). Therefore, it is important to review the dose of medication in patients with impaired organ function, using a start low, go slow approach, with careful titration while monitoring effects and adjusting drug doses in a timely fashion. There may also be specific risk factors such as peptic ulcer disease for oral corticosteroids or selective serotonin reuptake inhibitors

Step 5: Is the patient taking any high-risk medications or experiencing adverse drug reaction?

From empirical and consensus-based studies in both primary and secondary care, many tools have been developed to identify high-risk medications and also prioritise patients for review. A recent review and national guidance set this out and which drugs should be considered (Mair et al. 2020; Scot Gov 2018).

In summary, the main areas that could be considered are:

(a) Non-steroidal anti-inflammatory drugs and antithrombotics.

Gastrointestinal bleeding due to NSAIDs and antiplatelet agents was the leading cause of drug-related hospital admissions, accounting for approximately a third of all drug-related admissions and half of drug-related deaths (Pirmohamed et al. 2004).

(b) Antipsychotics
Used with aim of reducing symptoms of stress and distress in people with dementia. Drugs have (time-) limited benefits, and elderly patients are

particularly vulnerable to their adverse effects (Maust et al. 2015), so should be used as the last resort.

(c) Long-term use of benzodiazepines (hypnotics and anxiolytics)

Long-term use is not appropriate (Nazareth and Burkhard 2016) and is associated with numerous risks, including drowsiness and falls, forgetfulness, confusion, depression, irritability, aggression, impulsivity, digestive problems and dependence. The maximum recommended duration of treatment for most patients is three to four weeks.

(d) Antidepressant drugs

Antidepressant drugs are effective for treating moderate to severe depression associated with psychomotor and physiological changes such as loss of appetite and sleep disturbance (BNF 2020). Patients' treatment should be monitored every one to two weeks at the start of treatment and, following remission, should be continued at the same dose for 6–12 months after individual assessment.

Antidepressants have been implicated in causing falls, and some patients report a withdrawal effect on discontinuation.

Some tricyclic antidepressants (TCAs) are also used at low doses for the management of neuropathic pain. TCAs have more anticholinergic and cardiotoxic effects than most other antidepressants and should be used with particular caution in patients with cardiovascular comorbidities.

(e) Anticholinergics

Apart from causing symptoms such as dry mouth, constipation and urinary retention, exposure to anticholinergic agents has also been linked to impaired cognition as well as increased risk of falls, functional decline, cardiovascular events and mortality.

The anticholinergic effects are dose-dependent (Risacher et al. 2016; Nishtala et al. 2016; Bishara et al. 2016); however, sensitivity to anticholinergic effects varies significantly between individuals. It is therefore essential to understand an individual patient's experience.

(f) Centrally acting analgesics

Honest conversations may be required to manage patients' expectations as many patients with chronic pain do not achieve full symptom remission. This may help patients cope on a day-to-day basis. In addition to opioids, gabapentin and pregabalin have been associated with dependency, harm and abuse (Public Health England 2014; Wills 2005).

(g) Antihyperglycemics

There are some important principles to consider when managing diabetes in people who are older and/or frailer, especially when they have comorbidities. Smoking cessation, adequate blood pressure control and lipid management are also indicated in patients with type 2 diabetes and, for many patients, may take priority over achieving glycemic control, especially for preventing macrovascular complications (Qaseem et al. 2018; SIGN 116 2017). Tight glycemic control (HbA1c $<$ 53 mmol/mol) may be appropriate in patients who are relatively healthy, have a long life expectancy and will live long enough to derive the benefits, such as reducing microvascular events (Qaseem et al. 2018; SIGN 116 2017).

As life expectancy reduces, patients will reach a tipping point when tight glycemic control does more harm than good, and their management should be reviewed.

(h) Medications associated with increased risk of falls

Certain medication classes, including benzodiazepines, antidepressants, antipsychotics, antihypertensives and diuretics, have been associated with an increased risk of falls, and detail can be found in the review, *"Addressing the challenge of polypharmacy"* (Mair et al. 2020).

Falls and fall-related injuries are common in the elderly, with about 30% of community-dwelling older adults falling every year and about half of these experiencing multiple falls. In those older than 80, this can rise to 50% (O'Loughlin et al. 1993). Risk factors for falls are complex and involve intrinsic and extrinsic risk factors, and medications are modifiable extrinsic risk factors. Polypharmacy has also been linked to falls in many studies, and this risk is exacerbated when there are specific fall-inducing drugs or combinations of drugs (Beers criteria 2015).

Step 6: Cost-effective medicine

Is the medication the most cost effective for the patient?

Step 7: Agree and share the plan with the patient

In this step, it is important to consider if the patient is willing and able to manage their medicines in a way that avoids non-adherence to medication. In order to consider this, Adopting a person centred decsion-making approach is recommended as described in the next section.

27.3 Patient-Centred Decision-Making

For patients with multiple morbidities, therapeutic decision-making should be made by clinical evidence together with what is known about the pharmacological principles. Patient decision involves balancing risks and benefits of the drug treatment with a patient's clinical and psychosocial circumstances and preferences. Additional factors that should be considered are:

(i) Frailty

Frailty due to a general reduction in homeostatic reserves in an individual is often associated with polypharmacy (Saum et al. 2017).

Polypharmacy may be both a consequence and a cause of frailty, while frailty also increases vulnerability to adverse drug events (Saum et al. 2017; Konig et al. 2018; Clegg et al. 2016). In patients with frailty, the balance of risks and benefits, especially of preventive treatments with delayed benefits, will therefore be less favourable, and a drug's continued use should be scrutinised.

(ii) Multiple morbidity and deprivation

Epidemiologic data indicates that multimorbidity increases markedly with age, being prevalent in almost two-thirds of individuals aged 80 years and older (Barnett et al. 2012; Ornestein et al. 2013). On average, those with multimorbidities have at least three long-term conditions, with cardiovascular (87.7% of individuals), metabolic (e.g. diabetes; 62.2%) and rheumatoid conditions (40.2%) being the three most common. Multimorbidity is associated with increased economic burden due to complex healthcare needs with greater use of health services, including interactions with community-based health services (twice as high as non-multimorbid) and hospitalisation (three times higher) (Koberlein et al. 2013; Clegg et al. 2016; Benetos et al. 2015; Hansen et al. 2010; Boyd and Fortin 2010; Van den Bussche et al. 2011; Panagioti 2015). In addition to age, deprivation greatly impacts both multimorbidity and polypharmacy. Programmes should therefore consider how they widened their focus to include patients with multiple morbidities who are on 10 or more medications, irrespective of age (Scot Gov 2018).

(iii) Adherence

Step 7 of the seven-step drug review process outlined in the NHS Scotland Polypharmacy Guideline is designed to enable discussion of adherence issues as part of the review, checking patient understanding and involving the patient throughout in shared decision-making (Health lit place 2019).

Case Mrs. MP: With the 7-step approach, the prescriber would have found through step 1, what was important to her and the needs of the medication. The risks and benefits of the oral steroids should be considered as she has osteoporosis, step 3. Step 4 identifies that the medication is not working, and step 5 would address that she was experiencing side effects from the oral steroids.

27.4 Which Patients Should We Prioritise for Review?

Patients with the highest risk of inappropriate polypharmacy are those with the greatest frailty, on the most medicines, and taking high-risk medicines (Scot Gov 2015; Panagioti et al. 2015). The most vulnerable patient groups often include older patients above the age of 65 and patients who are living in care homes who are susceptible to effects of drug–drug interactions, a higher risk of falls, adverse drug reactions, cognitive impairment, non-adherence and poor nutritional status (Panagioti et al. 2015; Shah et al. 2012; Davies et al. 2015; Hubbard et al. 2013; Molokhia et al. 2017; Stewart et al. 2016). Identifying such patients is substantially facilitated when electronic medical records are available so that the assessment of risk factors, including high-risk or potentially inappropriate prescribing, can be automated.

Where this is not the case, it might be appropriate to discuss or prioritise patients by the following:

- Patients are on high-risk medications (mediations causing harm) as defined by empirical studies or known criteria (Pirmohamed and BEERS, STOPP/START)
- Those in care home as they tend to be frail
- Those in deprived communities who are taking or need to be taking multiple medications
- Adults of any age approaching the end of life
- Those over the age of 75 taking 10 or more medications

27.5 How to Implement a Polypharmacy Programme

The Stimulating Innovation in the Management of Polypharmacy and Adherence in the Elderly (SIMPATHY) was an EU project that was undertaken in the EU. It identified six key principles to ensure a successful implementation of a programme:

(a) Use a systems approach that has multidisciplinary clinical and policy leadership.
(b) Nurture a culture that encourages and prioritises the safety and quality of prescribing.
(c) Ensure that patients are integral to the decisions made about their medicines and are empowered and supported to do so.
(d) Use data to drive change and measure outcomes.
(e) Adopt an evidence-based approach with a bias toward action.
(f) Utilise, develop and share tools to support implementation (Mair et al. 2017).

27.6 How to Measure Effectiveness of a Programme

In order to measure the effectiveness of any programme, initial benchmarking is essential. The aim of a polypharmacy programme should be to ensure patients are on appropriate medication. As a result, deprescribing may be needed but should not be the aim. Deprescribing is the process of reducing and stopping medication. The national programme in the UK found that when taking this approach on average, 1–2 medicines were stopped per patient per review, so that the rates of polypharmacy decreased. However, in terms of measuring for appropriate prescribing, use of medication safety indicators is more appropriate.

Countries such as Scotland and Sweden have a range of indicators that are used nationally, and the OECD has also identified a couple of these indicators.

27.7 The WHO Challenge: Medication Safety in Polypharmacy

In March 2017, the WHO launched its third patient safety challenge, *Medication without Harm* (WHO 2017). Patient safety is an important component of healthcare delivery which is essential to achieve universal health coverage and move towards the Sustainable Development Goals. It is estimated that over half of medicines globally are prescribed, dispensed or sold inappropriately. Medicines are the most common therapeutic intervention, and in recognition of this, the goal of the challenge is to reduce severe avoidable harm by 50%, over the next five years. It is estimated that globally the annual costs associated with medication errors are US $42 billion.

This challenge like the previous challenge recognises that errors are not inevitable. Human factors such as fatigue, poor working environment and staff pressures might lead to errors during the stages of the medication process. Such errors could occur at prescribing, transcribing, dispensing, administration and monitoring that result in harm and can result in death. Although the majority of errors occur on administration of medicines, they can occur at any stage of the process.

The challenge sets out a strategic framework to consider the fundamental problems and how healthcare professionals and the public can play an active role in taking this forward:

- **Patients and the public**—Patients are not always health literate so how can we support patients make taking their medications safer?
- **Medicines**—Within the pharmacy, with complex names and packaging that can either “look alike or sound alike”, can be a common source of error and medication-related harm that can be addressed. Information has also been produced to support patients with the safe management of their medication.
- **Healthcare professionals**—How do healthcare professional need to work across the multi-professional teams to prevent any increased risk in harm to patients.
- **Systems and practices of medication**—Consider the process across the organisation that could have an impact on the safety of medication use. For example, the process of prescribing medication for patients should be shared across the organisation so that the patient does not receive conflicting messages. The culture across the organisation should also support multi-professional discussions regarding medication.

In order for the challenge to make improvement, key stages of the medication process have been identified: prescribing, dispensing, administering, monitoring and use.

The WHO has identified three early priority areas, and these are illustrated by considering the following case:

Mrs W is a regular customer who is 58 years old. She has a history of asthma and COPD, and you regularly dispense inhalers for her. Recently, you notice that she has not been herself and has bought some over the counter remedies for back pain, co-codamol (a combination of paracetamol and codeine) tablets after an injury of falling off the pavement a couple of months ago when the weather was bad and the ground slippery. The pain has stopped her doing her normal activities, and she tells you that she's looking for some anti-inflammatories and something to pick up her mood and help her sleep. Her friend told her that ibuprofen should help and St John's Wort is a pretty good pick me up and she's been taking these for the last month. She also presents a prescription for omeprazole for indigestion and heart burn.

- **Medication safety in high-risk situations**
  This will be considering either situation where medications of high risk or situations are inappropriate. In the scenario above, the high-risk situation is the lady buying multiple medications and also the fact that some of the medications she is self-medicating with are medications that are known to either cause admission to hospital or have a higher likelihood of causing harm (Routledge, WHO 2019)
- **Medication safety in polypharmacy**
  As people suffer from multiple morbidities, they take more medications. The challenge is to ensure that the patient will gain benefits from these medications as they are added in and not experience any harm. In the UK, up to 11% of all admissions to hospital have been estimated to be due to medications with half of these being preventable (Mair, WHO 2019).
- **Medication safety in transitions of care**
  It is important that as patients move to access care across care settings the same principles are applied. Therefore, as the lady approaches the pharmacy to add to her treatment, we need to ensure that the medications are appropriate and that none of the medications are going to be harmful (Kirke, WHO 2019).

27.8 Case Study

The following case study provides examples of how different countries have tried to address the challenge of addressing appropriate polypharmacy and integrated care.

The EU-funded SIMPATHY project (Stimulating Innovation Management of Polypharmacy and Adherence in the Elderly) had the goal of delivering tools to implement polypharmacy management programmes throughout the EU in the context of quality, economic and political factors.

The project included a range of case studies (summarised in this section), benchmarking survey and literature reviews. The research demonstrated that there are some effective polypharmacy management programmes in the EU, but that they are too few in number.

In its final report (see www.simpathy.eu), the project made a call for EU countries to work together in a focused way to manage and prevent inappropriate polypharmacy, and improve medicine adherence, through the use of a change management approach that is coordinated and collaborative in order to deliver better patient outcomes. It suggested six key recommendations and developed a roadmap that depicted healthcare teams and healthcare processes against this vision (Fig. 27.3).

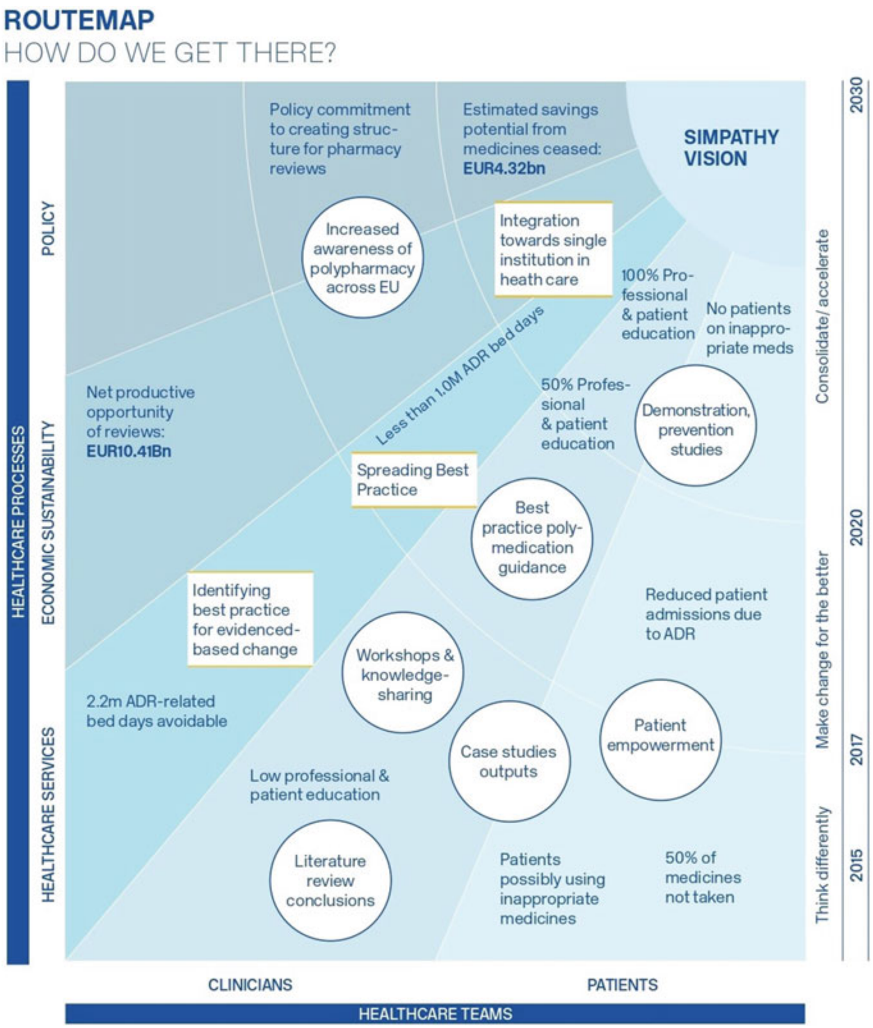


Fig. 27.3 SIMPATHY route map to address polypharmacy across the EU *Source* (Mair et al. 2017)

27.8.1 Scotland: Changing Culture to Implement at Scale

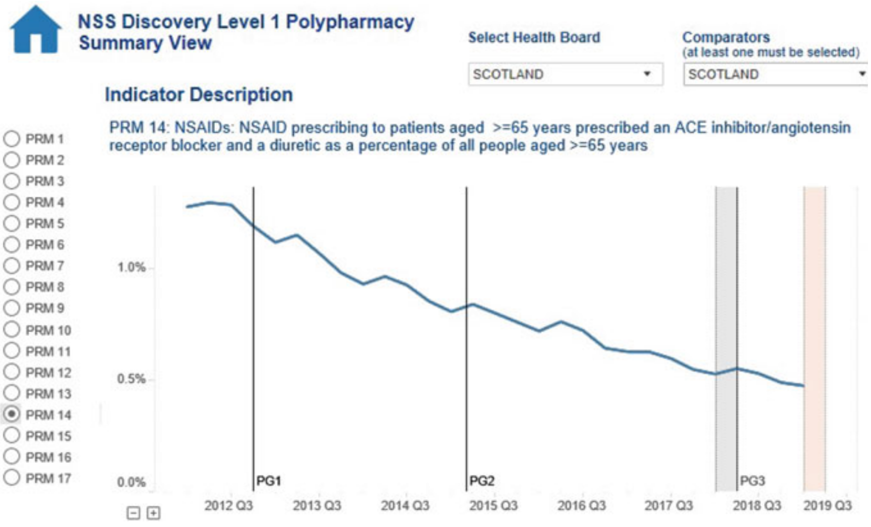
In Scotland, since 2012, a system's wide approach has been taken to implement the 7-step process described in the chapter, nationally. In order to do this, a change management process was used to facilitate the change, notably Kotter's 8 steps (Kotter, 2017).

Through this, a multidisciplinary team, a pharmacist working in each general practice was implemented to ensure patients received polypharmacy reviews.

As a result, in Scotland, outcome measures include monitoring the prevalence of specifically targeted high-risk prescribing and are focused on improving the quality of prescribing appropriateness and safety. This is ongoing, with current work looking at changes in the incidence of admissions related to over- or under-treatment with medications. The figures below show the stabilisation and later reduction in polypharmacy in the elderly following publication of the guidance in 2012 and reductions in high-risk drug combinations (here NSAIDs with ACEI/ARBs and diuretics) since publication of the guidance in 2012, respectively (Figs. 27.4 and 27.5).

27.8.2 Catalonia: Government Sponsored and Institutional-Based Programmes

In Catalonia (Spain), two distinct models in different practice settings were identified: a government-sponsored programme targeting complex chronic patients in



NSS Discovery Level 1 Polypharmacy Summary View

Select Health Board: SCOTLAND

Comparators (at least one must be selected): SCOTLAND

Indicator Description

PRM 14: NSAIDs: NSAID prescribing to patients aged >=65 years prescribed an ACE inhibitor/angiotensin receptor blocker and a diuretic as a percentage of all people aged >=65 years

● PRM 14

Fig. 27.4 Reductions in high-risk drug combinations with each publication of the polypharmacy guidance (PG). *Source* Colin Daly, Public Health Scotland

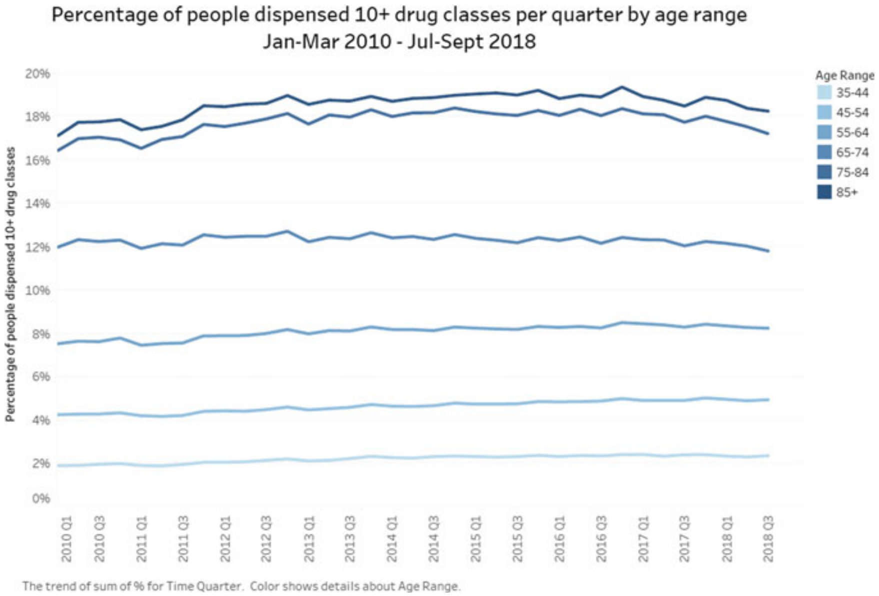


Fig. 27.5 Stabilisation and later reduction in polypharmacy. *Source* Colin Daly, Public Health Scotland

primary care and an institutional network programme targeting older adults admitted to hospital, long-term care or nursing homes. The government-sponsored model utilised a vertical approach to implementation, focusing primarily on patient safety and individual physician prescribing. The goal of this programme was to implement the programme in a standardised way throughout the entire primary care system. A major driver of this programme was the goals outlined in the Catalan Health Plan and the service contract between primary care centres and the government.

In contrast, the institutional network model utilised a horizontal implementation strategy led by both clinicians and managers in Consorci Hospitalari de Vic. The focus was on providing holistic patient-centred care via a multidisciplinary team, with polypharmacy management as one component. This component, named patient-centred prescription model (PCP), demonstrated positive impact in the improvement of medication appropriateness in frail patients. The model includes the following phases:

(a) Patient-centred assessment: This is a multidimensional geriatric assessment of clinical, functional, cognitive and social indicators. It is important to understand and keep in mind the progress of the chronic disease and to use this understanding to guide the establishment of the therapeutic goals.

(b) Diagnosis-centred assessment: Each medication should be mapped to a specific patient's health problem. For that health problem, it should belong to one of the following categories: preventive therapy, therapeutic/curative treatment or symptomatic therapy.

(c) Medication-centred assessment: Each drug should be assessed against its benefits/risks.

(d) Treatment plan: The resulting treatment plan represents an agreement among the participants in the multi-professional team, but it also needs an agreement with the patient and his/her carers. Therefore, proper communication is important.

27.8.3 Sweden: A National Legislation Model

In 2012, the Swedish government introduced national legislation to increase and ensure the quality, safety and sustainability of pharmaceutical care in Sweden, with a main focus on polypharmacy in the elderly. This legislation ordered medication reconciliation and comprehensive medication review to optimise the patient's medication treatment and to minimise the incidence of drug-related problems.

In spite of this, deployment across the different Swedish counties is somewhat variable. The national policy brought about some significant achievements. Thus, there are good sets of national prescribing indicators and studies that permit to show the importance and urgency of a polypharmacy management strategy. There are also key driving individuals, at healthcare facilities, university and governmental bodies, that are leading collaboration at regional level. Finally, the national policy facilitated the investment in education and the formation of multidisciplinary healthcare teams at regional level.

However, there has been no national strategy about how to fully implement and evaluate the medication review legislation and policies. This might have caused certain doubts about medication review as an essential and effective intervention and also because there was no consensus about by who and how these reviews should be performed.

27.8.4 Greece: Incipient Developments

Polypharmacy and adherence medication programmes are only starting in Greece. The activities of the Hellenic Society of Pharmaceutical Practice (HSPP) can be seen as an example of a good practice that fills gaps in the continuity of care, mainly at primary healthcare level. However, this is a voluntary not reimbursed initiative. At the completion of the SIMPATHY project, clear policies at country level did not exist.

Collaboration and partnership among stakeholders seem difficult to accomplish in Greece, notably in the context of a prolonged economic crisis that has imposed a "top-down" approach in the development of policies and the management of resources. For most health system administrators and managers, the main concern is budget and expenditure, with little time put on promoting innovative practices.

Provision of health care remains fragmented with poor coordination across level of care. And the way health professionals are trained (disease management and specific fields) further limits this communication. Additionally, the information technology available is applied to the collection of data and less to using data to support patient and medication management.

27.8.5 Italy: Growing Awareness and Pilot Studies

Similar to the case of Greece, at the time of completion of the SIMPATHY project, Italian Health Authorities had not released official policy statements or regulatory guidelines on polypharmacy. However, a growing awareness of the problem had been documented in different studies released by national study groups and scientific societies.

These studies recommended to take action at different levels. In order to improve the quality of prescribing for older people, training courses focused on multimorbidity and polytherapy management were needed within the healthcare curricula. Additionally, multidisciplinary teams should be promoted and computerised decision support systems should be used to support the application of appropriateness criteria.

The Campania Region and, particularly, the Naples metropolitan area are among the front runners in following some of these recommendations. A pilot study undertaken by several departments of Federico II University Hospital adopted a multidisciplinary approach to identify patients at risk of drug-related problems. This identification was then followed by medication review over a period of time. During this period, the application of inappropriateness criteria was supported by computerised decision support and electronic prescribing systems. In practice, the result was a comprehensive geriatric assessment model with a focus on achieving the best-tailored pharmacotherapy for each patient.

27.8.6 Northern Ireland (UK): A Regional Model for Medicine Optimisation in Older People

The strategic approach in Northern Ireland is one that embeds personalised care into daily healthcare practice for frail people. This includes: preventing disease progression, providing self-management care, personalised health care, optimising appropriate telehealth, improving prevention, early detection and risk prediction measurements and, importantly, involving older people as partners in care.

Multiple comorbidities and complex social needs are common among older people, as well as polypharmacy. In the integrated pharmaceutical care service established in Northern Ireland, a consultant pharmacist is tasked with the role of case managing older persons. This consultant pharmacist leads a specialist team working at the acute, intermediate and community interfaces. They act as medicine advocates for this old group of people with complex medicine needs while remaining an integral part of the multidisciplinary healthcare team.

The introduction of this consultant-pharmacist-led pharmaceutical care programme was recognised as a positive intervention that improved patient outcomes but also provided financial benefits to the healthcare sector. Since March 2016, the Medicines Optimisation Quality Framework provides guidance about the activities that people can expect when medicines are included in their treatment. The framework highlights the importance of appropriate polypharmacy and improved adherence in older people suggesting the scale-up of the consultant pharmacist model.

27.8.7 Poland: No Policies, Other Pressing Issues

At the time of completing the SIMPATHY project, no policies regarding polypharmacy had been approved in Poland, where polypharmacy was seen as a major challenge for Polish health care. A first initiative, promoted by the Ministry of Health, was the creation of a working group tasked with developing a pharmaceutical care programme. The main result was an Internet-based application to help pharmacists to prepare, analyse and correct pharmaceutical care plans and patient education.

Not all Polish health professionals share the same level of awareness about the importance of polypharmacy management, possibly due to the existence of more pressing health issues. Additionally, there is a lack of effective communication among professionals, notably between pharmacists and physicians, as well as a poor development of tools supporting information exchange (electronic patient records).

27.8.8 Portugal: No Programmes But Promising Measures

Portugal does not have any polypharmacy management programme, and there are no prospects for one in the near future. Awareness of its importance seems to be low. The latter might be related to the absence of national studies, deficient IT systems in healthcare institutions and lack of multidisciplinary culture in healthcare teams. It is also important to consider here the impact that the implementation of cost-effectiveness policies in recent years had in the healthcare landscape in the country. The cuts in budgets had a detrimental effect in many areas certainly limiting the adoption of innovative practices: reduction in the number of healthcare professionals; less investment in new technologies; limitation in the introduction of new drugs; and an intensification of medicine price control by the administration.

There are, however, some measures implemented in the Portuguese National Health System that could help to facilitate a polypharmacy management and patients' adherence programme in future. This is the case of the electronic prescription system already in use. Also, since all health system units/organisations are centrally administrated by the Ministry of Health and under the government's authority, the implementation of national strategic measures, once available, could be scaled up quickly.

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Digital Health Systems in Integrated Care

28

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28.1 Introduction

Information communication technologies, ubiquitous across different facets of societies globally, are increasingly central to delivery of health and social care services. The World Health Organization and European Commission have referred to these as eHealth or digital health (Commission 2012; WHO 2020). The growing literature in the space seems to agree of the potential value that digital health systems can bring to service delivery (Baltaxe et al. 2019) in particular its potential to improve quality of care delivery (Ossebaard and Van Gemert-Pijnen 2016). Digital health systems may play a particularly important role in the delivery of integrated health and social care, as suggested by Goodwin:

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> It is simultaneously the grease that allows integrated care systems to operate as smoothly as they can through good communication of information between care professionals and services users, but it is also the glue that binds care systems together. (Goodwin 2018)

Goodwin's contention that digital health technologies are both the "grease" and the "glue" of integrated models of care is an argument shared by many in the field. While obvious in their utility, adoption of digital health technology remains elusive for many organizations seeking to build integrated models of care. This chapter will overview how digital health technologies can be used to enable activities of integrated care, presenting three common integrated care "problems" that have been addressed using and implementing digital technologies, and offering practical recommendations and strategies to help you move your organization toward a network model (Europe et al. 2016).

28.2 Defining Digital Health-Enabled Integrated Care

To understand the role technology can play in integrated care, we must start with a clear definition of: (1) digital health technology and (2) integrated care. While the literature is wide and deep in both these areas, we offer here the more common definitions and frameworks as an introduction to the topic.

Digital Health Technologies

Digital health technologies, also often referred to as *health information systems* or *eHealth* technologies, have been defined and redefined many times in the literature. One of the most highly cited definitions of eHealth is from Eysenbach in 2001 (Eysenbach 2001) which places eHealth at the "intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies" emphasizing eHealth as being a "state of mind" that seeks to use information communication technologies to improve health care. Fundamental here are technologies that both enhance care delivery (e.g., diagnostic tools specific to healthcare) and business applications which supports organizing, planning, allocating resources and coordination of care across organizations, which are equally fundamental requirements for integrated network care services along with interoperability and exchange of information (Guldemond and Hercheui 2012).

Recent work by Shaw and colleagues sought to unpack the concept further and provide operational clarity, building on seminal definitions such as Eysenbach's to undergo an exploratory qualitative study with key informants in the field (Shaw et al. 2017). They identified three dominant purposes for digital health solutions:

(1) Monitoring and tracking health information for patients;
(2) Enabling communication between providers, patients and families; and
(3) Collecting, managing and using health data.

Numerous technologies exist today to support each of these three purposes. Telemonitoring systems that use phone, mobile and sensor-based technologies are being used to support the monitoring and tracking of patients. Mobile and web-based portal systems can also be used to support communication between providers, and medical record systems like electronic medical records (EMRs), electronic health records (EHRs), and patient personal health records (PHRs) can support the collection and management of data, while also enabling communication when messaging and shared systems are in place (Burton 2004; McLean and Sheikh 2009; Medicine 2003; Pagliari et al. 2007; Seto et al. 2012; Townsend et al. 2013). With the burgeoning area of artificial intelligence and machine learning, technologies like interactive "bots" that can support, or even take over, clinical decision-making (Huckvale et al. 2019) and therapy (Karyotaki et al. 2017), are likely to become prominent technologies to be considered when shifting to models of integrated health and social care service delivery.

Box 28.1 Definitions of digital health

There are many different terms and concepts related to digital health technologies. Here are some of the more prominent terms and their definitions.

eHealth: The "intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies" (Eysenbach 2001).

mHealth: A component of eHealth, mHealth or mobile health refers to the use of mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants and other wireless devices to support delivery of health care services and public health practices (WHO Global Observatory for eHealth; https://www.who.int/goe/publications/goe_mhealth_web.pdf).

Telehealth/telemedicine/telecare: Communication technologies used to support direct delivery of health and social care services to patients or users (Stowe and Harding 2010).

Electronic Health Records: It is an electronic record of patient encounters with the care delivery settings, which can include demographics, progress notes, problem lists, medications, vital signs, medical history, immunizations, laboratory data and radiology reports. EHRs include data from single or multiple care settings. HIMSS. (2018). Electronic health records. Retrieved from: https://www.himss.org/library/ehr.

Health Information Exchange: It is an exchange of health information between different systems that store patient data. Exchange can be directed (sending and receiving as part of coordinated care efforts), query-based (specific requests for information), or consumer mediated (patients aggregating and control their own health data) https://www.healthit.gov/topic/health-it-and-health-information-exchange-basics/what-hie.

Big data, health: "High volume, high diversity biological, clinical, environmental, and lifestyle information collected from single individuals to large cohorts, in relation to their health and wellness status, at one or several time points." https://genomemedicine.biomedcentral.com/articles/10.1186/s13073-016-0323-y.

Artificial intelligence in health care: A branch of computer science that seeks to mimic human intelligence through iterative, complex pattern matching. Applied to health care, it seeks to identify clinically useful patterns from large data sets to support clinical decision-making. https://jamanetwork.com/journals/jama/article-abstract/2718456?casa_token=gK8-d_riogoAAAAA:h4bUWaIbD5rvc-t4Gj3jxSraclJdToZasW1Z1c1IVxo9rN9vG6avWR8knD17Ek8dzr4trmzvtA.

Beyond the operational uses of digital health systems, is the emerging discussion of digital health as a catalyst for change in how care is traditionally delivered. In exploring digital health as a disruption to the traditions of health care, Mesko and colleagues argue "using digital health is a teamwork, thus the era of lonely doctor heroes will end. The success of providing care depends on collaboration, empathy and shared decision-making." (Meskó et al. 2017) Here, we see a clear line between how digital technology not only supports the information exchange aspects of care delivery, but could also act as a key member of the integrated care team. As integrated care marks a diversion from status quo work, we must ask how digital health solutions can work to purposively transform and redesign systems (Steele Gray et al. 2018) and professional practices

Digital Health in Integrated Care

We need to attend to two facets of digital health technology systems in relation to integrated models of care. First, the operational uses of technology in the delivery of health and social care services. Second, that technology can act as a catalyst for cultural change, contributing to normative integration. Turning to the literature on integrated models, Valentijn's Rainbow Model of Integrated Care (Valentijn 2016) offers a useful heuristic on which we can append both the operational (functional) and cultural (normative) roles that technology can play in enabling delivery of integrated care.

The Rainbow Model (see Figure 1.6 in Chap. 1) describes 21 key features of integrated care intended to address the triple aim outcomes of high-performing health systems, organized into three categories (Valentijn et al. 2015). The model includes attention to: (1) the scope of the integrated care model, e.g. is your model person-focused or population-focused; (2) the type of integration ranging from micro- to macro-levels (clinical, professional, organizational and system level integration); and (3) enablers of integrated care that may be functional (processes and other technical aspects of care delivery) or normative (cultural conditions and belief structures that drive behaviors). If we return to Goodwin's conceptualization of digital health in integrated care, the "grease" refers to technologies support functions, whereas the "glue" refers to digital health's influence on norms.

Table 28.1 European Union eHealth network interoperability framework

Legal and regulatory level	Compatible legislation and regulatory guidelines define the boundaries for interoperability across borders, but also within a country or region
Policy level	Contracts and agreements between organizations have to be made. The purpose and value of the collaboration must be set. Trust and responsibilities between the organizations are formalized on the policy level. In governance documents, the governance of collaboration is anchored
Care process level	After the organizations have agreed to work together, specific care processes are analyzed and aligned, resulting in integrated care pathways and shared workflows. This level handles the tracking and management of the workflow processes. The shared workflow prescribes which information is needed in order to deliver the integrated care
Information level	The functional description of the data model, the data elements (concepts and possible values) and the linking of these data elements to terminologies that define the interoperability of the data elements
Applications level	Agreements are made about the way import and export of medical information are handled by the healthcare information systems. The technical specification of how information is transported is at this level (communication standards). The information systems must be able to export and import using these communication standards Another aspect in this level is the integration and processing of exchanged information in user-friendly applications
IT infrastructure level	The generic communication and network protocols and standards, the storage, backup, and the database engines are on this level. It contains all the "generic" interoperability standards and protocols

Table 28.1 *Operational activities supported through digital health.*

To illustrate the role that technology can play across these multiple features of integrated care, the following section presents three common "problems" in integrated care that can be addressed using digital health solutions. We draw on real-world examples where technologies have been used as a functional enabler. The final section provides a reflection from these examples on how technology also played a role as a normative enabler, helping to drive culture change needed as systems move from silos to networks.

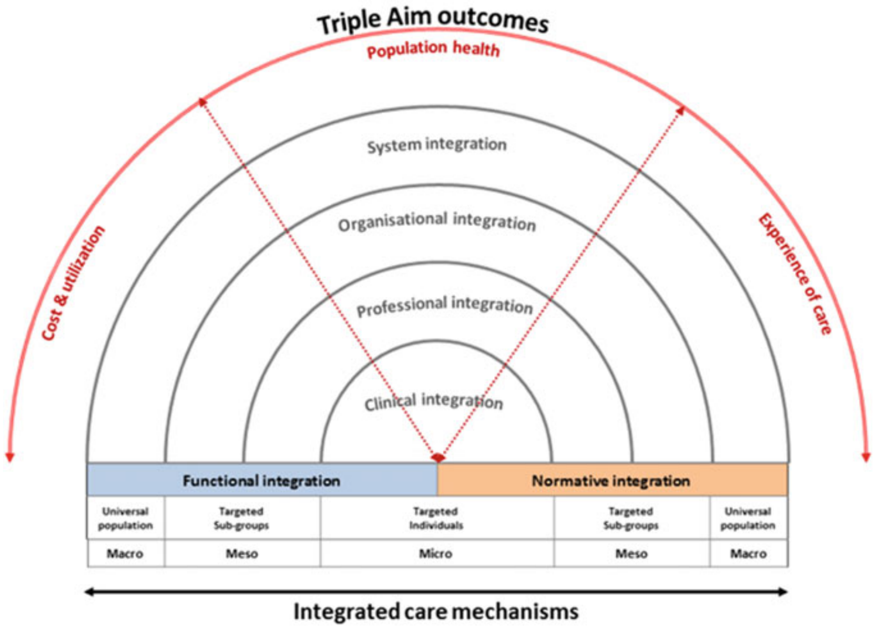

Fig. 28.1 Valentijn's rainbow model of integrated primary care

28.3 Digital Health Solutions to Three Common Problems

Problem #1: Communication and Information Sharing Across Professional and Organizational Boundaries

> "Integrated models of care require integration of digital systems"

Communication is a common activity across all components of the Rainbow Model. The type, nature and purpose of that communication and information sharing of course will be different depending on the level of interaction but the literature is clear that, at all levels, good communication is a critical success factor. At the clinical level, person-centered communication between patients and their providers during and between clinical encounters as part of the management of their care has been found to improve patient satisfaction, treatment adherence, and patient self-management (Levinson et al. 2010). At the professional level, good communication is a key for inter-professional collaboration, and effective teamwork (Baxter and Markle-Reid 2009; Körner et al. 2016; Molyneux 2001) needed to support strong care coordination for patients. At the organizational level, strong networks and increased communication that crosses organizational boundaries enable improved chronic disease management in integrated models of care, with digital solutions acting as key catalysts for this positive outcome (Kadu and Stolee 2015). Finally at the system level, communication across regions and sectors is foundational to developing cross-sector partnerships (Pratt et al. 2017) that can support resource management, planning, and quality improvement efforts include performance monitoring (such as collecting patient outcome data) to improve health service delivery at local, regional and national levels.

Glasby et al. (2011) suggest that information sharing is the first step toward more meaningful partnership which is required as we increase the breadth and depth of partnerships required in integrated models of care. Despite the strong evidence in support of good communication, and particularly digitally enabled communication, many organizations and networks seeking to adopt integrated models of care still struggle to implement robust systems. In an international study of models of integrated care, the implementing integrated Care for Older Adults with Complex Health Needs (iCOACH) project, it was found that even exemplar models were underutilizing digital solutions to enable information sharing and communication, with notable gaps when it came to supporting information sharing across professional and organizational boundaries (Steele Gray et al. 2018). However, there are examples from these cases and others where these communication barriers can be broken down to facilitate smooth communication at all levels of integration.

Case Example Solution: Establishing Inter-Operable Systems in Ontario, Canada

The service delivery context in Ontario, Canada, is diverse with pockets of integrated models popping up to meet local community needs (Tenbensel et al. 2017). One example in the east end of Toronto, Canada's largest city, is a partnership model in which an interdisciplinary primary care clinic partnered with their local hospital and community care service delivery body to design an integrated model for their older adult patients with complex care needs (Breton et al. 2017). The digital landscape in Ontario is a largely fragmented one, with most clinics and health organizations having their own, standalone EMRs with few centralized data integrating mechanisms, and only a handful of centralized digital assets (for example, the Ontario Laboratory Information System which collects all laboratory data for patients which can be access by providers and patients, with some instances of direct integration to clinic EMRs). To address this fragmentation, the partnership model leveraged strong relationships, a shared vision and collaborative leadership approaches to develop system integration across key information systems of partners, adopting four novel solutions to address the communication gap:

- They established integration between the primary care practice and hospital EMR systems to support two-way information exchange. In this way, the primary care clinic was aware when their patients were in the emergency room or admitted to the hospital, and the hospitalists could see the patient's primary care history including medications and care plan.

- Where direct information integration was not possible, namely between the community care and primary care partner, they co-located staff who had personal access to both systems and could act as the information integrator in the primary care clinic.
- They adopted dedicated virtual care solutions to support home-bound patients to get specialist consults. These consults would be attended by the physician assistant with a nurse or the primary care physician in the patients home and allowed for a real-time inter-professional consult with the patient and caregiver in the room.
- A unique information system integration was established with the Toronto ambulatory service so that anytime emergency services were called to a patient's home, the primary care clinic would receive an alert in their EMR and information about the nature and outcome of the visit. This was particularly helpful if patients went to other hospitals where there was not an established connection to the primary care EMR.

With all these systems in place, this model was able to establish a more seamless communication pathway between the hospital, primary care and community service partners which supported improved patient care and enabled strong relationships between partners. More challenging is the connection back to social care services which is still a work in progress for this model. While the integrated team works with social care and community partners, information sharing with this group remains a challenge as partners do not always have established electronic information systems and are often have fewer resources. The additional challenge working across health to social care and community partners is the high likelihood of a culture-gap between medical and non-medical sector which can cause communication and teamwork challenges whether information systems are there or not.

In the east, Toronto example establishing interoperability between the hospital and primary care systems made a significant difference in supporting communication and information sharing across boundaries. The European Union eHealth Network defines interoperability as a "situation in which two organizations [or systems] are lined up to work together in order to provide collaborative healthcare" (p.5). The eHealth Network offers a useful framework to help think about six key levels of interoperability of systems (Network 2015; European Commission 2015) (Table 28.1).

Problem #2: Supporting Decision-Making

Providers, managers and policy-makers in integrated systems often struggle to make decisions about care delivery. Both communication and decision-making needs to occur at all levels of integration within Valentijn's Rainbow Model. Decision-making requires having the right information at the right time. At the clinical and professional levels, decision-making will relate to patients, families and providers having all the information necessary to make care decisions. While important, computerized and online decision-support tools are not often implemented in EHR systems (Melchiorre et al. 2018). There is the additional challenge that providers may resist systems that are overly prescriptive and reduce space for professional judgment.

Inability to pull together necessary data to inform decision-making is particularly problematic when integrated models seek to target adults and older adults with complex and evolving health and social care needs. These individuals include older adults and individuals with multi-morbidity in addition to complex bio-psycho-social needs that change over time (Barnett et al. 2012; Bayliss et al. 2007; Couturier et al. 2016; Marengoni et al. 2011; Schaink et al. 2012). Although representing a smaller group of overall national population, they are often the highest users of health and social care services worldwide (Conditions 2012; Emanuel 2012; Heslop et al. 2005; Rosella et al. 2014). These individuals stand to benefit most from coordinated care delivery from an inter-professional service team that spans health and social care services (Kuluski et al. 2017). As such, these patients will have their care information shared across multiple different providers in the system. Digital health technologies can thus play a vital role for these teams to communicate, coordinate efforts, focus action on shared common clinical targets, and connect easily to each other in service of this small, yet high-needs, high-cost group.

Organizations and systems will often need population and performance-based information to support service delivery planning decisions, funding decisions, and quality improvement work. Being able to pull in data from multiple sources to inform decision-making is critical to shift toward a “learning health system” (Ainsworth and Buchan 2015)—a model increasingly being adopted in health systems worldwide. Information management is found to be a key component of health system priority setting (Sibbald et al. 2009), and electronically available health system data can be key to surveillance of need and planning health service delivery (Salcher 2017; Virnig and McBean 2001). However, adoption of IT supported clinical decision-support tools is still generally underdeveloped worldwide (Schoen et al. 2009).

Case Example Solution: One Patient ID and Shared EHR Systems in New Zealand

One approach that New Zealand is taking to better integrate primary health care and other community-based services are through their District Health Boards (regional bodies responsible for planning service delivery to citizens in their region with some services delivered directly and others contracted) and Primary Health Organizations (non-government based organizations that contract services from primary care providers). Both these organizations need to have agreements in place to stimulate contracting and collaboration to achieve shared outcomes (Tenbensel et al. 2017). The District Health Boards and Primary Health Organizations have data assets at the regional level which include health system utilization information to help the bodies engage in system planning. They additionally engage in population health management by being able to look across their population, for example, for vaccination rates and identifying individuals in need of specific vaccines.

At the clinical level, decision-making by clinicians is supported through two key data assets. The first is having embedded decision-support tools in clinic-based EMR systems to enable adoption of evidence-based guidelines in practice. The second is the use of a patient unique identifier system, so that all patient information across clinic and organizational EMRs and District Health Board data systems can be easily linked so a clinician can pull multiple records easily and get a full picture of the patients' history and service utilization. This second feature also addresses the first problem in integrated care around improved communication in addition to supporting clinical information sharing.

Problem #3: Supporting Adoption and Organizational Change

> "New ways of working has implications for the use of digital solutions and vice versa. Technology should be part of the redesign process."

The organizational behavior literature demonstrates that even when presented with new models of care (or systems) that have demonstrated effectiveness, individuals and organizations struggle to change and adopt new ways of working (Greve and Taylor 2000). Recent work in this area confirms high rates of non-adoption and abandonment of digital innovations in the health care setting (Greenhalgh et al. 2017). Returning to Goodwin's editorial on the role of digital health in enabling adoption of integrated care (Goodwin 2018), he suggests that "technology-enabled integrated care must be cognized as a complex service innovation that requires strong stakeholder relationships at all levels to facilitate the change." Once again Valentijn's model is helpful here to point out the many levels and relationships that require attention as Goodwin suggests. This means attending to all individuals at all levels in the model, including patients and families, providers, managers and system leaders, when adopting new technologies.

Important here is to acknowledge two types of path dependency (dependence on established processes) that can stymie adoption of digital health solutions to support integrated care. First is clinical path dependency (traditional ways of working in the model of care). Second is technological path dependency (e.g., having legacy systems already in place). The literature has shown however that dependency will not necessarily mean an inescapable tendency to maintain old routines; rather, organizations are able engage in path creation (new ways of working) (Sydow et al. 2012). Furstenau et al. (2016) study of the adoption of a digital solution as part of an integrated model of care for patients with Chronic Obstructive Pulmonary Disease (COPD) shows that existing organizational and digital structures of one private company were able to be shifted to create a path toward integrated care through repositioning the identity of the organization, and expanding and adapting the skill base of their employees to support this identity such that they were well positioned to support the integrated care scenario. Here, we see the importance of a

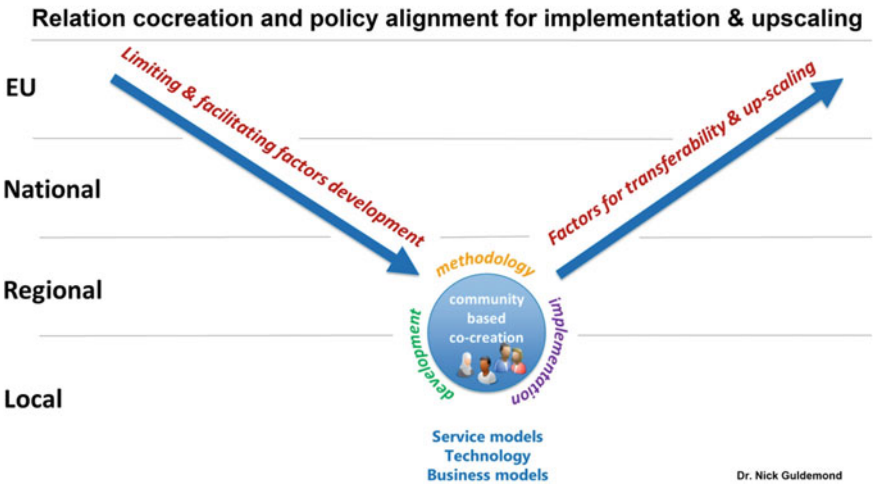

Fig. 28.2 Bottom-up and top-down approach to co-designing system solutions

clear vision that enabled a shift in culture (a normative change) by engaging actors across levels along the way.

In order to create new paths, one approach that is getting lots of attention is the adoption of user-centered co-design methods both in the design of technologies and service models using both bottom-up and top-down approaches. Figure 28.2 offers a visual depiction of how top-down structures (such as enabling policy environments) can create fertile ground for community-driven co-design of innovation (technological or otherwise) that can then be scaled and spread locally, nationally and beyond.

Case Example Solution: Catalonia's Purposefully Developed Model

The Chronicity Prevention and Care Program delivered in Catalonia, Spain, was set up as part of the 2011–2015 Health Plan for Catalonia. This program helped to support the development of an integrated care model within the context of a national strategy to address chronicity that was put in place in 2012 (Mariana Dates et al. 2018). Central to rolling out the Chronicity Prevention and Care Program was the adoption of an interactive and inter-operable health information system via a shared EHR (across all providers in the system) and patient-facing PHR system. Providers were obliged by the funder to use this system regularly as part of their clinical reports, charting and performance measures(Contel 2015). The shared EHR system was put in place explicitly to support the health plan which included an aim of better integrated care delivery with a specific action item around "sharing information, transparency and assessment." To address this action item, the region brought together multiple disparate EMR systems through the development of an infrastructure that pulled data from these systems into a central repository owned by the Catalan Department of Health. The central repository did not overtake the private vendors, but rather pulled data into a central space where clinicians could connect via a web-browser and mobile web app (Contel 2015; Modol 2017).

The shared EHR system was a key part of driving behavior change of providers and organizations, by providing supportive information needed shift workflows. The shared EHR also includes explicit support of this initiative and was rolled out alongside policy and model changes. For example, including a "complex chronic condition" and "advanced chronic disease" label onto patients files in the system which would offer to providers information needed to better manage their care (diagnosis, pharmacy, services used, crisis response recommendations and advance care directives) (Contel 2015). At the organizational and system level, the shared EHR supported the implementation of system priorities of efficiency, continuity and integration by providing a standardized method for information sharing across providers who were being held to account to the same performance indicators (Contel 2015; Modol 2017).

With regard to patients, a PHR (Carpeta Personal de Salut later named Cat@-Salut La Meva Salut) was developed to support the shift toward an integrated model. The PHR was populated by the shared EHR system and connected to a patient web-based portal system and supported connections to accredited third party monitoring devices. Although not explicitly co-designed at the start, 90 citizens were engaged through the pilot process to support usability of the system, with multiple iterative rounds of development (Modol 2017). Similar to the development and implementation of the shared EHR, the development of the PHR was done alongside policy and model changes, aligning functional requirements of the system to the aims and vision of the new policies put in place. This resulted in purposeful development and implementation of digital assets that met the needs of all users, which not only supported use of the system, but also the shift toward greater integrated service delivery.

28.4 Moving Toward a Networked Model: Attending to Normative Integration Through Implementation

While each of the above examples demonstrates how digital health solutions were used to solve common integrated care problems, what they all share is that they did not simply implement and adopt a new technology into their model, but rather they were engaging in largely new ways of working that were enabled by technology. What the examples further demonstrate is that the technology implemented does not simply enable the functional processes, but also serves to enable a normative shift in the organizations and networks. One essential function of technology then could be to make the desired activity (or the "right" activity) easier. Thus, the "right" activity becomes "normal" in the sense that it becomes usual and expected. This shift speaks to the normative integration component of Valentijn's model.

The normative integration component is defined as the "development and maintenance of a common frame of reference (i.e., shared mission, vision, values and culture) between organizations, professional groups and individuals (Valentijn et al. 2015)." This dimension of integrated care points to the human side of the interaction with technologies and allows us to consider how technology can be used to enable these shared understandings and values underpinning integrated models of care. Huckvale and colleagues suggest (citing Granja et al. 2018) that to realize the transformative potential of technology, we much recognize that it is "the way in which humans interact with technologies, not abstract properties of technology, that is critical to the success of that vision." (Huckvale et al. 2019) We thus not only need to attend to the function of the technologies in our integrated system, but how the humans in our models interact with those technologies, and how those interactions may enable (or disable) the shared meaning and understanding needed to drive integration.

Addressing this requires attention to two critical factors when thinking about adopting digital health solutions into your model of care: (1) determining whether solutions were designed with all potential users of that technology across the professional and organizational boundaries that will be represented in your model of care (e.g., where these solutions developed through user-centered co-design methods? Which users were consulted and in what ways?); and (2) engaging with all end-users through the implementation process of these technologies to help guide the human–technology interactions, and adapt implementation to meet the needs of individuals and teams working in our models.

With regard to the former, adopting a user-centered co-design approach to both development and implementation of digital assets can help engage all users through the development process (Subramanyam et al. 2010; Devi et al. 2012). These methods have been shown to contribute to improved adoption, acceptance and satisfaction with systems (Chan et al. 2011; Kujala 2003). As noted earlier, this can also contribute to normative integration, by adopting technologies that meet the needs of the people involved, leading to wider adoption, and subsequent shift in behaviors and culture that are better aligned with the integrated model.

With regard to the latter, there are a number of implementation frameworks available to guide how end-users can be engaged through the implementation process. One such model is the Value Proposition Design approach which offers guidance on how to implement technology while attending to perceived valued of all users throughout the process (Shaw et al. 2018). Important to this model is attention to routines of the teams that deliver care to help to uncover clinical and technological path dependencies that can serve to enhance or hinder the adoption of a new digital health tool.

28.5 How to Know You Are on the Right Track

While organizations may establish some good processes and plans, draw on frameworks like value proposition design to guide role out, and engage all users well, there is still a strong likelihood of some degree of failure in any technology implementation. The key is to determine whether your overall strategy is on the right track, and determining when small versus larger adjustments to your plans for digital health technologies are warranted. Evaluating your model of integrated care is addressed in greater detail in other chapters in this book (Part 4) and as such we will not go into depth here. We do, however, present a few useful tools and approaches for you to consider with regard to digital health adoption in relation to evaluating your broader programs.

One notable offering is the e-Health Implementation (e-HIT) Toolkit (Murray and May 2010) developed out of University College London and was evaluated positively by a diverse set of actors across multiple European countries (MacFarlane et al. 2011). The toolkit addresses context, technology (intervention) and user (workforce) components and has been found to help facilitate discussion and decision-making by managers assessing the implementation of their digital assets (MacFarlane et al. 2011). The toolkit and resources required to use it are open source and available here:

https://www.ucl.ac.uk/iehc/research/primary-care-and-population-health/research/ehealth/resources/tools-accordian/e-hit.

Beyond the toolkit, we generally recommend viewing any digital health technology as a member of your integrated care team. The WHO guideline for digital health interventions released in 2019 (WHO 2019) suggests digital health tools are not a silver bullet but a critical enabler of health systems. Given the centrality of relationships in models of integrated care, we would extend the WHOs argument to include Mesko's contention that "using digital health is a teamwork," and as such, managers should view their digital health assets as members of their integrated care teams. As Leutz reminders us: "integration costs before it pays" (Leutz 1999). We must invest time, resources and attention into digital assets, as we do into our human resources up front before we see the benefits of our integrated model. To make the most of your investment in your digital assets, we suggest treating it like any other team member and regularly check-into ask: *what is the role of this team member?; what value do they add to the team?;* and *what do we need to invest in them to help them achieve their full potential?*

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Data Integration in Health Care

29

Maya Leventer-Roberts and Ran Balicer

Health data integration is considered a key component and, in some cases, a pre-requisite in nearly every systematic attempt to achieve integrated care. In the context of health care, data integration is a complex process of combining multiple types of data from different sources into a single infrastructure, allowing multiple levels of users to access, edit, and contribute to an electronic record of health services (EHRs). The types of data integration that are performed depend on the quality, quantity, and capability of the service performing the integration as well as the needs of the current and future users of the new framework (Johnson et al. 2008). In the following chapter, we describe six basic types of data integration, the pathways by which data integration facilitates integrated care, the main players of healthcare data integration, and key challenges to integrating data.

29.1 Types of Data Integration

29.1.1 Horizontal Integration

Horizontal data integration occurs when the data segments being combined originate from similar kinds of sources. Two examples are combining data from multiple nursing shifts in an inpatient setting (Flaks-Manov et al. 2015) or from various community healthcare providers within a single clinic (Balicer et al. 2014).

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Horizontally integrated data is inherently non-hierarchical, and there is no inherent weight or priority given to the different sources of data. The main obstacle to horizontal integration is combining the data in a way that all the data is consistently represented: one source may measure and record weight in kilograms (kgs) while another, in pounds (lbs) and one may not weigh at all, resulting in missing values. We delve deeper into data consistency later in the chapter when we discuss data quality.

29.1.2 Vertical Integration

Vertical data integration occurs when data from different types of sources is combined into one database. For example, vertical data integration would combine the information documented by a nurse who performs weekly home visits with the information recorded by a physician who performs a quarterly physician review of a diabetic treatment regimen. This type of integration requires a thoughtful organization of how to nest and correlate the findings from each assessment, which contains a hierarchical provider structure. Sources are likely to serve both independent and yet interrelated goals; a nurse may monitor patient medication compliance in a weekly visit which may drive a physician to change treatment goals at the subsequent review. Alternatively, ranking or prioritizing a single diagnosis when a patient has been seen by multiple general practitioners and referred to varying sub-specialists creates challenges when data managers have to apply subjective interpretations to previously objective documentation.

29.1.3 Historical Integration

The merging of patient health records from multiple systems and of different formats (including paper charts) often requires additional processing or review in order to reconcile basic or summary information to serve as a reference for future use. This manual compilation of data can be tedious, costly and full of error, all of which are reasons EHRs were not adopted quickly (Evans 2016).

29.1.4 Longitudinal Integration

The data captured on a patient is a dynamic process over time, as certain conditions resolve and others may develop. Therefore, healthcare data integration requires flexibility to allow for new entries and new types of entries. Furthermore, as our understanding and management of treatment advance over time, we are increasingly in need of the new methods of capturing and storing data that can still be merged consistently with less precise information.

29.1.5 Cross-Indexing Integration

The ability to relate an individual's medical records with their family member's current medical care or medical history presents a unique opportunity to expand the detail present and accessible across multiple generations as well as multiple exposures (living within the household of smokers identifies ones as exposed to second-hand smoke or to other health risks increased by a shared living environment, such as type 2 diabetes). Such a level of data integration requires a cross-indexing mechanism to ensure that multiple records can be updated simultaneously.

29.1.6 Alternative Sources

Patient-reported outcomes, social media, biomonitoring data from various sensors, genome sequencing, and even open-chart models are increasingly becoming relevant sources of data for holistic processing of patient health records (Frey et al. 2015). Data integration that includes these types of data can offer new dimensions of insight.

29.2 The Importance of Data Integration

Data integration is a key facilitator of integrated people-centred care. Un-integrated data strongly hinders any attempt to integrate the provision of care and to empower patients. Decision-making processes that occur in isolation of known, documented, and managed data are inherently problematic, from both the managerial and legal standpoint. While not all types of data will necessarily contribute to a given clinical decision, such as initiation of a therapy or transfer to an assisted living facility, an integrated system provides critical support for decisions that weigh the short- and long-term implications of a change in care to patient experience.

Recent studies have shown that it is beneficial for patient records be readily accessible not only to the care provider but also to patients themselves (Esch et al. 2016; Sustains 2014). Some organizations have taken this principle to the most extreme and adopted an open-chart system that allows for co-creation and management of EHRs by providers, caregivers, and patients. One recent study on such a system (Esch et al. 2016) found a direct relationship between "open notes" health records and improved medication adherence, self-care, and a high level of patient empowerment. This example of data integration demonstrates the importance of a thorough understanding of the quality and quantity of data that needs to be managed in a fully integrated record.

29.3 Impact of Data Integration

In addition to serving the needs of the patients and providers, data integration has a potential measurable impact on two key components of a high-quality healthcare delivery system: reducing waste and improving decision-making capacity.

29.3.1 Types of Waste that Can Be Reduced with Data Integration

29.3.1.1 Repeat Testing

One of the most commonly cited examples of the beneficial impacts of data integration is the ability to reduce repeat testing (Menachemi and Collum 2011). Patients who undergo testing at one institution, if upgraded to another more acute facility, do not necessarily have to undergo repeated testing for the purposes of internal or external validation.

29.3.1.2 Manual Integration of Data

In the absence of data integration, each provider that sees a patient may find themselves entering data into an unstructured format the reports symptoms, laboratory findings, mediation list, medical history, and additional key components of a medical history. This type of complete history and physical exam, which may be instructive as an exercise for the individual physician, is repetitive and prone to error when applied multiple times at multiple facilities.

29.3.1.3 Informal Reports

The sharing of information between providers may occur informally, particularly if there is no avenue for routine data integration. Specifically, there may be telephone or conversational discussions regarding patient care and management that are not readily documented for verification and for future reference which is important if there are follow-up questions to the decisions made during the transfer of care. While it is highly likely that these types of integration will continue and even potentially increase in frequency, it is, nonetheless, important to provide a platform for their inclusion in health records so they are not lost or repeated unnecessarily.

29.3.2 Improving Decision-Making Capacity

29.3.2.1 Individual Level

Patient-centred care requires not only the ability of the provider to consider the consequences of their decision-making on the daily management on the part of the patient but also the ability of the patient to determine and direct the priorities in his or her own management. Data integration creates a streamlined library from which a patient can review and respond to multiple aspects of their medical history and treatment pathways in order to play a proactive role in a conversation regarding his or her health.

29.3.2.2 Provider Level

Logic follows that providers who can actively and easily access complete medical records are more likely to prevent issues resulting from drug interactions or allergic reactions. Furthermore, using integrated medical records, they may be able to base their clinical decision-making processes on the most up-to-date information, which is important if a patient is unable to provide detailed history.

29.3.2.3 Policy Level

Both provider and payer organizations benefit from the collective input of multiple parties when reviewing their management of individual patients and of larger populations (at the clinic or district level). At the clinic level, data integration allows for real-time monitoring and evaluation of interventions and the quality of service delivery. At the district level, data integration supports the ability to compare the needs and outcomes of various clinics, resulting in the ability to focus on granular information, such as practice variation, needs-based planning, and quality improvement measures. Furthermore, the ability for an umbrella organization to proactively distribute resources (vaccines, nursing educators, and social workers) can be supported by the demonstrated and predicted needs within and between communities.

29.3.2.4 International Level

Standards of care, as supported by randomized control trials and large observational studies and driven by a panel of experts and policy-makers, have much to gain from all types and all levels of data integration (Bloomrosen and Detmer 2010). When organizations are able to integrate the healthcare utilization and practice patterns on a large scale, they are able to predict future needs, identify trends, and isolate previously untapped potentials for interventions such as practice variation and hot spots of disease or highly effective delivery of care. Ultimately, comparisons of local findings are best able to have global significance when they can be directly compared to similar system among various health care and resources utilization outcomes.

29.4 Key Challenges in Integrating Data

The main challenges that concern advocates of data integration include access to, quality of, and ongoing monitoring of integrated data (Lampsas et al. 2002).

29.4.1 Access and Privacy

Designing a system to provide meaningful access to data can range from simple access, which is open to everyone to complicated, in which different levels of access are required for each part of an EHR, determined by the privacy needs of the patient and the differing levels of responsibility multiple different decision-makers. The majority of systems find themselves with a combination of access levels, where the majority of integrated data is available to the patient and providers, with some key sensitive material flagged as requiring additional clearance (e.g. infectious disease data). Some may argue that providers must be able to access all types of data, such as a patient's psychiatric history when assessing medication adherence, and others argue that certain types of health records are at risk for a breach of privacy and at worst embarrassing and at best irrelevant, such as revealing the occurrence of a treated sexually transmitted disease on an asthma treatment plan several decades later. However, the decision-making power rarely rests with one person and often requires a case-by-case review. Patient-driven input is increasingly suggested as an important contribution in order to maximize the utility of a patient medical record (Sacchi et al. 2015).

29.4.2 Security

Data security is a challenge for all large data sets and is important for maintenance of both privacy and accuracy of the data stored. Data security issues may arise when there are outside forces seeking to access the data warehouse, but more frequently can arise when there is an unintentional breach in data security by a provider who is not sufficiently attentive to the needs of security. While the primary responsibility for the maintenance of a data security system rests on the central organization, any person with access to the data has the ability to compromise the data security; therefore, their use and modification of the data should be monitored accordingly.

29.4.3 Quality

The overall quality of integrated data is likely to be no greater than that of the lowest quality component. Integrated data is inherently dependent on its components, and a marked difference in quality in one component can have a substantial impact on the interpretation of other components.

29.4.3.1 Quality Assessment

Quality assessment may refer to both routine and random chart reviews in order to understand the extent to which data is inconsistent, contradictory, or nonsensical (Scheurwegs et al. 2015). Consistent data delivers the same message regardless of the format. Two examples of varying data formats are structured (coded) and unstructured (uncoded) data. Seemingly contradictory data can be present due to various healthcare providers documenting different assessments. Adopting a blanket hierarchical nature of data quality would prevent the documentation of nuances that may later serve the patients treatment. For example, a patient may report in a brief interaction to physician that he is overall experiencing “no pain,” but to a nurse may reveal “reduced pain” or a “change in pain.” These reports are not necessarily contradictory but, nonetheless, create a challenge to maintaining within an integrated system. Finally, the integration of data increases the risk for the presence nonsensical raw data due to the typographical errors in coding or transferring of data from one system to another. Each of these factors requires a different approach to minimize their impact on the overall quality of the data.

29.4.3.2 Quality Control

Quality control outlines the distinct steps undergone by a managing body to review and revise integrated data based on a quality assessment. Quality control may be a tedious process and may uncover minor and significant errors at similar rates that are difficult to distinguish. However, a perception of a high level of quality control is critical to achieve successful data integration because the extent at which patients and providers will use the data for their decision-making is inherently dependent on their perception of the quality of available data.

29.4.4 Tracking Use of Integrated Data

Monitoring the use of integrated data is the first step to evaluating its impact and limitations.

29.4.4.1 Providers

While the majority of users are likely to be the healthcare providers, the extent to which they create versus utilize data in an integrated system is an important marker in the ongoing monitoring process. Logic follows that the more accessibility a provider has to their system, the more likely he or she will use the clinical decision-making process. For example, providers who lack the ability to review, modify, and incorporate patient-reported data are probably less likely to invest in reviewing or applying it to their decision-making process. Furthermore, once fully situated, the use of an integrated system could reduce a provider’s time spent recording and reviewing clinical data.

29.4.4.2 Patients

Use of medical records by a patient might be an excellent barometer as to whether the relevant types of information are being stored and catalogued in a useful manner. Patient-centred care, which focuses on employing patients as driving factor in determining the integration of services, should substantially inform the characteristics of data that are being created through the use in the ongoing delivery of care. When patients are found to be actively accessing and responding to their providers' notes and messages, it is more likely that providers are capturing relevant information to the goals of their patients (Evans 2016).

29.4.4.3 Policy-Makers

Policy-makers are likely to be less concerned about the detailed interactions between social work and home nursing care and more likely to be concerned about the overall coordination of care between various levels of providers and the various levels of acuity. Transfers to long-term facilities or discharges from lengthy inpatient stays are transition points of high concern to policy-makers that have a high likelihood of benefiting from data integration. The extent to which the adoption of a comprehensive chart review and medication reconciliation is indeed a reality in practice upon transfer between facilities, and whether it has a successful and meaningful impact, must be assessed through strategic planned review between the institutions (MacLeod 2015).

29.4.4.4 Insurers

While patient privacy must be maintained and ownership is ultimately shared in various combinations between the creators of the data (i.e. patient, provider, insurer), policies which unduly limit data dissemination between parties involved in care provision and quality assessments can diminish the impact of integrated data on the delivery of care. When an insurer's priority is to know that the correct treatment is being delivered to the right patient, integrated data can provide a strong source for support in the decision-making processes for fee-for-service, bundled payments, and pay-for-performance, alike. The combination of documentation of services along with the documentation of provider reports and justification for those services can ultimately benefit not only the patient but also the overall efficiency of the healthcare system.

29.5 Summary

Healthcare data integration is a complex task but is considered a cornerstone of every systematic attempt to achieve integrated patient care. It requires detailed planning and ongoing assessment to ensure accurate and effective coordination of information. Ultimately, data integration has the potential to provide multiple stakeholders with critical, timely, and detailed information for short- and long- term decision-making and documentation, and it supports attempts to achieve structural and functional healthcare coordination and integration.

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Mobile Sensors and Wearable Technology

30

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The Internet of Medical Things and the integration of wearables and sensors to support optimization of health through self-management and remote monitoring have dramatically accelerated over the past decade. With this gaining momentum, wearable devices to measure individuals' physiology such as heart rate and activity levels have become highly popular, increasingly pervasive, and creating a cultural shift to help people to collect, quantify, and observe their own data relating to their behaviours in day-to-day life. This "quantified self" can increase self-awareness regarding behaviour and improve overall health and well-being (Swan 2009). With the potential to change health behaviour through these platforms, the general public has the ability to be more engaged and participatory in their own health. For healthcare providers, these devices are improving patient care through continuous objective reporting, remote monitoring, and precision medicine.

30.1 Commercial Mobile Sensors and Wearable Technologies

Commercial mobile sensors have been the driving force behind the popularity of data tracking for the general public. They allure is the ability to provide an array of program features such as reward systems, opportunities for social interaction, and measured behavioural outcomes, which can increase motivation to engage in healthier behaviours. With these novel features, along with perceptions of affordability, practicality,

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and ease of use, overall change in attitudes and adoption of these devices have improved considerably (Gaoet al. 2010; Kim and Shin 2015; Soliño-Fernandez et al. 2019). One of the most compelling features is the use of various self-regulation strategies to help individuals improve exercise, sleep, sedentary time, mental health, and diet. Users can understand and recognize the necessary steps to change their own behaviour through the use of these devices, which can create opportunities for integrated approaches to support health and patient care.

Google's notable acquisition of Fitbit in 2019 signifies not only the value and expansion of wearables in a global market, but also the acceleration of innovation in this particular domain (Fitbit Inc. 2019). Consumers keen on adopting a healthy and fitness-based lifestyle can purchase wearable technology from a plethora of manufacturers including Fitbit, Garmin, Apple, Samsung, Motorola, or Swarovski. These devices are able to consolidate the various functions found in accelerometers, pedometers, GPS, and heart rate monitors into one device. They can then provide useful measures and personalized feedback on variables such as step counts, physical activity intensity, maximal oxygen uptake, heart rate variability, total daily energy expenditure, sedentary time, and sleep quality. Recent advancements in wearable devices have begun to integrate other features such as fall detection, medication adherence, signs of atrial fibrillation, and environmental noise monitoring (i.e. exposure to noise levels that may pose a risk to a person's hearing). These wearable devices can transmit the collected data into mobile apps, allowing users to consolidate and centralize their personal health data into their own smartphones.

Recent literature has suggested that very few commercial devices have been validated (Bunn et al. 2017; Peake et al. 2018). For the limited number of wearable devices that have been evaluated, these particular devices have been found to be fairly reliable and capable of providing reasonably accurate step counts for adults with no mobility limitations (Evenson et al. 2015). Additional evidence has shown that some of these devices can yield physical activity estimates comparable to research-grade accelerometers (Ferguson et al. 2015; Lee et al. 2014). However, commercial devices have been found to underestimate variables like energy expenditure (O'Driscoll et al. 2018) and overestimate variables like total sleep time and sleep efficiency (Haghayegh et al. 2019).

At the crux of the commercial devices are the interface and software features that incorporate multiple self-regulation strategies to help individuals adopt and maintain health behaviour. Similar to previous content analyses performed on smartphone apps (Abroms et al. 2011; Azar et al. 2013; Breland et al. 2013; Cowan et al. 2013; West et al. 2012), researchers have investigated the use of behaviour change techniques in 13 commercially available sensors (Lewis et al. 2015). The study's results showed that self-monitoring and feedback on behaviour, setting goals, and outlining potential discrepancies between measured performance and goal were strategies commonly used in these devices. Though, strategies like problem solving, action planning, prompting or cues to action were less prevalent. According to intention-based behaviour theories, these particular strategies are important considerations for translating intention into behaviour and forming habitual behaviour (Rhodes and Yao 2015). Wearable devices have incorporated more of these health behaviour strategies in recent years, particularly in the area of physical activity and sedentary behaviours. In fact, recent evidence has shown that wearable devices can promote short-term changes to physical activity and sedentary behaviour in both healthy and clinical populations (Brickwood et al. 2019; Kirk et al. 2019; Lewis et al. 2015; Stephenson et al. 2017). However, the efficacy of these devices in improving other health behaviours such as sleep remains unclear.

30.2 Clinical Mobile Sensors and Wearable Technologies

Mobile and wearable sensor technologies have begun to expand into the healthcare landscape. Unlike commercial devices, which are generally centred on physical activity levels, mobile sensors and wearables in the clinical domain focus on accurate and continuous measurement of physiological variables and biomarkers to support clinical decision making and treatment for various health conditions and diseases (Alemdar and Ersoy 2010; Appelboom et al. 2014; Chan et al. 2012; Chen et al. 2011). These devices can be integrated into adhesive bandages and clothing, and can track and monitor cardiac function (i.e. electrocardiography), heart rate, blood pressure, respiration, oxygen saturation (i.e. pulse oximetry), skin conductance, glucose levels, kinematics, body and ambient temperature, and global positioning. With aggregated measures of these variables, insight into medical status (e.g. vital signs, level of self-care and self-management), chronic disease risk, and physiological anomalies can be observed and captured to help inform clinicians and patients about appropriate treatment. Recently, these diagnostic tools have been applied to preventative health care and the detection of abnormal heart conditions. For instance, atrial fibrillation can be fairly transient and asymptomatic and is not often diagnosed until a serious health incident like a stroke or syncope occurs. Devices such as AliveCor have been used to monitor the electrical activity of the heart via a bipolar electrode in clinical and non-clinical populations, and allow patients to share ultrasound and electrocardiogram data with their healthcare provider (Baquero et al. 2015; Ferdman et al. 2015; Haberman et al. 2015).

Clinical sensors can also extend beyond the patient and be integrated into a broader wireless network, linking the patient to his or her immediate surroundings and to the healthcare provider. An early example of this was the Advance care and alert portable telemedical MONitor (AMON) project, which used a wearable monitoring system to remotely track and relay health information and data between the patient and clinician (Anliker et al. 2004). Aimed at supporting individuals at risk of cardiac and respiratory disease, this wrist-worn device included a number of features such as vital sign (blood pressure, oxygen saturation, pulse, ECG) and physical activity monitoring, online analysis and emergency detection, and a communication interface (e.g. SMS). Despite issues in measurement accuracy, the device demonstrated a feasible approach to improve outpatient care while encouraging patients to self-monitor and live independently.

In the USA, rigorous testing is necessary in order for devices to be approved and classified as a medical device. In recent years, there has been an increasing number of US Food and Drug Administration's (FDA) approved devices and made available to the public, such as the aforementioned AliveCor device (AliveCor Inc. 2020). Furthermore, FDA approved devices that have appeared on the market address a number of different medical conditions. Most recently, the Apple Watch received FDA clearance for the electrocardiogram and irregular rhythm notification functions as Class II medical device (U.S. Food and Drug Administration 2020a). Another illustration of this growing development is the approval and categorization of Adherium's digital inhaler add-on as a medical device (U.S. Food and Drug Administration 2020b). This digital inhaler monitoring device has been found to improve medication adherence among patients with asthma by tracking medication use and providing reminders to patients via an online portal (Chan et al. 2015). As well, there has been a rise in the adoption of wearable glucose monitoring sensors among diabetes patients (e.g. FreeStyle Libre Flash) (Welsh and Thomas 2019). These types of digital monitoring system provide a cost-effective way to continuously receive real-time biofeedback on glucose levels from the interstitial fluid via a sensor patch (Kompala and Neinstein 2019). The sensor can relay data to a smartphone and cloud drive, allow the user to check their readings and trends, and notify the user of hyperglycemia and hypoglycemic episodes—thereby helping people alter their behaviour and manage their diabetes more effectively (e.g. exercise, caloric intake, decisions to prevent hypoglycemic episodes) (Kompala and Neinstein 2019).

In essence, devices such as the AliveCor and Apple Watch illustrate the coalescing of commercial and medical devices and a trend towards affordable and accessible technology becoming available to the public and opportunities for the public to monitor their own health. Furthermore, these medical diagnostic tools have an immense potential to prevent and detect serious health conditions and diseases. As more of these devices continue to develop and become adopted by the general public, so will the integration of these technologies into medical practice.

30.3 Using Mobile Sensors and Wearable Technologies to Change Health Behaviour

An important area that warrants thorough exploration is the coupling of clinical monitoring with behavioural change theory to improve health-related behaviours and health outcomes. A recent qualitative investigation exploring the role of sensor technology to sustain behaviour change found that simply tracking health data alone is insufficient to sustain patient motivation to achieve health goals (Miyamoto et al. 2016). Applying behaviour change theories to the development of these devices may address the dynamic nature of patient motivation.

The importance of theoretical models lies in their ability to produce a nomenclature of psychosocial determinants, understand the mechanisms for why a behaviour might occur, and subsequently, target key constructs to elicit behaviour change (Davis et al. 2014). For instance, theoretical frameworks such as the social cognitive theory indicate goal setting and reflection on own performance are both necessary in order to stimulate and anchor behavioural modification (Bandura 1986). A recent systematic review examining the potential of smartphone technology to measure and influence physical activity behaviour found that the most commonly applied theoretical framework was the social cognitive theory (Bort-Roig et al. 2014). Moreover, the review further highlighted five behaviour change strategies commonly found on these devices that were associated with changes in physical activity behaviour: physical activity profiling, goal setting, real-time feedback, social support networking, and online expert consultation.

Research studies investigating the efficacy of sensors and wearables in the clinical domain have begun to incorporate behaviour change strategies to address patient motivation regarding chronic disease self-management behaviours. Examples of clinical studies that have integrated and explored the use behaviour change strategies in the technology include:

- A feasibility study using wireless blood pressure monitors, glucose monitoring, and weight scales to support diabetes self-management and health outcomes utilized the social cognitive theory to frame the intervention. After three months, patients saw improvements in weight, systolic blood pressure, and haemoglobin A1C levels, decreased level of distress, and felt more empowered in managing their diabetes (Ho et al. 2015).
- A quality improvement evaluation of a web-based tool coupled with electronic home monitoring that supported individuals with heart failure with patient self-management and telemonitoring by health professionals used the Connelly Framework for Self-Care in Chronic Illness (Connelly 1993) to guide the development of the app’s behaviour change strategies, which resulted in decrease in heart failure-related hospitalizations and all-cause hospitalizations, and improved clinical, quality of life, and self-care outcomes (Ware et al. 2020).

30.4 Current Limitations and Potential Impact on Health

Undoubtedly, mobile sensors and wearable technology are continuing to develop and improve and the long-term impact of these devices is warranted. One of the major barriers to understanding the long-term impact to health behaviour and health outcomes has been adherence to the wearable sensor itself. Previous research has shown that adherence to commercial devices tends to decline after six months (Kim and Shin 2015). Potential reasons for this may be related to equipment itself (e.g. usability, comfort, and battery life) and a diminishing novelty effect (Alemdar and Ersoy 2010), lack of professional support to help the user to understand the context and meaning of the data collected (Miyamoto et al. 2016), and the lack of key psychosocial constructs that are important for translating intention into behaviour and forming habitual behaviour (Rhodes and Yao 2015). Use of wearables in healthcare faces similar challenges, with two additional challenges: health professionals not co-monitoring the data with patients, and measurement of discrete diseases rather than part of a comprehensive service to support patients holistically (Arsenijevic et al. 2018).

Despite the current limitations, mobile sensors and wearable devices can improve patient delivery and care. In the context of patient care, these sensors can continuously collect personal data in various environmental contexts as part of an all-encompassing health network. In turn, the amassed data can be used in multifactor analyses to identify the user's specific needs and prevent further decline in health (Banaee et al. 2013). As well, clinicians will be able to remotely monitor their patient's current condition in real-time and appraise overall data trends, be notified of any immediate changes to health status (e.g. irregularities, decompensation), and better administer appropriate actions and treatment (e.g. modify medication dosage, curtail adverse events). While in healthy populations, the data collected would allow for the prediction and detection of anomalies in behaviours to encourage and support healthy lifestyle behaviours.

Mobile sensor and wearable technology can also ease the care process and establish the patient's sense of safety and support from their healthcare team. The devices can allow health professionals work as an interdisciplinary team to remotely monitor and concurrently manage their patients and the data collected can expedite continuous care (e.g. from emergency medical care or community-based care and the patient's home), while helping patients feel supported and safe by being closely monitored by their provider. Moreover, this technology can enable healthcare professionals extend services to previously underserved areas.

Ultimately, the adoption of mobile sensors and wearable technologies can considerably increase a healthcare provider's ability to provide adequate and timely care through active provider-patient engagement, which can improve the patient's health and well-being and the overall patient experience. Furthermore, the integration of these technologies into patient care can alleviate healthcare costs, enhance the quality and efficiency of healthcare services, and advance preventive care.

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Legal Aspects of Data Protection Regarding Health and Patient Data in the European Context

31

Mag. Theresa Karall

31.1 Integrated Care and Data protection—A Crucial Requirement

Integrated care aims for new organisational arrangements and healthcare reforms that focus on more connectivity, alignment and collaboration within and between the healthcare sectors and providers. One of its goals is to enhance quality of care and thereby enhance the quality of life, satisfaction of consumers and efficiency of the systems used. eHealth system, telemedicine and electronic health records have the potential to improve the effectiveness and quality of treatments significantly and to support the implementation of integrated care.

The implementation of integrated care and essentially every progress in the medical field *depends above all on data, i.e. health and patient data*. Thus, *harmonised* and *high standards of data protection regulations* are crucial.

The following chapter therefore focuses on the European data protection regime, in particular on health and patient data while also providing insights into the different kinds of data, the lawfulness of processing data, the main data subject rights as well as the measures that controllers and processors of personal data have to comply with.

31.2 Harmonised European Health Data Protection?

The basis for a harmonised data protection in the European Union (EU) is stipulated in Article 16 of the Treaty of the Functioning of the EU (TFEU). This basis inter alia concerns data protection in the healthcare sector.

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With the General Data Protection Regulation (GDPR) (EU 2016/976) entering into force, the EU took a significant step towards a harmonised data protection regime. However, the GDPR still does not establish a uniform data protection law in the EU regarding the healthcare sector. Rather, it allows Member States—in certain circumstances—to use opening clauses to accommodate special national features (Kühnl et al. 2018).

It is noteworthy that in order to gain a comprehensive view of an EU Member State's data protection regime, one must take into account not only the GDPR (and other EU laws) but also respective national data protection laws.

31.2.1 The European General Data Protection Regulation

The GDPR came into force on 25 May 2018 (Art 99 para 2 GDPR). Its subject matter and objectives are to *protect personal data of natural persons*, especially in *regard* to the processing of personal data and to *set rules regarding the free movement of personal data.* The protection of fundamental rights and freedom of natural persons is one of the key aspects of the GDPR. Furthermore, the GDPR regulates that the free movement of personal data within the EU cannot be restricted or prohibited for reasons connected to the protection of natural persons with regard to the processing of personal data (Art 1 para 1–3 GDPR). The protection of the free movement of personal data concerns not only the EU and must therefore be seen in an international context. Consequently, the objectives set in Article 1 of the GDPR are relevant not only in the European single market but also on the global market (Art 44 GDPR regarding the general principle for transfers).

31.2.2 Scope of Application

The *material scope* of the GDPR comprises the processing of personal data wholly or partly by automated means and the processing of data by means other than automated means if these form part of a filing system or are intended to form part of a filing system (Art 2 GDPR).

In view of the *territorial scope*, three areas of protection are set by the GDPR.

Firstly, the processing of personal data is protected by the GDPR, when in context of the activities of an *establishment* of a controller or a processor *in the EU*, regardless of whether the data processing takes place in the EU or not (Art para 1 GDPR; Recital 22 GDPR).

Secondly, the processing of personal data of *data subjects* who are *in the EU* (e.g. a person resides in an EU country) by a controller or processor who is *not established in the EU* (Article 3 para 2 GDPR; Recital 23–24 GDPR).

Thirdly, the GDPR applies to the processing of personal data by a controller or processor *not established in the EU*, but in places where the law of a Member State applies by virtue of public international law (e.g. embassies, consulates) (Art 3 para 3 GDPR; Recital 25 GDPR).

31.2.3 Definitions

The following definitions are given by the GDPR and constitute the basis for further legal analyses of the protection of health and patient data in the EU context.

'personal data' *means any information relating to an identified or identifiable natural person ('data subject'); an identifiable natural person is one who can be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person* (Art 4 para 1 GDPR);

'processing' *means any operation or set of operations which is performed on personal data or on sets of personal data, whether or not by automated means, such as collection, recording, organisation, structuring, storage, adaptation or alteration, retrieval, consultation, use, disclosure by transmission, dissemination or otherwise making available, alignment or combination, restriction, erasure or destruction* (Art 4 para 2 GDPR)*;*

'data concerning health' *means personal data related to the physical or mental health of a natural person, including the provision of healthcare services, which reveal information about his or her health status* (Art 4 para 15 GDPR)*;*

'**controller'** *means the natural or legal person, public authority, agency or other body which, alone or jointly with others, determines the purposes and means of the processing of personal data* (Art 4 para 7 GDPR)*;*

'**processor'** *means a natural or legal person, public authority, agency or other body which processes personal data on behalf of the controller* (Art 4 para 8 GDPR).

31.2.4 The Distribution of Roles When Processing Personal Data

Any assessment regarding the lawfulness of data processing must first consider the *roles of the parties involved:*

- The data subject is the natural person whose personal data is processed.
- The data *controller* is the person who decides the purposes and means of processing the personal data.
- *Joint controllers* are two or more controllers who together determine why and how personal data should be processed. It is crucial that a joint controller enters into arrangements setting out the respective responsibilities for complying with the GDPR (European Commission 2020a).
- A *processor* is someone who processes data on behalf of a controller (Jahnel 2019). The duties of the processor towards the controller need to be specified in a contract or another legal act. Inter alia it is crucial to regulate what happens to the data once the contract is terminated. Furthermore, it must be noted that a

processor cannot subsequently appoint another processor without prior notice to the controller (European Commission 2020a).

In the medical field, the *health service provider* usually takes the position of the controller and is thus subject to the essential obligations under the GDPR. The controller may engage a *processor* for certain IT services, such as the processing of patient data. The health service provider and the engaged processor must conclude a contract for processing. If personal data is passed on to other health service providers or social insurance institutions (e.g. for billing purposes), they are usually *independent controllers,* and the lawfulness of the data transfer must be assessed individually (Jahnel 2019).

A frequent case in the healthcare sector and a good example for the importance of defining the roles of the parties involved is one, where a public authority establishes a national exchange point regulating the exchange of patient data between different healthcare providers. The plurality of controllers may result in an untransparent situation for the data subject (patient), since it is difficult to identify which controller to approach with questions, complaints, etc. Since the public authority established the switch point, meaning that it is responsible for the design of the processing and the way it is used, the public authority shall take the role of the joint controller. This means that the public authority as the joint controller is the contact point for data subjects (patients) (Article 29 Data Protection Working Party 2010).

31.2.5 Personal Data in the Health Context

Data concerning health, genetic and biometric data are *personal data.* As defined the GDPR, health data as personal data is data that relates to the physical or mental health of a natural person. Furthermore, personal data concerning health includes all data regarding the past, current and future physical and mental health status of a data subject, information from genetic data, biological samples and information pertaining, inter alia, to a disease, disability, disease risk or to a medical history from any source in the medical field (Recital 35 GDPR). Generally speaking, this means that *all patient data* in the medical field *is health data and protected by the GDPR.*

Note that *social security numbers* are not considered personal data under the GDPR. This is due to the fact that social security numbers as such do not refer to the physical or mental health of a natural person, nor do they provide information on the state of health of a natural person. However, Recital 35 of the GDPR indicates that personal data concerning health includes '*a number, symbol or particular assigned to a natural person to uniquely identify the natural person for health purposes*' (Recital 35 GDPR). Following Recital 35, social security numbers would clearly qualify as health data and therefore personal data. This begs the question as to whether such an interpretation, being based on Recital 35, is still covered by the definition of *data concerning health*. Based on the jurisprudence of the European Court of Justice (ECJ), the preamble to an EU act does not have binding legal force and therefore cannot be used for derogating from the actual provision in the GDPR or for the interpretation of the respective provision (ECJ, C-345/13; C-136/04; C-162/97). Therefore, social security numbers do not fall under the term of health data.

31.2.6 General Aspects of Processing Personal Data

Personal data may be processed only when it is not feasible, within reason, to carry out processing in another manner. *Anonymous data* should preferably be used, otherwise the data used should be adequate, relevant and limited to what is truly necessary for the purpose (data minimisation). A controller is responsible for assessing how much data is needed and *ensuring that no irrelevant data is collected*. To ensure that data is not kept longer than necessary, the controller should establish *time limits* for erasure or periodic reviews (Recital 39 GDPR).

In general, personal data should only be stored for *the shortest time possible.* When setting the storage time, the reason for processing personal data as well as any other legal obligations for keeping data for a fixed time should be taken into account (European Commission 2020b).

The processing of personal data, which includes non-sensitive and sensitive data, is lawful when (Article 6 para 1 GDPR):

- the data subject has given *consent to the processing* of data for one or more specific purposes (e.g. a person using a health app and giving consent to the processing of data; consent to use electronic medical records);
- processing is necessary for the *performance of a contract* to which the data subject is party (e.g. medical treatment contract);
- processing is necessary for compliance with a *legal obligation* to which the controller is subject (e.g. reporting obligation regarding certain diseases);
- processing is necessary in order to *protect the vital interests* of the data subject or of another natural person;
- processing is necessary for the performance of a task carried out in the *public interest* or in the exercise of official authority vested in the controller (e.g. big data analyses of health data in order to prevent the spread of a disease);
- processing is necessary for the purposes of the *legitimate interests* pursued by the controller or by a third party (Art 6 para 1 GDPR).

Note that Member States are allowed to determine more specific requirements for processing personal data in regard to points c. (legal obligation) and e. (public interest).

31.2.6.1 Non-sensitive and Sensitive Data

The GDPR distinguishes between non-sensitive and sensitive data, stipulating different requirements for the processing of non-sensitive and sensitive data, given the fact that one of these categories needs more protection.

Sensitive data, as defined by the GDPR, is data revealing the racial or ethnic origin, political opinions, religious or philosophical beliefs, or trade union membership, as well as genetic data, biometric data, data concerning health or data concerning a natural person's sex life or sexual orientation (Art 9 para 1 GDPR). *Non-sensitive data* is all other personal data not falling under sensitive data.

In general, the processing of sensitive data is prohibited by the GDPR. However, there are certain exceptions.

31.2.6.2 Processing of Sensitive Data

Sensitive data may be processed inter alia when (Art 9 para 2 GDPR):

1. the data subject has given *explicit consent* to the processing of personal data for one or more specified purposes (Art 9 para 2 lit a GDPR);
2. processing is necessary to protect the *vital interests* of the data subject or of another natural person where the data subject is physically or legally incapable of giving consent (Art 9 para 2 lit c GDPR);
3. processing is necessary for reasons of substantial public interest, on the basis of *EU or Member State law* (Art 9 para 2 lit g GDPR);
4. processing is necessary for the purposes of *preventive or occupational medicine*, for the assessment of the working capacity of the employee, medical diagnosis, the provision of *health or social care* or *treatment* or the *management of health* or *social care systems* and *services* (Art 9 para 2 lit h GDPR);
5. processing is necessary for reasons of public interest in the area of *public health*, such as protecting against serious cross-border threats to health or ensuring high standards of quality and safety of health care and of medicinal products or medical devices, on the basis of Union or Member State law (Art 9 para 2 lit i GDPR).

Note that the processing of sensitive data for the purpose specified in Article 9 para 2 lit h of the GDPR (see point d. above) may only be carried out by or under the responsibility of a professional subject to the obligation of processional secrecy under EU or Member State law.

In addition to the requirements for processing sensitive data, the *general provisions* established in Article 6 of the GDPR (see 2.6) *must be complied* with as well.

This means that, as the first step, the controller or processor must identity the relevant exemption of the processing prohibition (Article 9 para 2 GDPR). As the next step, the controller or processor must check whether one of the conditions set in Article 6 para 1 GDPR applies. Both regulations must be complied with, otherwise rendering the processing of personal data unlawful.

31.2.7 Administrative Duties

According to Article 30 GDPR, any controller or processor is obliged to maintain a *record of processing activities* and its responsibilities. These records must be made available to the supervisory authority if requested. The list of processing activities has to contain the following:

1. the name and contact details of the controller and data protection officer;
2. the purposes of the processing;
3. a description of the categories of data subjects and the categories of personal data;
4. the categories of recipients to whom the personal data has been or will be disclosed, including recipients in third countries or international organisations;
5. if applicable, transfers of personal data to a third country or international organisation;
6. where possible, the time limits laid down for erasure of the various categories of data;
7. if possible, a general description of the technical and organisational measures taken to ensure the protection of personal data.

31.2.8 Data Protection Impact Assessment

Whenever processing of personal data is likely to result in a *high risk to the rights and freedoms of a data subject* (e.g. a patient), a data protection impact assessment (DPIA) is required. In the following cases, a DPIA is required regardless:

1. the systematic and extensive evaluation of the personal traits of an individual;
2. the processing of sensitive data on a large scale (Article 9 para 1 GDPR);
3. the systematic monitoring of a publicly accessible area on a large scale (Art 35 para 3 GDPR).

National data protection authorities in cooperation with the European data protection board may publish a list of cases where a DPIA is necessary and a list of cases where it is not (so-called Blacklists or Whitelists).

A key aspect of a DPIA is that it is conducted before the processing of personal data starts. Furthermore, it is understood as an evolving tool rather than as an one-off exercise (European Commission 2020c). Regarding the health sector, a DPIA may inter alia be necessary when a hospital implements a new health information database with patients' health data; when billing through social security; when transmitting health reports to a third party; or when analysing and shipping blood samples.

The minimum standard of a DPIA is

1. a systematic description of the envisaged processing operations and the purposes of the processing, including, where appropriate, the legitimate interests pursued by the controller;
2. an assessment of the necessity and proportionality of the processing operations in relation to the purposes;
3. an assessment of the risks to the rights and freedoms of data subjects;
4. the measures envisaged to address the risks (Art 35 para 7 GDPR).

31.2.9 Data Protection Officer

A data protection officer (DPO) is required when the *core activity* of a company/institution, i.e. a controller or processor, is the processing of sensitive data on a large scale or when it involves large scale, regular and systematic monitoring of individuals (European Commission 2020d). According to Recital 97, the core activities of a controller relate to '*primary activities and do not relate to the processing of personal data as ancillary activities*'.

However, core activities should not be interpreted so as to exclude activities where the processing of data forms an indispensable part of the controller's or processor's activity. For instance, the core activity of a hospital is to provide health care. However, without processing health data, such as patient health records, a hospital would not be able to provide health care effectively. Therefore, the processing of heath data by a hospital is considered a core activity of the hospital and calls for the designation of a DPO (Article 29 Data Protection Working Party 2018).

Moreover, public authorities/administrations always have an obligation to appoint a DPO (except for courts acting in their judicial capacity).

It is up to the company/institution whether the DPO is a *member of the organisation* or *contracted externally* on the basis of a service contract. Regardless, the DPO may be an individual natural person or an organisation.

Regarding the healthcare sector, a DPO is mandatory, inter alia, when a hospital processes large sets of sensitive data. In contrast, a DPO is not mandatory, inter alia, when a local community doctor processes data of their patients (Recital 91 GDPR).

31.2.9.1 Responsibilities of a Data Protection Officer

The DPO's main task is to assist the controller or processor in all issues related to the protection of personal data. At the same time, the controller and processor are obliged to support the DPO by providing the resources necessary to carry out its task and maintain its expert knowledge (Art 38 GDPR).

The DPO's tasks are

1. informing and advising the controller or processor and the employees regarding their obligations according to the GDPR;
2. monitoring compliance with the GDPR and any other relevant national data protection regulation, including audits, assignment of responsibilities, awareness-raising and training of staff involved;
3. providing advice regarding the processing of personal data;
4. cooperating with the supervisory authority; and
5. acting as the contact point for the supervisory authority (Art 39 para 1 GDPR).

It is crucial that a DPO is involved in the data processing of a controller or processor at an early stage. Furthermore, the DPO cannot receive any instructions from the controller or processor regarding its tasks. The DPO directly reports to the highest level of management of the respective organisation (Article 29 Data Protection Working Party 2017).

31.2.10 Data Breach Notification

31.2.10.1 What is a Personal Data Breach?

According to the GDPR, a *personal data breach* is a '*a breach of security leading to the accidental or unlawful destruction, loss, alteration, unauthorised disclosure of, or access to, personal data transmitted, stored or otherwise processed*'.

'Destruction' of personal data means that the data does no longer exist or no longer exists in a way that is of any use to the controller. 'Alteration' of personal data can be understood as data being damaged, corrupted or no longer compete. 'Loss' of personal data may be interpreted to mean that the respective data may still exist, but the controller has lost control over or access to it or no longer has it in its possession. 'Unauthorised' processing of personal data may include disclosure of personal data to or access to personal data by an unauthorised recipient (third party) or any other form of processing personal data which is in violation of the GDPR (Article 29 Data Protection Working Party 2017).

In the health sector, an example of such a data breach would be the electronical transfer of patient and health data to one or more recipients not authorised to receive them.

31.2.10.2 How to Prevent a Personal Data Breach

In order to prevent a personal data breach and to ensure the security of personal data, *appropriate technical and organisational measures* have to be taken and implemented in the controller's and processor's systems. This includes protection against unauthorised or unlawful processing and against accidental loss, destruction or damage of personal data (Art 5 para 1 lit f, Art 32 GDPR).

31.2.10.3 Potential Consequences of a Personal Data Breach

A range of *significant adverse effects* on individuals may be caused by a personal data breach. It can result in physical, material or non-material damage. The GDPR posits that this includes, inter alia, loss of control over personal data, limitation of rights, discrimination, financial loss, damage to reputation or any other significant economic or social disadvantage to the natural person concerned (Recital 75, 85 GDPR).

31.2.10.4 Notification of the Personal Data Breach

In general, notification of a breach is *mandatory,* unless a breach is unlikely to result in a risk to the rights and freedom of the individuals affected (Art 33 para 1 GDPR). This may be the case when personal data is sufficiently encrypted on a device that was lost or the data was unavailable only during a brief power outage (Jahnel 2019). The GDPR regulates that the *competent national supervisory authority* must be notified in case of a personal data breach no later than 72 h after the controller has become *aware* of the breach (Art 4 para 21 GDPR). Being *aware* in this sense can be understood as a reasonable degree of certainty that a security incident has occurred and has led to personal data being compromised. However, this assessment depends on the individual case of the specific breach (Article 29 Data Protection Working Party 2018). Moreover, *processors* also play an important role in the data breach notification process—they need to notify the controller of any data breach (Art 33 para 2 GDPR). In case of a *cross-border breach*, the lead authority must be notified (Art 33 para 1, 55, 56 GDPR).

Furthermore, if there is a high risk of adverse effects, the controller must *communicate the personal data breach to the individuals* whose personal data has been affected (Article 29 Data Protection Working Party 2018) This way, the controller can provide information on the risks resulting from the personal data breach and the steps the affected individual can take to protect themselves from potential consequences (Article 29 Data Protection Working Party 2018) Note that if certain conditions are met, the controller does not need to communicate the personal data breach to the data subject (Art 34 para 3 GDPR). Appropriate ways of communication are direct contact to the data subject by direct messaging (e.g. email, text message, postal communication) or public communication by Website banners, notifications or advertisements in print media (Article 29 Data Protection Working Party 2018).

Overall, it is crucial *that controllers and processors plan in advance* and *establish specific processes* to be able to *detect and promptly contain a breach*, to assess the risk of individuals, and to determine the necessary steps to follow upon a potential breach. A response plan's focus should be on the protection of individuals and their personal data.

Note, moreover, that other notification regimes (national or EU level) may also apply to the respective data breach and will call for additional notifications.

31.2.10.5 Documentation of Breaches

A controller has the obligation to keep *documentation of all breaches*, regardless of whether or not the breach must be communicated to the supervisory authority. This allows the supervisory authority to verify compliance with the data breach notification regulations. The supervisory authority may request to see data breach records. Therefore, controllers are encouraged to set up an internal register for data breaches (Art 33 para 5 GDPR).

31.2.11 Rights of the Data Subject Under the GDPR

In term of time, the company/ organisation that the data subject approaches in order to make use of its rights must reply to such requests without undue delay and, in principle, within *one month of receiving the request* (Art 12 para 3 GDPR).

31.2.11.1 Right to Information

At the time of collecting and processing, the data subject (e.g. patient) must be clearly informed about the following at least:

1. who the controller is;
2. why the controller will be using the personal data (purpose);
3. the categories of data that are concerned and from which source the personal data originated, when personal data has not been obtained from the data subject;
4. the legal justification for the processing;
5. the storage time of the data;
6. other possible recipients;
7. as to whether the personal data will be transferred to a recipient outside the EU;
8. information on the rights of the data subject, such as the right to receive a copy of the data (right to access personal data);
9. the right to lodge a complaint with the data protection authority;
10. the right to withdraw consent at any time;
11. if applicable, the existence of automated decision-making, including profiling (Art 13, 14 GDPR).

The above-mentioned information has to be given in writing, orally or by electronic means. The controller must do so in a concise, transparent, intelligible and easily accessible way, in clear and plain language and free of charge (Art 12 GDPR). Note that under certain circumstances the controller may be exempted from the obligation to inform the individual (Art 13 para 4, 14 para 5 GDPR).

31.2.11.2 Right of Access by the Data Subject

In order to be aware of and verify the lawfulness of the processing of personal data, the data subject (e.g. patient) has the right to access the personal data that has been collected. The data subject has to be able to exercise this right in an easy manner exercised easily and at reasonable intervals. This right concerns, inter alia, the data subject's right to have *access to data concerning its health,* for example, the data in medical records containing information such as diagnosis, examination results, assessments by treating physicians and any treatment or interventions provided (Recital 63 GDPR).

When a data subject requests access, a company/organisation has to

1. state whether or not it is processing data concerning the data subject;
2. provide a copy of the data that is collected and
3. provide information regarding the processing, such as purpose, categories of personal data or recipients.

In general, a copy of the collected data is free of charge; for further copies, a reasonable fee can be charged (Art 12 para 5 GDPR). Note that the right to access data is closely linked to the right to data portability, which means the data subject's ability to transmit its data to another organisation.

31.2.11.3 Right to Erasure ('Right to Be Forgotten')

Article 17 para 1 GDPR regulates the right of the data subject to request the erasure of its personal data or of its data no longer being processed if there are specific reasons for this. Reasons can be, inter alia, personal data no longer being necessary to the purpose for which it was initially collected or processed or the data subject withdrawing its consent.

Additionally, there are specific exceptions to the right to erasure:

1. the personal data is needed to exercise the right of freedom of expression;
2. there is a legal obligation to keep the personal data and
3. for reasons of public interest, such as public health, scientific, statistical or historical research purposes (Recital 65 GDPR).

An example for an exception to the right to erasure is a patient calling for the erasure of its personal data during the legal retention period.

Note that this right does not release the controller from its obligation to check regularly, even without the request of the data subject, as to whether the data processed should be deleted. The GDPR did not introduce a right to automatic erasure after a predefined period of time (Jahnel 2019).

31.2.11.4 Right to Data Portability

As mentioned in connection with the right to access personal data, a data subject also has the right to data portability. This means that any company or organisation as a controller or processor must provide the requested data in a structured machine-readable format and has to transmit the data to other companies or organisations. Note that this right may only be exercised when the personal data is collected in the context of a contract or on the basis of consent and the data is processed by automated means (Art 20 para 1 GDPR).

In the context of health care, a frequent example for data portability would be a patient moving from one clinic to another. The patient would ask the first clinic, which keeps electronic files of the data, to provide them to the patient in a structured machine-readable format, to allow the patient to transmit the data to the 'new' relevant health professionals. A commonly used open format should be used by the first clinic (e.g. XML, JSON, CSV). When selecting a data format, the clinic should consider how the individual format will impact or hinder the patient's right to re-use the data. For example, it may not be sufficient to provide the patient with a PDF version of its personal data.

31.2.12 Data Transfer to Third Countries

In today's globalised world, a large amount of personal data is being transferred cross-border and sometimes stored on servers in different countries. The rules of the GDPR continue to apply regardless of where the data transmitted to, meaning that the protection offered by the GDPR travels with the data. This applies to data transferals to EU Member States as well as to third countries (countries where the GDPR is primarily not applicable).

The GDPR provides a number of tools to frame data transfers from the EU to a third country: adequacy decisions, standard contractual clauses, binding corporate rules, certification mechanisms and code of conduct.

Adequacy decisions are made by the European Commission and declare that a third country is offering an adequate and comparable level of protection of personal data through its national laws and international commitments. As a result, personal data can be transferred from an EU Member State to the third country without being subject to any further safeguards or authorisations (European Commission 2017).

Standard contractual clauses (transfers between companies) or *binding corporate rules* (transfers within or between corporate group) can be used when an adequacy decision is not available. Standard contractual clauses are targeted at the requirements of a particular sector and could, for instance, be used for specific safeguards when processing sensitive data in the health sector (European Commission 2017).

Approved *codes of conduct and accredited third-party certification* provide processors (e.g. a health institute) the opportunity to create tailor-made solutions for international transfers. In this regard, the processor transferring data to a third country should obtain binding and enforceable commitments of the recipient to apply appropriate safeguards in order to protect the transferred personal data (Recital 108, 109 GDPR).

31.2.13 Sanctions

In case of non-compliance with the GDPR, the national data protection authorities may issue a warning if an infringement is likely or an infringement is confirmed.

The options include a reprimand, a temporary or definitive ban on processing, and a fine of up to EUR 20 million or 4% of the controller's or processor's total annual worldwide turnover (Art 58, 83 GDPR).

Abbreviations

EU	European Union
ECJ	European Court of Justice
GDPR	General Data Protection Regulation
TFEU	Treaty of the Functioning of the EU

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Part IV
Evaluation and Health Services Research

Tools and Frameworks to Measure Health System Integration

32

Esther Suter, Nelly D. Oelke, and Michelle Stiphout

32.1 Introduction

Integrated care is considered a powerful remedy for most health systems ailments in developed economies: poor performance with increasing costs, fragmentation of services, and lack of human resources to care for the ageing population (Hebert and Vail 2004; Lyngso et al. 2014; Strandberg-Larsen and Krasnik 2009). In their definition, Kodner and Spreeuwenberg (2002) define "Integrated Care" as "a coherent set of methods and models on the funding, administrative, organizational, service delivery and clinical levels designed to create connectivity, alignment and collaboration within and between the cure and care sectors" (p. 3). This definition like many others (e.g. WHO Regional Office for Europe 2016) alludes to the broad and intertwined dimensions of integrated care.

Despite far-reaching support for integrated care, evidence on the outcomes of integrated care is still mixed (Baxter et al. 2018; Busse and Stahl 2014; Goodwin et al. 2012; Karimi et al. 2018; Nolte and Pitchforth 2014; Ovreveit 2011). Integrated care comprises diverse delivery strategies targeting various parts of the healthcare system, while engaging multiple stakeholders in their execution. The complex interplay of structures, processes and outcomes of integrated care is dif-

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ficult to disentangle (Nuno Solinis and Stein 2016; Van Deusen Lukas et al. 2002). There is a growing body of research concerned with measuring advances in integrated care (e.g. Martinez-Gonzales et al. 2014; Nuno Solinis and Stein 2016; Singer et al. 2018). Continued progress towards integrated care will depend much on our ability to contrast and compare the impact of strategies across different levels and contexts, using appropriate measurement tools.

32.2 Tools Measuring Individual Dimensions of Integrated Care

Tracking down existing measurement tools is not an easy task given that they reside within a dispersed body of literature (Armitage et al. 2009; de Jong and Jackson 2001). A number of systematic reviews and tool inventories have emerged in an effort to consolidate measures of integration and make them easier to access (e.g. Agency for Healthcare Research and Quality 2014; Bautista et al. 2016; Lyngso et al. 2014; Schultz et al. 2013; Strandberg-Larsen and Krasnik 2009; Suter et al. 2017).

As implied by the name, the Care Coordination Measures Atlas, compiled and updated by the Agency for Healthcare Research and Quality (2014), contains tools that specifically measure care coordination. To meaningfully catalogue the tools, they developed a framework that distinguishes between care coordination activities (such as communicating, creating a plan of care, linking to community resources) and broader approaches related to care coordination (such as medication management, teamwork). They further divided the tools based on the measurement perspective, i.e. patient/family, healthcare professionals, and system representatives. Their inventory contains 80 tools with the highest number of tools falling under care coordination from a patient and family perspective.

The systematic review by Schultz et al. (2013) builds on the original Care Coordination Measures Atlas and also captures care coordination tools. The authors used care coordination frameworks from the literature (Antonelli et al. 2009; National Quality Forum 2006) to search for and catalogue the instruments. Their search identified 96 instruments that measured primarily aspects of communication from the patient perspective.

Bautista et al. (2016) used the Rainbow Model for Integrated Care (RMIC) developed by Valentijn et al. (2013) as their organizing framework for their tools review. The framework presents six dimensions of integrated care: clinical, professional, organizational, system, functional, and normative integration, with the last two dimensions supporting the linkages across the health system levels and the other dimensions in the model (Valentijn et al. 2013). The review found 209 instruments. About 84% of the tools could be mapped to the RMIC's clinical integration dimension with more than 50% related specifically to patient-centred care. Fewer tools related to professional (3.7%), organizational (3.4%), and functional (0.5%) integration dimensions. Looking at the measurement properties of instruments, they found that many instruments lack the desired quality.

While not using a framework per se, Strandberg-Larsen and Krasnik (2009) set some strict inclusion criteria for their studies and focused on approaches for structural, cultural, and process measures of integrated care. This targeted search yielded 24 relevant studies that documented different ways of measuring those aspects of integration. The approaches to measure these concepts ranged widely across the 24 studies; however, survey tools were the most commonly used data source.

Lyngso et al. (2014) aimed to find instruments that measure the level of integration across healthcare sectors. Within their search, they differentiated between measures that capture structures, processes, and outcomes based on Donabedian's framework on quality of medical care (2005). They found 23 instruments that measure a range of organizational elements central to integrated care. Within these instruments, they found eight organizational elements: (1) information technology/ communication, (2) culture and leadership, (3) commitment to integrated care, (4) clinical care, (5) education, (6) financial incentives, (7) patient focus, and (8) quality improvement. No measurement instrument covered all organizational elements, but almost all studies included well-defined structural and process aspects, and six included cultural aspects.

In our own systematic review (Suter et al. 2017), we used the ten key principles from our earlier research to select and categorize measurement tools. The key principles are (1) comprehensive services across the continuum of care, (2) patient focus, (3) geographic coverage and rostering, (4) standardized care delivery through inter-professional teams, (5) performance management, (6) information technology, (7) organizational culture and leadership, (8) physician integration, (9) governance structure, and (10) financial management (Suter et al. 2009). Each principle contained one or several domains established through a Delphi process (Suter et al. 2017). The review yielded 114 unique tools that measured 16 individual domains. The majority of the instruments (94) were questionnaires. Over 50% of instruments found measured care coordination across the continuum/sectors, and patient and family involvement. Twelve tools measured team effectiveness. There were only 14 instruments for the remaining nine domains. These domains could be classified as representing functional, system, organizational, and normative integration.

Collectively, these studies have uncovered several hundred instruments that measure some aspects of integrated care. It is noteworthy that the two newest studies (Suter et al. 2017; Bautista et al. 2016) found significantly more tools than earlier ones, attesting to the recent progress made in integration measurement. From these systematic reviews, it is evident that there are many instruments that measure care coordination and various dimensions of patient-centred care (e.g. Agency for Healthcare Research and Quality 2014; Bautista et al. 2016; Suter et al. 2017), as well as team effectiveness (Suter et al. 2017). These instruments are typically self-reported questionnaires, and the quality and psychometric properties of the tools are not always high (Bautista et al. 2016; Lyngso et al. 2014; Strandberg-Larsen and Krasnik 2009; Suter et al. 2017). Far fewer instruments capture functional, system, organizational, and normative dimensions of integrated systems (Bautista et al. 2016; Lyngso et al. 2014; Strandberg-Larsen and Krasnik

2009; Suter et al. 2017), although these dimensions have been recognized as critical for successful integration (Valentijn et al. 2015).

The need for broader measures of integration

While tool inventories offer easy access to available instruments, they create the challenge of how to select the most appropriate instrument for a given initiative, system, and context. Furthermore, these instruments do not really capture the complexity and interwoven nature of integrated care as they typically focus on isolated components.

Some have stressed the need for frameworks around integrated care concepts to guide the measurement of integration. For example, Nuno Solinis and Stein (2016) state that "If integrated care initiatives are to be truly able to provide the depth of evidence that we need, then a measuring and monitoring framework should form an integral part of the overall transformational change strategy" (p. 1). Similarly, Singer et al. (2018) argue that "Lack of a comprehensive theoretical model linking different definitions of integration has constrained development of a systematic approach to understanding and empirically verifying relationships among types of integration" (p. 2). Others add that such frameworks must be robust enough to understand the intricate interplay between multi-component interventions across contexts and settings (Gonzales-Ortis et al. 2018).

Indeed, such frameworks are emerging, and they hold great promise for advancing the rigour of evaluating integrated care systems and their outcomes.

32.3 Integration Frameworks and Theoretical Models

In the following, we describe and summarize key aspects of a number of frameworks that have been developed with the purpose of guiding design, monitoring, and evaluation efforts of integrated health systems. This is not meant to be a comprehensive list of models; rather, the aim is to highlight some of the work in the field that can help to further evolve our thinking around measuring integrated care. The first two frameworks are of more theoretical nature, the second group of frameworks aids current state assessment, and the last group aims to capture outcomes and performance. Details of each framework are provided in Table 32.1.

32.3.1 Models that Focus on Structure, Function, Process, and Capacity Dimensions of Integrated Care and Their Interactions

32.3.1.1 Theoretical Model of Integration Constructs (Singer et al. 2018)

The aim of Singer et al. (2018) was to develop a theoretical model that synthesizes and extends past frameworks of integration and provides a more complete representation of the various, disparate constructs of integration. On top of structural,

Table 32.1 Summary of select integration measurement frameworks and models

Author	Main focus of the study	Framework components	Proposed measurement approach	Proposed benefits of the framework
Theoretical model of integration constructs Singer et al. (2018)	Create a comprehensive theory describing how integrating structures, processes, and people within and across organizations might lead to integrated patient care and improved outcomes, including technical quality, efficiency, patient health, and both patient and provider experience	Structural, functional, normative, interpersonal, and process components of integration • Structural and functional types refer to organizational features related to how structures and systems are set up • Interpersonal and normative types describe social features related to what people believe and how they behave together • Process integration describes a course of care delivery actions or activities such as referral management and use of shared care plans Contextual factors are also considered and refer to features of the market and organizational context that affect integration types Integrated patient care is considered a possible intermediate outcome of	The different types of integration captured in this model might require different measurement approaches and data sources	Defining the key dimensions of integration for healthcare organizations and clarifying the hypothetical relationships among them can improve efforts to compare and contrast disparate interventions seeking to improve integration in health care This work provides a theoretically informed basis for empirically exploring and making sense of how various integration types relate to each other and to critical health system outcomes, with clear implications for policy makers and practitioners

(continued)

Table 32.1 (continued)

Author	Main focus of the study	Framework components	Proposed measurement approach	Proposed benefits of the framework
		organizational, social, and activity integration Outcomes, including better technical quality of care, efficiency of care, patient experience of care, provider experience of care, and patient health, might result directly from organizational, social, and process integration or indirectly through integrated patient care		
Structure, function and capacity dimensions of service network integration Browne et al. (2007)	Conceptualize a comprehensive approach to the measurement of multiple dimensions of integrated human service networks based on a review of integration measurement approaches	Dimensions of human service integration measures are (1) Observed (current) and expected structural inputs, or the mix of agencies that comprise the network (e.g. extent, scope, depth, congruence within an agency, and reciprocity between agencies) (2) Functioning of the network both in terms of the quality of the network or partnership functioning and ingredients of the integration of the networks' working arrangements and	Proposes a comprehensive approach to the measurement of integration of human service networks drawing on existing tools that measure the three components of the model	This approach to measuring network integration can be related to measures of effectiveness from client, family, service agency, and system perspectives and can be analysed longitudinally to document change overtime Future work would help establish the relative importance of each of these dimensions to client and system outcomes

(continued)

Table 32.1 (continued)

Author	Main focus of the study	Framework components	Proposed measurement approach	Proposed benefits of the framework
		range of human services provided (3) Network outputs in terms of network capacity (e.g. what is accomplished, for how many and how quickly given the local demand) measured from dual perspectives of the agency and the family The combination of concepts was derived from existing theoretical, policy, and measurement approaches in order to establish the content validity and comprehensiveness of the proposed measure		
B3-Maturity Model (B3-MM) as part of the European SCIROCCO project Grooten et al. (2018)	Measure the maturity of integrated care. More specifically: (1) Test the appropriateness of dimensions, indicators, and assessment scale of the B3-MM (2) Test the content validity of the B3-MM	12 dimensions of integration maturity: (1) Readiness to change (2) Structure and governance (3) Information and ehealth services (4) Finance and funding (5) Standardization and simplification (6) Removal of inhibitors (7) Population approach	A self-assessment tool measures integrated care maturity across the 12 dimensions Uses a scale of 1–5 for each of the dimensions to create a "spider diagram" to map the maturity of integrated care for a region or health systems	Measurement of maturity facilitates the identification of challenges experienced in integrating care, as well as factors for successful integration Provides important information to develop further integrated care initiatives in the best ways possible

(continued)

Table 32.1 (continued)

Author	Main focus of the study	Framework components	Proposed measurement approach	Proposed benefits of the framework
	Literature review and Delphi were used to test the content validity of the B3-MM	(8) Citizen empowerment (9) Evaluating methods (10) Breadth of ambition (11) Innovation management (12) Capacity building	Includes identification of strengths and weaknesses for each dimension	Information sharing across jurisdictions is encouraged to improve integrated health services delivery
Project INTEGRATE Framework Cash-Gibson et al. (2019)	Develop a framework to guide healthcare service managers to self-assess their organization's integrated health services, in particular, the care process Test the validity and utility of the framework	Seven dimensions of integrated care (Read et al. 2019): (1) Person-centred care (2) Professional integration (3) Clinical integration (4) Organizational integration (5) Systemic integration (6) Functional integration (7) Normative integration	A self-assessment tool was developed to assist healthcare managers and planners in developing, implementing, and evaluating integration Uses a series of questions across the seven domains that are explored through discussions	Focused on people-centred integrated care (PCIC) processes Project management can be very helpful in developing and delivering PCIC Resources need to support PCIC within a health system or success will not be realized Important to note what is happening at each stage to inform subsequent steps of integrated care Provides practical guidance for health services managers and planners to develop and implement PCIC Advocates for the inclusion of patients, families, and caregivers (service-users) at various stages of the process

(continued)

Table 32.1 (continued)

Author	Main focus of the study	Framework components	Proposed measurement approach	Proposed benefits of the framework
The Development Model for Integrated Care (DMIC) Minkman (2016)	Conceptualize a validated, generic management model for integrated care Context: multiple integrated care settings, e.g. stroke, acute myocardial infarct, dementia	89 elements were grouped into nine clusters: (1) Quality care (2) Performance management (3) Inter-professional teamwork (4) Delivery system (5) Roles and tasks (6) Patient-centredness (7) Commitment (8) Transparent entrepreneurship (9) Result-focused learning The elements of integrated care are present in four developmental phases: (1) The initiative and design phase (2) The experimental and execution phase (3) The expansion and monitoring phase (4) The consolidation and transformation phases Elements of integrated care are more important or relevant in specific development phases	A Web-based self-assessment tool was developed and tested allow organizations to objectively assess their integrated care and define areas for improvement The tool has three parts: (1) Collecting information about the integrated care service (2) Scoring the 89 elements (3) Presenting and assessing the development phases Can be completed by one person or multiple people representing the network	Offers a model and tool to apply the model in practice Helps identify existing activities and develop additional ideas and strategies around expanding integrated care activities Helps identify differences in perceptions of integration elements and developmental phases if completed by multiple partners

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Table 32.1 (continued)

Author	Main focus of the study	Framework components	Proposed measurement approach	Proposed benefits of the framework
The Rainbow Model of Integrated Care (RMIC) Valentijn et al. (2013) Valentijn et al. (2015) Fares et al. (2019) Valentijn et al. (2019)	Develop and refine a conceptual framework to understand integrated care from a primary care perspective Tools developed and tested in the Netherlands, Singapore, and Australia in a number of different contexts	The conceptual framework is based on the integrative functions of primary care. It combines person-focused and population-based perspectives A taxonomy of 59 key features are distributed among six dimensions of integration: (1) Clinical integration (Micro) (2) Professional integration (Meso) (3) Organizational Integration (Meso) (4) System integration (Macro) (5) Functional integration (linking micro, meso, and macro) (6) Normative integration (linking micro, meso, and macro) A Delphi study indicated that 34 of the 59 key features, the features associated with the professional and organizational dimensions, are appropriate for achieving integration in a primary care context	RMIC measurement tool (RMIC-MT) was developed The self-assessment questionnaire assesses the six RMIC domains Items were developed based on a literature review and qualitative synthesis process. The content validity was assessed through three modified Delphi studies	Was designed to provide a better understanding of the inter-relationships among the dimensions of integrated care from a primary care perspective Provides a way to describe and analyse various types of integrated service models The tool has been tested based on integrated care projects in The Netherlands, Singapore, and Australia. Variations have been developed for different care contexts (e.g. renal care, mental and physical health care), countries, and target audiences (i.e. patient, provider)

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Table 32.1 (continued)

Author	Main focus of the study	Framework components	Proposed measurement approach	Proposed benefits of the framework
Context, Outcomes and Mechanisms of Integrated Care (COMIC) Model Busetto et al. 2016	Develop a model for the comprehensive evaluation of integrated care interventions that provides insights into when, why and how successful outcomes can be achieved	COMIC model: Mechanisms are the different components of integrated care interventions and categorized according the Chronic care model: • Health system, self-management support, delivery system design, decision support, clinical information system, community Context is the setting in which the mechanisms are brought into practice and described by outlining the barriers and facilitators to change encountered in the implementation process: • Innovation, individual professional, patient, social context, organizational context, health system context, economic, political, and legal context Outcomes are the effects triggered by mechanisms and context: • Effectiveness, efficiency, accessibility,	Recommends qualitative data collection through semi-structured interviews to ensure sufficient information can be captured on the interplay between mechanisms, context, and outcomes	The COMIC model can be used to systematically and comprehensively study the different intervention types, settings, and outcomes of integrated chronic care interventions, as well as the interplay of these elements

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Table 32.1 (continued)

Author	Main focus of the study	Framework components	Proposed measurement approach	Proposed benefits of the framework
		patient-centredness, equity, safety, satisfaction		
Integrated Care Performance Assessment (ICPA) Model European Commission (2018)	Develop an evidence-based conceptual framework and a set of indicators that can be used to monitor current state and performance of integrated care systems across different country contexts in Europe	Five relevant domains for integrated care systems: (1) Advancement of integration (2) Use of health services (3) Health outcomes (4) Patients' satisfaction and quality of life (5) Financial outcomes For each of the domains, 3–6 relevant indicators were selected through large stakeholder consultations. A comprehensive tool was developed (including definitions and proposed measures for the indicators) to facilitate the use of the framework	Recommends the use of a set of 18 core indicators, together with the accompanying tool to provide a flexible and coherent framework to support the implementation of integrated care	The evidence-based framework, and accompanying tool, will allow users to further develop their integrated care systems based on context and current state and assess their performance over time

functional, and process dimensions, their model differentiates between normative and interpersonal aspects that have been largely neglected by others but may be critical to integrated patient care. Integrated patient care is a possible intermediate outcome of organizational, social, and activity integration.

Their model also introduces hypotheses as to the relationships among all key types of integration. Singer et al. (2018) argue that this is an important step as the magnitude and directionality of these relationships may differ in important ways across integration types. The first hypothesized relationship underlying the conceptual model is that elements of context are typically precursors to organizational and social types of integration. The second hypothetical relationship is that greater organizational-type integration is associated with greater social-type and activity integration (e.g. normative, interpersonal, and process integration). The third major hypothetical relationship conveyed is that the five types of integration will collectively affect intermediate and ultimate outcomes. Obtaining data on relationships may lead to a better understanding of which specific types of integration may lead to better-integrated patient care.

A unique feature of their model is that it differentiates aspects of integration that system leaders and policy makers can manipulate directly from those aspects that are more likely to be influenced indirectly (e.g. as a consequence of leader actions or policy). This is thought to lead to better decision-making among practitioners and policy makers.

32.3.1.2 Structure, Function, and Capacity Dimensions of Service Network Integration (Browne et al. 2007)

Browne and colleagues (2007) were concerned with developing a measurement approach to assess the level of integration between agencies that have traditionally delivered services in an autonomous way. Such agencies would typically have independent processes, funding sources, governance structures, and service agreements that for the purpose of integration will need to be restructured. This focus on integrated human service networks is somewhat unique and valuable as many of the existing evaluation tools and approaches focus on integration within entities rather than across agencies.

The theoretical framework of their proposed model draws on existing literature, notably on Provan and Milward’s work on health services delivery network (2006), that represent theoretical, policy, and measurement perspectives. Their elaboration of the literature that conceptualizes human services networks led to the development of the Human Services Integration Measure.

They identified the following dimensions of human service network integration that require measurement: (1) observed (current) and expected structural inputs, or the mix of agencies that comprise the network (e.g. extent, scope, depth, and congruence within an agency, and reciprocity between agencies); (2) functioning of the network both in terms of the quality of the network or partnership functioning and the ingredients of the integration of the networks’ working arrangements and range of human services provided; and (3) network outputs in terms of network capacity (e.g. what is accomplished, for how many, and how quickly given the local demand) measured from the dual perspectives of the agency and the family. Each of these structure, function, and capacity dimensions of service network integration are distinct aspects of integrated service. They propose the use of existing tools to measure each of the three components. Collectively, these measures should provide a comprehensive picture of the level of integration.

32.3.2 Models and Frameworks for Current State Assessment/Maturity of Integrated Care Systems

32.3.2.1 B3 Maturity Model (Grooten et al. 2018, 2019)

The B3 Maturity Model (B3-MM) was developed to create a standardized approach to scale up integrated care. An observational study with interviews with decision-makers in 12 European countries and/or regions within countries was used to create the B3-MM. Interviews focused on the current state of integration, how integration was achieved, and plans for further integration (Henderson et al. 2016). Twelve dimensions were created. The B3-MM was then validated through a systematic literature review and Delphi survey with experts from countries and regions in Europe with expertise in integrated care (Grooten et al. 2018). The systematic review was based on the literature review by Batista et al. (2016). Three rounds of Delphi were completed. In the first round, there was sufficient agreement on the 12 dimensions, but less agreement on the indicators for each of the dimensions. Agreement was then achieved on rephrased indicators in Rounds 2 and 3 of the Delphi. The tool was later renamed the Scaling Integrated Care in Context (SCIROCCO) tool(s); the Website includes the dimensions as well as the indicators. Further research is to be carried out through the SCIROCCO project. Structural validity through factor analysis was later completed (Grooten et al. 2019). Internal consistency was rated as good, but further research is needed for continued testing of validity and reliability of the tool.

The B3-MM/SCIROCCO tool includes both dimensions of integration and dimensions necessary to implement integrated care (https://www.scirocco-project.eu/). Research of both the tool and other materials to promote integrated care are ongoing with the model. SCIROCCO provides a Maturity Model with an online self-assessment tool to determine readiness for integrated care across 12 dimensions. The Model and assessment tool can be used by programs, organizations, and geographic regions to inform changes to policy and practice related to integration. The process used includes assessment with analysis of data on the four dimensions, encouragement of dialogues to develop consensus on actions needed, and an option for healthcare leaders and providers to participate in coaching opportunities. These tools provide a comprehensive approach for building integrated health systems.

32.3.2.2 Project INTEGRATE Framework (Cash-Gibson et al. 2019)

The Project INTEGRATE framework is designed as a tool to assess integrated care processes and the steps involved. The framework was created using a three-phased approach: a review of the literature (including operations, service, and project management business literature and healthcare literature) to identify core components to support sustainable and effective people-centred integrated care (PCIC) processes. Four projects were then reviewed (four Project INTEGRATE cases) for additional core components. The framework includes six key dimensions of integration (professional, clinical, organizational, systemic, functional, and normative) surrounding patient-centred care, the central theme of the framework (Read et al. 2019). The tool itself provides many questions/items to consider in developing and implementing the Project INTEGRATE framework and requires extensive discussions with different stakeholder groups to arrive at meaningful data. Once the first iteration of the framework was developed, it was tested for validity and utility with another Project INTEGRATE case. The framework needs further testing to apply and evaluate it to cases other than those outlined on the Project INTEGRATE Website (projectintegrate.eu). The Project INTEGRATE framework has been used in various settings including chronic disease management, mental health, geriatrics, and children and youth (https://www.projectintegrate.eu.com/case-studies, Read et al. 2019). It was found to be helpful in determining progress towards integration and identifying barriers and facilitators for integrated health systems (Read et al. 2019).

32.3.2.3 Development Model for Integrated Care (DMIC, Minkman et al. 2016)

The Development Model for Integrated Care (DMIC) aims to understand and define how integrated care processes develop over time and the characteristics and key issues in the developmental process. A literature review and Delphi study informed the DMIC by focusing on the different phases in integrated care development and the integrated care practices within those phases. Four phases were identified: (1) initiative and design phase; (2) experimental and execution phase; (3) expansion and monitoring phase; and (4) consolidation and transformation phase. Within those phases, 89 elements (an element is defined as an activity focusing on integrated care development) of integrated care were also identified, which were grouped into nine clusters.

The developmental phases were validated in three studies and further validated through the development, testing, and validation of the DMIC self-assessment tool (Minkman et al. 2013; Minkman 2016). The DMIC was validated through an evaluative survey administered in integrated stroke, acute myocardial infarct, and dementia services in the Netherlands. The study confirmed the four phases of the DMIC, and further validation of the model and the self-assessment tool (Minkman 2016) found that the 89 elements of integrated care were found relevant in practice, although practices differed in different groups and contexts. The 89 elements have also been linked to each of the four phases. Although there is fluidity in those activities, certain elements are more likely to be present in specific phases (Minkman 2016).

To help with the practical application of the DMIC, an online self-assessment tool was developed and has been validated in a number of different contexts.

The DMIC is unique from other health systems integration models because it focuses on enablers of quality care, has multiple performance dimensions for multiple stakeholders, and assumes dynamic relationships between performance and implementation enablers.

32.3.2.4 Rainbow Model of Integrated Care (RMIC, Valentijn et al. 2013)

The Rainbow Model of Integrated Care (RMIC) was developed to understand integrated care from a primary care perspective. A literature search of concepts related to primary and integrated care, and group meetings and expert panels were used to identify and define the framework (Valentijn et al. 2013). The model identified three levels of integrated care: macro, meso, and micro, which describe system integration (macro), organizational and professional integration (meso), and clinical integration (micro). The three levels are linked by functional and normative integration, and the model is framed by person- and population-focused care.

The RMIC was further refined by developing a taxonomy that identified 59 key features distributed across the six integration dimensions (clinical, professional, organizational, system, functional, and normative) (Valentijn et al. 2015). The key features were identified through a literature search for features needed to achieve integrated service delivery and a thematic analysis to organize the key features into the RMIC dimensions. The taxonomy was verified through a Delphi study with integration experts from the Netherlands (Valentijn et al. 2015).

Because no tool existed which measured all the domains of the RMIC, a measurement tool was developed. The tool has been tested in a number of contexts and countries and continues to be refined and validated. Most recently, a RMIC Measurement tool (RMIC-MT) was developed and tested for renal care patients and providers in the Netherlands (Valentijn et al. 2019), and a shortened version was developed and tested for providers in mental and physical health care in Australia (Fares et al. 2019). Both tools were found to have good validity and reliability and contribute towards developing an integration tool that can be applicable in multiple contexts and countries.

32.3.3 Models and Frameworks that Focus on Integration Systems Performance and Outcomes

32.3.3.1 Context, Outcomes, and Mechanisms of Integrated Care (COMIC) Model (Busetto et al. 2016)

The study by Busetto et al. (2016) was motivated by the need to understand when, why, and how some interventions led to integrated patient care while others do not. Hence, they put great importance on the context in which interventions are being implemented. The authors developed a preliminary model based on the Context + Mechanism + Outcome Model and further developed it into the COMIC model (Context, Outcomes, and Mechanisms of Integrated Care interventions). The COMIC model assumes that an intervention is introduced using certain mechanisms, which are met with particular context factors (described by barriers and facilitators), which combined, contribute to specific outcomes.

Mechanisms were defined as the different components of integrated care interventions (categorized according to the Chronic Care model by Wagner). Context refers to the setting in which the mechanisms are brought into practice and is described by the barriers and facilitators to change experienced during the implementation process (categorized according to the Implementation Model). Outcomes were defined as the effects triggered by mechanisms and context (categorized by the WHO dimensions of quality of care).

In applying the COMIC model to implementation studies published in the literature, they found it to be limited as it did not provide insights into relationships between the different components. In contrast, when applied to two case studies, it allowed for a better understanding of relationships between components due to the detailed data collected. This resulted in their recommendation to collect data through semi-structured interviews as part of detailed case studies to elicit sufficient information on the interplay, relationships, and links between the model's elements.

32.3.3.2 The Integrated Care Performance Assessment (ICPA) Framework (European Commission 2018)

The European Commission set out to develop a framework for the assessment of performance of integrated care that can respond to the extremely varied and heterogeneous state of integrated care initiatives in different parts of Europe. The Integrated Care Performance Assessment (ICPA) framework was established through extensive engagement and consultation with stakeholders from 30 countries and collaboration with European Union funded projects.

Based on a comprehensive literature review of existing frameworks and a co-design process, the key domains and indicators for the framework were identified. The domains include (1) advancement of integration; (2) use of health services; (3) health outcomes; (4) patients' satisfaction and quality of life; and (5) financial outcomes. For each of the domains, three to six relevant indicators were selected through stakeholder consultations and pre-established criteria. The criteria for the core indicators included validity and reliability; relevance and actionability, but also international feasibility and comparability to make the framework useful across different country contexts.

The accompanying Integrated Care Performance Assessment (ICPA) framework (available at https://ec.europa.eu/health/sites/health/files/systems_performance_assessment/docs/2018_icpa_en.xlsx) allows for the practical application of the core indicators. This includes definitions and proposed measures for the indicators; a list of optional indicators identified in the literature that, depending on the context, may also be important for assessing the performance of integrated care; and a proposed model to monitor and assess the allocation of funds and how it is linked to the performance of the integrated care initiative, and thus provide a financial evaluation to inform future expenditure decisions. The tool and indicators allow users to assess the performance of integrated care, monitor the allocation of funds, and understand how resource allocation is linked to performance.

32.3.4 Summary and Critical Appraisal

Recognizing the need for a more holistic approach to measurement, the focus in recent years has been on developing integration models and frameworks to guide evaluation efforts. The eight models highlighted in this chapter represent a range of concepts and focus areas. For example, Singer et al. (2018) have developed a comprehensive theory describing how integrating structures, processes, and people within and across organizations might lead to integrated patient care and improved outcomes. Similarly, Browne et al. (2007) draw on network theory to help understand structure, function, and effectiveness of integration networks. Both examples are not measurement tools per se but require data from multiple sources. While this is likely time consuming and perhaps too onerous for wide practical application, these theoretical frameworks can help formulate and test specific hypotheses for evaluation and steer the user to the most appropriate tools for measurement.

Other frameworks have clearly been built with application in mind, such as the SIROCCO, Project INTEGRATE, DMIC, and RMIC. Project INTEGRATE is unique as it focuses primarily on the processes that need to be in place to achieve integrated care (Cash-Gibson et al. 2019). The need for comprehensive collection of information across seven domains and discussions with multiple stakeholders takes substantial time and resources and perhaps limits its applicability to smaller local settings rather than large systems. The SCIROCCO tool was designed to map the maturity of integrated care for a region or a health system by identifying strengths and weaknesses for each dimension (Grooten et al. 2018). Similarly, the DMIC measurement tool is a self-assessment tool which allows users to reflect on the level of integration along the model's 89 elements (Minkman 2016). The RMIC measurement tool looks at whether integrated care projects have successfully implemented integration strategies (Valentijn et al. 2013, 2015, 2019; Boesveld et al. 2017; Fares et al. 2019). All three of these frameworks have developed user-friendly, mostly Web-based tools that facilitate data collection. They also have been successfully tested across different types of care settings, and in different countries, thus enhancing the validity and applicability of the tools. In addition, these tools help ground and provide a common language to the complex concept of health system integration and ultimately provide a place to start planning, developing, and measuring existing integration efforts.

The previous frameworks facilitate the planning and implementation of integrated services or the assessment of the current state rather than outcomes of integrated care strategies. In contrast, the COMIC and the ICPA models are more focused on outcomes or performance. The COMIC model is interesting as it looks at how certain types of interventions play out in different contexts and what the results are. This systematic approach to evaluating the effects of different interventions will help identify the ones that lead to the most beneficial results. While appealing, the model requires collection of comprehensive qualitative data to understand the interplay between the different dimensions, which can be time consuming. The ICPA model might have more practical appeal as it offers a core set of 18 indicators across five domains, which makes it relatively easy to assess performance over time.

32.4 Conclusions

There are many tools that measure individual dimensions of integration with a focus on care coordination and patient-centred care (e.g. Agency for Healthcare Research and Quality 2014; Bautista et al. 2016; Schultz et al. 2013; Suter et al. 2017). This is perhaps not surprising; these domains are the focus for many healthcare system reforms as progress in these areas directly influences patient care and experience (Luxford and Sutton 2014). In contrast, few tools focus on functional, system, organizational, or normative dimensions of integrated care (Bautista et al. 2016, Lyngsø et al. 2014; Suter et al. 2017) despite their importance for successful integration (Valentijn et al. 2013, 2015). These remain poorly measured aspects of integrated care, pointing to an important evidence gap. The vast majority of instruments are self-report questionnaires to be completed by the healthcare provider or the patient. A popular choice due to the ease of implementation, the limitations of self-report tools has been well recognized (Paulhus and Vazire 2007). Also, many of the instruments were not tested for psychometric properties to support instrument validation.

More recent efforts have focused on the development of comprehensive integration frameworks and models that capture a range of integration dimensions. Despite the breadth of focus and dimensions captured in the frameworks, they are all designed to create conceptual clarity about the different components of integration and potentially the relationships between the components. These multilevel conceptual frameworks are critical to understanding the increasingly complex and multilayered relationships emerging in healthcare systems. They also highlight the importance of clarity about the type of integration and level of analysis when examining health system integration, in order to identify clear measures and empirical approaches that capture various types of systems and strategies (Singer et al. 2018). None of the frameworks offers a unified approach to measurement; different measurement approaches may require different data sources to achieve a comprehensive understanding of health system performance (Singer et al. 2018).

Many of the frameworks were developed in countries within the European Union. Some of the frameworks (e.g. the Scirocco tool, DMIC, RMIC) are undergoing significant testing to determine their validity and reliability. For example, the Scirocco tool has been tested in 40 regions across five countries including Australia, Europe, New Zealand, Singapore, and the United States (International Foundation for Integrated care, 2018). For most tools though, more research is needed to ensure relevance to all contexts and integrated care systems. Also, while the validation and spread of integration measurement frameworks is encouraging, it will ultimately lead to a number of competing frameworks, thus preventing a coalesced international approach to measurement. Rather than developing a framework in a specific country and then trying to spread the same, which is what currently is happening, we propose that stronger international cooperation needs to occur in the development of the frameworks. Others have highlighted the need for a unified measurement framework (Nuno Solinis and Stein 2016), including recommendations on indicators and measurement instruments that have validity across countries and contexts. We support this call. Being able to evaluate the success of integration strategies in a consistent way will ultimately lead to better health system design and improved health outcomes for patients.

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Claims Data for Evaluation

33

Enno Swart

33.1 Background

Integrated care aims at reorganizing and/or continuously enhancing care structures and processes to improve patient-related outcomes and economic results in standard every-day care. It also aims to boost patients' and care providers' satisfaction with and acceptance of medical care. The question is therefore to what extent we may use data generated in standard care when it comes to evaluating integrated care.

Contrary to traditional clinical research which relies on randomized studies to explore the efficiency of new approaches in therapy in a standardized defined clinical setting with typically closely defined inclusion and exclusion criteria of study participants, claims data offers opportunities for a higher external validity (often at the expense of a lower internal validity) without narrowing down the patients involved in advance.

This paper will examine if claims data generated in standard medical care is suitable for evaluating integrated care. To do so, we need to describe the structure and contents of relevant data and explain its advantages as well as the methodological challenges of using such data for evaluation research. Selected short examples will illustrate how to use the data and the conclusions drawn from the results for practical application. This paper ends with a description of the potential of the data in addition to approaches pursued in clinical research. In order to do so, we will examine to what extent the conclusions drawn for Germany can be applied to other countries based on a number of examples.

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33.2 Claims Data

In 2020, approximately 73 million people, i.e. about 89% of the German population, had statutory health insurance. Civil servants, members of the police and armed forces, freelancers and self-employed people are not required to have statutory health insurance. They must or can take out private health insurance. Employees subject to statutory health insurance whose income exceeds the income threshold have the right to opt for either statutory or private health insurance. Family members (spouses that do not work and children) are covered by the insurance plan (family insurance) of the income earner (Bormann and Swart 2014). A catalog binding for all currently existing 103-plus statutory health insurers (as of spring 2021) lists the mandatory services covered by statutory health insurance plans. It comprises medical, dental and psychotherapeutic services provided in inpatient and outpatient care (including prevention measures such as vaccinations or screening), drug prescriptions and prescriptions of remedies and medical aids (e.g., physical therapy and ergotherapy or wheelchairs, optical aids) as well as medical rehabilitation if not covered by other social welfare services (e.g., the statutory pension insurance fund) and expenses for sick pay for people with a long-term work incapacity. The services mentioned make up about 90% of the total expenditure of more than € 220 billion (2017; see www.gkv-spitzenverband.de).

Services are provided as non-cash benefits. That means that the statutory health insurers or self-governing bodies directly or indirectly pay doctors and non-medical service providers for their services. Insured people only pay for services not listed in the statutory health insurance service catalog or for over-the-counter drugs. This does not apply to limited contributions paid by the insurant for drug prescriptions and prescriptions of remedies and medical aids, dental prostheses or hospitalization. All services covered by statutory health insurance are subject to standardized documentation, which the German Social Code (Book V) regulates specifically for each care sector (Swart 2014) (see Table 33.1), and are thus available for scientific use under certain conditions. Due to the system, statutory health insurers do not document services paid for by the insurant.

In summary, the data comprises socio-demographic information about the insured person [age, gender, place of residence, to a limited extent social attributes such as education and income, insurance periods, in case of death the day of death (but not the cause of death)], diagnoses documented by outpatient health care providers and hospitals (ICD coded). However, collected data not only includes the diagnosis to be treated but also secondary diagnoses, outpatient medical services as well as diagnostic, operative (surgical) and therapeutic services provided by hospitals (coded according to OPS), the type and quantity of drug given out by pharmacies (ATC coded), the type and quantities of remedies and medical aids provided. The information also includes the date of the services provided, the duration of work incapacity and the diagnosis justifying it. A precise description of the structure and content of claims data is contained in Swart et al. (2014).

Table 33.1 Provisions in the social code book V on the transmission of routine data from the statutory health insurance

	Health care sector	Case-related contents (among others)[a]
§295	Outpatient care	Type of case (e.g., direct contact, referral, emergency), specialties of the treating physician and any referring physician, diagnoses (ICD), services (uniform value scale [“Einheitlicher Bewertungsmaßstab”; EBM], German procedure classification [“Operationen- und Prozedurenschlüssel”; OPS])
§295	Incapacity to work	Diagnosis (ICD) that justifies the incapacity to work, initial versus follow-up certificate
§300	Pharmaceutical prescriptions	Proprietary medicinal products; central pharmaceutical number (PZN) indicates active ingredient, price and quantity of the pharmaceutical (anatomic-therapeutic-chemical-[ATC]-Code); prescription date
§301	Inpatient care	Admitting hospital, diagnoses at admission and discharge, secondary diagnoses (ICD), procedures and diagnostics (OPS), reimbursement (DRG), reason for admission and discharge, date of admission and discharge
§302	Prescriptions of non-pharmaceutical therapies and technical aids	Rendered services by type, quantity and price as well as medical diagnosis

[a] Member-related data (age, sex, etc.) is available for every sector. *Source* Swart (2014)

This paper will only examine the use of claims data provided by statutory health insurers and not look at administrative data collected by other social security providers that may also be used for scientific purposes under certain conditions (Swart et al. 2014).

The paper primarily focuses on the situation in Germany where specific (strict) general conditions exist pertaining to the scientific use of health insurance claims data. The methodological considerations of the strengths and weaknesses of the data also apply to claims data from other countries. At the end of this paper, we will list a number of general criteria that may be used to assess the usability of claims data for evaluation purposes.

33.3 Methodological Aspects of Using Claims Data

The administrative data collected by statutory health insurers primarily serves to pay for medical services. This primary purpose of use defines the provisions, the variables to be transmitted and the type of coding. This circumstance must always be taken into consideration when discussing the advantages and drawbacks of the scientific use of claims data (also referred to as “secondary data” in Germany because of this secondary use) particularly in the context of evaluating integrated care. The characteristics of the data determine its validity and later processing as central steps prior to the actual analysis of the data. What follows is a short description of the strengths illustrating why the data is suited for research.

- *As it relates to a defined population*: With the help of the data, it is possible to calculate epidemiological parameters that are typically calculated as the rate of an absolute number of target events as the numerator and a definable and quantifiable population denominator. This makes it possible to show treatment frequency (e.g., the number of diabetic patients per 1000 insured people) or identifiable events (e.g., the number of hospital stays of patients diagnosed with diabetes as their principle diagnosis). It can be further differentiated by age, gender and other sociodemographic or disease-related characteristics. Incidences (new diseases or more precisely the first documentation of a diagnosis) and prevalence (number of patients treated or documented with a certain diagnosis) can be determined accurately using standard statutory health insurance data based on the number of insured persons at a certain date or within an observation period (so-called population at risk). For instance, this makes it possible to determine the number of insurants in a defined integrated care project. Typically, information about the use of medical services obtained from primary surveys as well as from other secondary data (from doctor's offices, hospitals or disease registers) does not relate to the population to the same precise extent (Grobe and Ihle 2014).
- *As it relates to individual persons*: Claims data collected by statutory health insurers is so important for evaluating specific care options and structures because care processes pertaining to individual insured persons (e.g., within an integrated care project) can be mapped both retrospectively and prospectively over a longer period of time for that person. With the help of a person's health insurance number, pseudonymized for scientific use, all contacts of that patient can be combined across sectors and irrespective of the service provided and the place of service provision (Grobe and Ihle 2014). However, statistics relating only to incidents and sectors lack this feature and cannot be differentiated by individual insurants. For instance, it is not possible to derive from official German diagnosis statistics how many patients account for the more than 19 million hospitalizations in Germany (2018; see www.gbe-bund.de).
- *As relating to place of residence and location*: Based on the postal code of the insurant's place of residence, it is possible to map epidemiological data on a regional level. No other care data currently has the ability to depict the care context with a clear population reference on a small-scale regional level. By adhering to data protection regulations, it is also possible to perform local care analyses with regard to service providers (Swart et al. 2008). Below we will describe how this feature is used to evaluate an integrated care project in a control group design.
- *Completeness*: Since the data is used for payment purposes, we can assume that most claims data is nearly 100% complete, and thus, the danger of a selective reporting bias, which is always a problem with primary surveys, is very low.

However, the data is only complete with regards to services covered by statutory health insurance. By definition, it does not include information on privately paid services (see above) such as over-the-counter medicine. This information is not systematically documented. Short-term sick leave of no more than 3 days is also underrepresented in the data on work incapacity because employees are obliged by law to furnish a certificate of incapacity for work starting on the fourth day of sick absence (Meyer 2014).

- *Data quality*: In view of its primary use, standard claims data is assessed for completeness and correctness, e.g., with regard to the consistency of information on diagnoses and surgery relevant for compensation. At the same time, one should keep in mind that the data owner must separately assess the validity of data variables not assessed for quality, such as information on departments or the reason for hospital admission. One should also take note of the fact that the diagnoses entered must first be understood as diagnoses eligible for compensation that must be validated internally and possibly externally in a disease-specific analysis (Schubert et al. 2010; Schubert and Köster 2014).
- *Expenses*: Claims data is generated in a standardized way as part of standard care procedures. In terms of costs, the care researcher is particularly interested in expenses incurred by the data owner for data processing, provision and transmission. Normally, the data is available in a form easily suitable for further computer-assisted processing. However, the financial and personnel costs arising in connection with providing claims data may oppose the intended scientific use in light of the standard responsibilities of the data owner (Reis 2005; Holle et al. 2005).

More in-depth insights regarding the content and methodological aspects of analyzing and processing claims data can be found in Swart (2014) and the monograph by Swart et al. (2014) and the individual descriptions of sector-specific data in these works.

33.4 Methods

In the 1990s, the science community first published several basic fundamental publications on the chances and perspectives of using health and social data (von Ferber and Behrens 1997). However, the concrete use and development of specific approaches and methods for analyzing and processing this data was limited to a few working groups, until at the beginning of this century when a larger group of researchers discovered the opportunities the data offers as a result of the establishment of care research and its linkage with clinical subjects. The memoranda of the German Network of Care Research (Deutsches Netzwerk Versorgungsforschung; see www.netzwerk-versorgungsforschung.de) expressly talk about the equal usage of secondary data and primary data (Glaeske et al. 2009; Neugebauer et al. 2010). This development called for transparency beyond the data itself as a prerequisite for scientific use and validated methods for processing and analysis. To this end, researchers could rely on existing standards of statistics and epidemiology only to a limited extent. Good epidemiologic practice insufficiently accounted/accounts for the specific general conditions and preconditions of methodologically grounded secondary data analysis (Hoffmann et al. 2019). This encouraged the work group on secondary data collection and usage ("Arbeitsgruppe Erhebung und Nutzung von Sekundaerdaten" (AGENS)) of the German Society of Social Medicine and Prevention (Deutsche Gesellschaft für Sozialmedizin und Praevention; DGSMP) and the German Society for Epidemiology (DGEpi) to develop a good practice of secondary data analysis based on the standards of good epidemiologic practice which was published for the first time in 2005 and has been revised twice since (Swart et al. 2015; available both in German and English online at www.dgepi.de).

At the same time, the use of this data became easier and was fostered by the fact that the handbooks (Swart and Ihle 2005; Swart et al. 2014) not only described the contents of claims data in great detail but that they contained numerous descriptive examples of application as well as a description of the relevant specific processes such as (diagnosis) validation, risk adjustment or matching (Horenkamp-Sonntag et al. 2014; Mostardt et al. 2014; Lux et al. 2014).

In light of the specific German context, AGENS currently works on modifying the well-known STROBE statement (Vandenbroucke et al. 2007) since this reporting standard does not address a large number of important aspects of secondary data analysis required for a critical assessment. After publication of a first draft of the so-called STROSA checklist (STandardized Reporting of Secondary Data Analyses; Swart and Schmitt 2014), a working group of AGENS revised this checklist and presented a new version recently (Swart et al. 2016). Parallel, an international initiative published a similar reporting format named "RECORD (Reporting of studies Conducted using Observational Routinely-collected Health Data)" on the basis of STROBE (Nichols et al. 2015; Benchimol et al. 2015; see www.record-statement.org).

33.5 Prerequisites for Data Usage

In Germany, the scientific use of claims data is subject to strict legal requirements. As data owners, health insurers may use this primarily administrative data only within the scope of their responsibilities pursuant to their by laws, defined in the German Social Code, Book V [online available on the website of the German Federal Ministry of Health; https://www.bundesgesundheitsministerium.de/].

The further use of the data by third parties is also limited by its special character as "social data". It is not only protected by German data protection law (Bundesdatenschutzgesetz; available on the Web site of the German Federal Commissioner of Data Protection and Freedom of Information (https://www.bfdi.bund.de/) but also by the restrictions stipulated by the German Social Code, Book X, which makes usage subject to meeting strict requirements. It permits, however, data utilization for research if it is necessary for reaching the research objective and if the public interest in the research considerably outweighs the private interests of those concerned with keeping their data private. If the researcher can reasonably be expected to obtain the informed consent of the participants in the study, s/he is obliged to do so (March et al. 2014). The supervisory authorities of the relevant data owners will assess in a specific application process if the prerequisites have been fulfilled. In addition, researchers and data owners are obliged to conclude an agreement regulating their collaboration pursuant to the requirements of good practice of secondary data analysis (Swart et al. 2015).

In view of the research process, the large number of regulations that need to be adhered to regarding the use of claims data means that from the very beginning and at the time of determining the study design it is essential to take data protection, technical, legal and organizational aspects into consideration and to calculate expenses in terms of time as well as personnel and financial costs.

For other countries, the technical and legal requirements of using claims data for evaluating integrated care must be assessed specifically. It is no secret that researchers in Germany face particularly high legal hurdles.

33.6 Examples

Two briefly described evaluation approaches to complex integrated care programs aimed primarily at chronically sick people and older insurants in Germany serve to illustrate the usability of claims data for care and evaluation research and the resulting insights and methodological further developments. For more details about these programs, we suggest further reading. We will briefly shed light on the data used, the design on which the evaluation is based and its results.

33.6.1 Evaluating Disease Management Programs

Implemented since 2002 for defined chronic diseases (diabetes mellitus type 1 and 2, breast cancer, asthma or coronary obstructive pulmonary disease, coronary heart disease), disease management programs (DMP) are structured treatment programs for chronically ill patients covered by statutory health insurance. They aim to provide coordinated care by general practitioners (GPs) and specialists in the outpatient sector and hospitals in line with applicable guidelines. By actively involving patients and individually determining care objectives, DMP strive to improve the quality of mid- and long-term care and to make it more effective. In Germany, disease management programs require accreditation by the responsible supervisory body (German Federal Insurance Authority; Bundesversicherungsamt; since 2020: Federal Office für Social Security, Bundeamt für Soziale Sicherung) and are subject to the standardized documentation of all patients enrolled and mandatory evaluation. Participation in DMPs is free for registered doctors and patients (Stock et al. 2010).

Since participation is voluntary and there is no control group design, fundamental methodological difficulties arise when it comes to performing a scientifically sound evaluation of the programs and comparing the mid- and long-term outcomes with regard to enrolled and non-enrolled insurants. The sole pre-post comparison of care outcomes based on the standard documentation of insurants enrolled in the program only cannot be used as valid proof of the program's success due to assumed selection effects (Birnbaum and Braun 2010).

With the help of claims data provided by statutory health insurers, it is possible to differentiate between enrolled and non-enrolled insurants. At the same time, it is possible to map hard endpoints of care, e.g., in case of diabetes mellitus hospital stays due to a derailed metabolism or obvious complications or long-term damage. Therefore, it should not come as a surprise that claims data has been used several times for the controlled evaluation of disease management programs.

So far, most studies available based on claims data have examined DMPs for diabetes mellitus. Following a survival period approach, Miksch et al. (2010) hint at the fact that the overall mortality of enrolled patients may be lower compared with a control group of non-enrolled diabetics that is formed based on age, gender, pension status, federal state, medicine provision costs and diagnostic groups. A study by Stock et al. (2010) where a propensity-score technique was applied to guarantee the structural equality of the intervention and control group came to similar conclusions. Linder et al. (2011) provide complex results because DMP patients had fewer emergency hospital stays and less hospital costs, but the intensity of outpatient care and pharmacotherapy increased.

It can be said that beyond all similarities and differences, claims data is generally suited for complex controlled evaluation designs facilitating a validated comparison of patients in different care regimes by controlling a number of confounders. However, structural equivalence can only be guaranteed with regard to features that the claims data depicts. “Soft” patient-related qualities such as health-related behavior or health models that fundamentally impact participation in a DMP but that cannot be operationalized in the claims data cannot be excluded as further determinants of the differences observed. This could explain why the three groups of researchers are hesitant in interpreting the effectiveness of DMPs.

33.6.2 Gesundes Kinzigtal

The triple aim evaluation of the “Gesundes Kinzigtal” project is an outstanding example of the use of secondary data to evaluate integrated care (IC). Running since 2005, the project has aimed at establishing new regional care structures involving and coordinating medical and non-medical service providers from all health care sectors plus other service partners such as sports clubs. The integrated care concept strives to (a) improve the health of the target population, (b) optimize individual care for individual patients and (c) make health care more resource-efficient in general.

The evaluation of the project rests on several qualitative and quantitative modules comprising surveys of service providers and patients as well as the scientific supervision of individual projects (Mnich et al. 2013). However, the focus is on using claims data provided by the two statutory health insurers involved (AOK Baden-Württemberg and LKK Baden-Württemberg). The data is used for a comprehensive evaluation of the overall project and to identify and reduce excessive, insufficient and wrong care provision. The data serves to explain the development of care quality in the Kinzigtal valley for selected frequent, primarily chronic diseases by applying parameters based on medical care guidelines (Hildebrand et al. 2015).

The use of claims data for insured persons who voluntarily enrolled in the IC project is based on a permission given at the time of enrollment (Swart et al. 2011). Moreover, the service data of all insurants living in the Kinzigtal valley may be used to compare developments in the Kinzigtal valley with a representative sample of insurants living outside the valley. The evaluation is based on a quasi-experimental controlled prospective study design (Hildebrand et al. 2012) using standard claims data and the deduction of validated raw and standardized outcome parameters. This includes, for example, the percentage of insured persons taking medication in accordance with guidelines or prescription costs incurred by the insurant.

In detail, service data from all care sectors is used with the contents described above. Target diseases may be chronic coronary heart disease, heart failure, diabetes mellitus, psychiatric conditions (incl. depression), dementia, chronic back pain. According to preliminary analyses, the evaluation shows in case of the indications mentioned for twelve out of a total of 36 process and structural indicators a significantly better development for all people insured in the Kinzigtal valley compared to a comparative age and gender-standardized population. For ten indicators, they found a slight, insignificant improvement or an analogous development, and only with regard to four indicators, developments in the Kinzigtal valley were not as positive as in the comparative region. Except for the supply with remedies, the Kinzigtal valley exhibits a relative reduction of health care costs (Hildebrand et al. 2015).

The strength of this evaluative approach based on claims data is that because of the intention-to-treat approach we may exclude selective distortions due to the preferred registration of so-called good risks. This makes it more difficult to evaluate other intervention programs such as the DMPs described (Siegel et al. 2014). By deriving indicators based on guidelines, it becomes clear that claims data can be used in a clinical care context closing the gap to clinical subjects. Finally, the individual permission given by the insured persons enrolled in the model makes it possible to individually link primary and secondary data in the scope of specific evaluation studies (Swart et al. 2011).

This paper cannot further detail the large number of other examples of using claims data for evaluating standard care provision. In a review published in 2009, Hoffmann (2009) already identified 70 publications from Germany alone in the field of pharmaco-epidemiology. The scientific use of this data has further increased.

As an example of the opportunities, which is by no means exhaustive, we would like to mention the evaluation of complications following (screening) colonoscopies (Stock et al. 2013), the determination of expenses for (standard) diabetes care (Köster et al. 2014), the effectiveness of various forms of geriatric rehabilitation (Abbas et al. 2015), guideline-based heart attack care (Egen-Lappe et al. 2013), the extent of contra-indicated drug supply (Schubert et al. 2013) or mapping the mid- and long-term quality of hospital care (Klauber et al. 2014).

Other examples illustrating the usage of claims data for transparency purposes are included in the annual sector-specific reports issued by large statutory health insurers and their umbrella organizations, e.g., report on medicine, absence, care, hospitals or remedies and medical aids published by the AOK Bundesverband (www.bv.aok.de) or the dentist, physician or care report by BARMER (www.barmer.de).

33.7 Limitations

The specific characteristics of standard statutory health insurance data and the short examples indicate the wide range of opportunities for use in evaluation research. This was already clear 30 years ago in the context of assessing the quality of surgical therapies: "Insurance claims data are population based, covering all services provided to a defined population regardless of where the care is obtained. [...] Their low cost and routine availability facilitate their use for monitoring outcomes over long periods. They are free of the reporting bias and inadequate follow-up that afflict case series studies and avoid the high costs required when special registries are organized." (Wennberg et al. 1987).

Nonetheless, we should not overlook the limitations of this claims data. In this context, two issues need to be stressed, i.e., the validity of diagnostic information and the transferability of the results of such studies to other populations when the analysis is based on claims data pertaining to a single or a small number of health insurers. A patient-related comparison of diagnostic information contained in GP patient records and diagnostic information contained in claims data found a considerable amount of underreporting in standard health insurance data (in 30% of the cases) mainly pertaining to frequent, less serious GP diagnoses and chronic diseases not treated with medication. At the same time, it revealed the over-reporting (in 19% of the cases) of currently not treated permanent diagnoses (Erler et al. 2009). Another study using claims data only revealed deficits in the continuous documentation of chronic diseases and inconsistencies between diagnostic coding and prescriptions of specific medication (Giersiepen et al. 2007).

The possibilities of using outpatient claims data since 2004 in connection with the coding of diagnostic safety introduced bindingly have increased the validity of diagnosis-related incidence and prevalence estimates. Nevertheless, overall diagnostic information requires a specific validation beyond the health insurer's error checks without considering information contained in patient records or hospital information systems a gold standard in the first place. Depending on the clinical symptoms, reliable outpatient and hospital-based diagnoses and if applicable specific prescriptions and services are used to validate and identify so-called epidemiologically clear cases. In case of a chronic disease, a singular documentation is typically not sufficient (Schubert et al. 2010).

If the observation period is short, it becomes a problem to differentiate between incidental and prevalent cases of chronic diseases because lighter versions that do not necessarily require medication or intervention treatment may not necessarily be documented in the claims data. In such cases, claims data should be available for a longer period of time to avoid an overestimation of incidences (Abbas et al. 2012). Normally, the external validity of secondary data analyses must be examined separately. Since the body of data used often comes from a single health insurer, results may not be automatically applied to people covered by other statutory health insurance plans. Incidence and prevalence estimates particularly depend on the insurer's insurant structure (Hoffmann and Icks 2012).

Nevertheless, in consideration of their strengths and weaknesses, claims data offers a great potential for evaluating models of integrated care, not only as an alternative to clinical studies based on randomized controlled designs but rather to supplement them while implementing principles and methods of clinical research and epidemiology as best as possible in the new research field of routine care and by applying its specific methods.

33.8 Perspective: Data Linkage

The lack of information on an individual's health-related behavior and concrete risk factors may be overcome by linking that person's primary and secondary data. Allegedly, this would be the best of two worlds in epidemiology as well as in evaluation research, but the approach does present a number of legal, technical and organization challenges (March et al. 2015). Current studies (March et al. 2012; Swart et al. 2011) demonstrate that it is technically feasible and legally permitted to link primary data but at a steep logistical price. The opportunity to gain new insights has encouraged the "NAKO Health Study" (German National Cohort; GNC Consortium 2014), the largest German epidemiological cohort study so far, to strive to link primary data with a wide range of secondary data (Jacobs et al. 2015; Schipf et al. 2020).

Depending on whether (1) secondary data is individually linked with primary data or whether (2)—the other way around—primary data is enriched by secondary data, individual data linkage offers a chance to overcome the limitations of the bodies of data concerned. In case (1), secondary data can be supplemented by individual socio-demographic features or risk profiles that facilitate a risk adjustment or an estimate of selection effects when comparing IC-participants and non-participants as well as an assessment of new care concepts for the insurant. Case (2) makes it possible to overcome the methodological limitations of primary data as regards information on the utilization of services (e.g., recall bias; Swart 2012) and problems of longitudinal study designs (e.g., drop outs).

Several scientists with pronounced experience in linking primary and claims data in health services research published a "Good Practice Data Linkage" which can be used as a guideline for data linkage also in evaluation of integrated care (March et al. 2018, 2020).

33.9 Conclusions

The German examples presented and the conclusions drawn specifically apply to Germany. It goes without saying that claims data is also used in other countries to evaluate integrated care projects. Although structures and contents as well as access and usage requirements vary from country to country, the operationalized process and outcome indicators derived from the data are similar. Consequently, a brief glimpse across the German border suffices. A London-based pilot project on integrated care for diabetics and patients 75 years or older used information [not specified in detail] generated from administrative data on the utilization of inpatient services in a mixed-methods evaluation (Curry et al. 2013). In the scope of an evaluation of several IC projects in Great Britain, data from Hospital Episode Statistics (HES; https://www.hscic.gov.uk/hes) was used in addition to questionnaires for patients and staff of the IC projects in order to compare the number of hospitalizations and outpatient contacts in hospitals of the NHS and outpatient and inpatient care costs incurred by patients in IC projects and non-enrolled standard care control patients in a certain design (Roland et al. 2012). Hser and Evans (2008) describe a very complex approach to evaluating care programs for addicts in California. Patient-related data was not only used to utilize the health care system for mentally ill people but also linked individually and with other government databases to obtain information on road accidents or driving under the influence of alcohol or drugs or convictions and detentions, for example. Linkage was based on matching variables identifying the person such as name, social security number and date of birth.

What follows is a list of internationally applicable criteria and key questions that help structure the evaluation of potential claims data or its suitability for evaluating integrated care projects:

- Do you have sufficient knowledge about how the data was generated, its inclusion and exclusion criteria and possibilities to precisely determine the reference population?
- Are all or at least all essential services used by patients participating in IC projects included in the claims data?
- Is a longitudinal patient-related analysis of the services provided possible so that pre and post-periods can be mapped?

- Are suitable matching methods available in order to make a valid comparison between the intervention and the comparison group in a controlled design?
- Is it possible to operationalize parameters needed for the evaluation (independent and dependent variables, confounders, moderating and mediating variables) and, if necessary, to validate them internally/externally?
- Is there sufficient knowledge about the strengths and weaknesses of the data in question in order to handle possible limitations?
- Is it possible to stratify the claims data in a valid way according to socio-demographic and socio-economic variables?
- Is the claims data available in a comparable quality for the entire evaluation period?

If you can answer these questions with YES, the claims data presents a valuable data source for the evaluation of integrated care whose validity may be even increased by linking it with primary data. Therefore, programmes of integrated care should be outlined from the beginning to use claims data for evaluation. No other data source delivers more and broader objective information on utilization of health care in terms of diagnoses, diagnostic, surgical or pharmacological interventions as well as costs. Also, specific methods of claims data analysis were developed enabling advanced epidemiologic study designs like case control or cohort studies with a potentially high degree of external validity.

On the other hand, as mentioned above, evaluation of integrated care should keep in mind limitations of claims data and therefore look for alternatives or supplements of claims data analysis in terms of an observational/intervention study or data linkage of primary and claims data. An evaluation of integrated bases solely on primary data of participants will always be prone to different kinds of bias, for example, selection bias.

At least, from the German point of view, it would be helpful if the legal limitations of using claims data for scientific purposes could be overcome by actual initiatives to change the respective paragraphs of social code, books V and X.

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Economic Evaluation of Integrated Care

34

Apostolos Tsiachristas and Maureen P. M. H. Rutten-van Mölken

34.1 Need for Economic Evaluation of Integrated Care

Health economists are increasingly interested in integrated care for chronic diseases. This is because the rapidly increasing prevalence of chronic diseases reduces population's health, increases the demand for health and social care (WHO 2011) and has macroeconomic consequences for consumption, capital accumulation, labour productivity and labour supply (Busse et al. 2010). Health economists support healthcare decision-makers with evidence in finding an adequate response to these challenges by investigating the efficiency of healthcare interventions, studying their financing mechanisms and advocating the efficient allocation of scarce resources. The findings of health economics support decision-makers to define the right mixture of health technologies to maximize the health and well-being of society as well as to meet the preferences and needs of patients.

One of these responses is the provision of integrated care, which refers to initiatives that seek to improve outcomes for those with (complex) chronic health problems and needs by overcoming issues of fragmentation through linkage or coordination of services of different providers along the continuum of care (Nolte and Pitchforth 2014). It puts the patients and their individual needs and preferences in the centre and organizes care around them. Integrated care is seen as a promising means to increase productive efficiency in care for people with chronic conditions

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(Epping-Jordan et al. 2004). According to the triple aim framework, as advocated by the Institute for Healthcare Improvement, integrated care aims to (1) improve population health, (2) improve patient experience with care and (3) reduce costs (Berwick et al. 2008).

Economic evaluation in integrated care is still in its early years, facing several difficulties. Difficulties come from the fact that integrated care is a complex package of interventions with varying definition, composition and application, which deviates substantially from simple technologies and healthcare interventions that are traditionally subject to health economic analysis. However, the urge for a wider implementation of integrated care to address the needs of people with chronic diseases and improve efficiency calls for more evidence-based decision-making based on thorough economic evaluations. The existing evidence about the economic impact of integrated care available in the thin scientific literature is inconclusive (Nolte and Pitchforth 2014). The main reasons are the great variation in interventions and the relatively weak methodological approaches to evaluate integrated care (Conklin et al. 2013). Many studies have called for more reliable and replicable economic evaluation of integrated care (Nolte et al. 2014) and recognized that current evaluative frameworks may not be sufficient to address complex interventions (Payne et al. 2013), because these interventions require a wider range of costs to be included and their outcomes extend beyond quality-adjusted life years (QALYs). Therefore, a modified framework with extended costing methods and outcome metrics that include the non-health benefits of integrated care may be needed.

34.2 Current Economic Evaluation Frameworks

The foundations of economic evaluation in health care lay in welfare economics, an area which is concerned with the analysis of conditions under which policies may be said to have improved societal wellbeing relative to alternative courses of action. Thus, economic evaluations should be comparative in nature, societal in scope and concerned with the resulting wellbeing of the individuals involved. In addition, economists have a preference for quantitative techniques and scientifically robust study designs that produce unbiased estimated of costs and effects.

Economic evaluations of health interventions have been defined as the comparative analysis of alternative courses of action in terms of both their costs and their consequences (Drummond et al. 2005). All economic evaluations assess costs, but approaches to measuring and valuing the consequences of healthcare interventions differ (see Box 19.1). Economic evaluations often rely on mathematical modelling to synthesize information from different sources, compare different treatment comparisons that have not been compared head to head empirically and extrapolate the time horizon of the analyses beyond the time horizon of empirical studies (Husereau et al. 2013). Economic evaluations are important because resources (i.e. people, time, facilities, equipment and knowledge) are scarce.

Box 19.1 Forms of economic evaluation

Specific forms of analysis reflect different approaches to evaluating the consequences of health interventions.

Cost-consequence analyses (CCA) examine costs and consequences, without attempting to isolate a single consequence or aggregate consequences into a single measure.

Cost-minimization analysis (CMA) compares costs only as the consequences are demonstrated to be equal.

Cost-effectiveness analysis (CEA) describes consequences in natural units, such as clinical cases detected or life years (LYs) gained.

Cost–utility analysis (CUA) measures consequences in terms of preference-based measures of health, such as disability-adjusted life years (DALYs) or quality-adjusted life years (QALYs).

Cost–benefit analysis (CBA) describes consequences in monetary units.

Although analysts may choose to use one or more forms of these analyses in their study, they should be aware that each form of analysis might have unique advantages or disadvantages for decision-making.

The terms cost-effectiveness, cost–benefit and economic evaluation are often used interchangeably, and therefore, the term economic evaluation is preferred to avoid confusion.

Adapted from Drummond et al. (2005) and Husereau et al. (2013)

They allow those charged with managing resources to either anticipate the potential impact or measure the real impact of any change to the delivery of health care. In the context of health research, they can aid researchers in demonstrating the potential or real economic impact on the health system of a new intervention that can in turn promote its uptake and adoption. For example, one review of telemedicine applications suggested “The absence of a cohesive body of rigorous economic evaluation studies is a key obstacle to the widespread adoption, proliferation, and funding of telemedicine programs” (Davalos et al. 2009). However, the need to make decisions based on economic evaluations may extend beyond the health system. The effects of public health interventions, for example, may extend into the justice and education systems and require different forms of analysis used in those sectors (e.g. such as cost–benefit analysis). Similarly, the effects of integrated care may extend into the informal care sector and the welfare sector. Economic evaluations may be also useful for private sector developers of technology, who must make research and development decisions based on an assumed return on investment (Ijzerman and Steuten 2011). Health system researchers may have to consider various private and public sector actors that will use an economic evaluation for future decision-making.

There are several handbooks describing the methods of economic evaluation (Drummond et al. 2005; Gray et al. 2011), and some of them focus on how to perform economic evaluation methods in complex interventions, mainly public health interventions (Parkin et al. 2015; Griffin et al. 2009). Several methodological challenges in the economic evaluation of public health intervention are discussed in the literature (Weatherly et al. 2009; Edwards et al. 2013; Goldie et al. 2006). However, researchers that perform economic evaluation of integrated care may face different challenges than evaluators of public health interventions and may need different solutions to overcome them.

34.3 Challenges and Recommendations in Economic Evaluation of Integrated Care

Integrated care, as being a complex intervention, requires complex economic evaluation (Byford and Sefton 2003). Therefore, the current economic evaluation methods may need to be adjusted or extended to address the challenges in performing economic evaluation of integrated care (Shiell et al. 2008). To do this, methodological challenges in the economic evaluation of integrated care should be thoroughly identified and supplemented with recommendations to overcome them. A description of such challenges and recommendations is presented in the next sections.

34.3.1 Defining the Intervention

For an intervention to be appropriately costed and evaluated, it should be accurately and comprehensively described (Drummond et al. 2005). This definition should include information on the setting where the intervention is delivered, the target population, the time frame, the intervention components, the actors involved, the frequency and duration of intervention delivery and the extent of coverage of the target population. For a package of care interventions such as integrated care, the details of the components and the relative intensities of their implementation often vary with every implementation site. That is because such an intervention needs to be tailored to the specific context in which it is implemented. Moreover, at one particular site, the interventions do not remain constant but are often continuously improved as more experience is gained. Contextual characteristics of intervention and/or control settings are also rarely static (Barasa and English 2011). Therefore, economic evaluation of integrated care should be accompanied with a process evaluation as described in Chap. 36.

34.3.2 Comparator

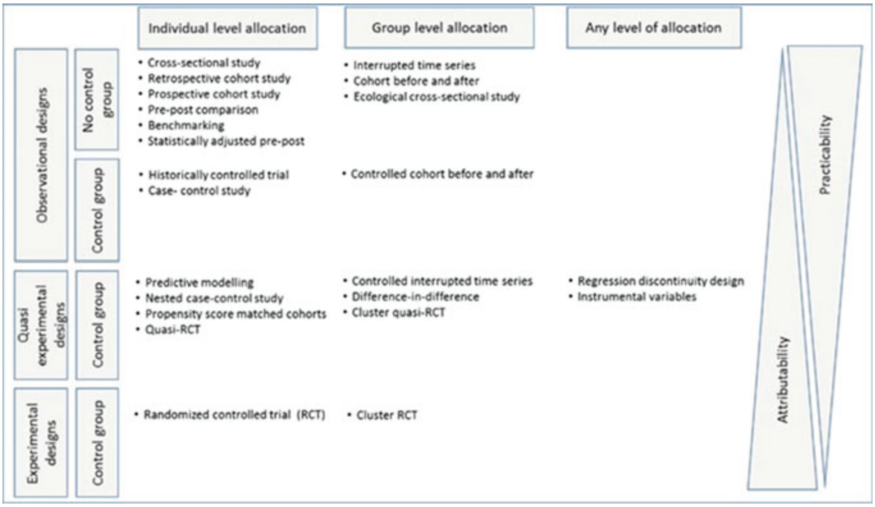
Economic evaluation is a comparative analysis. Even if it is not possible to identify control groups, the relative efficiency of integrated care still needs to be assessed. In general, comparators used in economic evaluations frequently include active comparators such as current practice, best available alternative, or alternative levels of treatment intensity and different variations of similar programs. Identifying an appropriate comparator for integrated care is challenging. Standard practice, frequently called usual care, is often an appropriate control, but it can be at least as complex as the intervention being evaluated and may change over time by national or regional policy reforms that stimulate the evolution of usual care for an individual with one or more chronic diseases towards integrated care. As a result, usual care may have become a low-intensity integrated care. Comparing integrated care models that differ in terms of their intensity or comprehensiveness may be a good alternative when appropriate control groups without integrated care are difficult to identify (Tsiachristas et al. 2014a, 2015). However, the room for improvement when comparing a more intense or comprehensive programme with a less intense or comprehensive alternative may be reduced. Summarizing, the competing alternatives to be considered in an economic evaluation include: (a) integrated care (complex intervention) to simple interventions delivered in current clinical practice, (b) integrated care to usual care (considered also as complex intervention), (c) various components of integrated care to each other or the sequence in which they were introduced or (d) all the above. Although it is not straightforward which pair of competing alternatives to choose and each option has pros and cons, evaluation guidelines suggest that the evaluation of a complex health intervention is accompanied by a detailed description of the components rather than disentangling the effects of the individual components (Craig et al. 2008; NICE 2007). Arguably, the interdependence of the interventions creates synergy effects. As a result, the total cost-effectiveness of integrated care is not a linear summation of the partial cost-effectiveness of the interventions provided. For example, a thorough diagnostic assessment, which is not followed by a mutually agreed treatment package based on a patient's personal goals, is unlikely to be of benefit to the patient (Bodenheimer and Handley 2009). However, the benefits of the latter are likely to be greater when based on a broad assessment of impairments, symptoms, functional limitations, disease perceptions, health behaviour and quality of life.

34.3.3 Study Design

For economic evaluations that are conducted alongside clinical studies, the clinical study design is an important issue. Most evaluation studies of integrated care are observational studies and very often lack a control group (Conklin et al. 2013). Besides the difficulty of creating an appropriate control group, other reasons for adopting an observational design include financial considerations, difficulties in identifying suitable participants, concerns about the generalizability of the results and ethical considerations (Conklin and Nolte 2010). However, observational studies raise major concerns about the potential sources of bias and confounding factors that may jeopardize attribution of effect (or causality). Experimental designs such as randomized clinical trials (RCTs) are considered as the most robust designs to infer causality. Since integrated care includes interventions on organizational level and the risk of contamination (i.e. the control group is affected by the intervention) is high, cluster RCTs could be considered as an adequate study design. In a stepped-wedge randomized trial, the order in which the clusters receive the intervention is randomized, so that at the end of the entire time period, all sites have received (Hussey and Hughes 2007). Even in those cases, experimental designs may face similar problems as observational studies in inferring causality when evaluating complex interventions such as integrated care. This is due to hidden differences in the context with which the treatment and control groups and periods interact that may critically affect the results (Rickles 2009). Standardization of interventions would be a solution to replicate the results in other settings, but in the case of integrated care, it would preclude its adaptability to the local context and would treat it as a simple intervention (Hawe et al. 2004). Moreover, it is recognized that health interventions that are observed to be efficacious and cost-effective in the context of highly structured randomized trials may not be effective or cost-effective once they are made available in practice, under less controlled conditions (Boaz et al. 2011).

Quasi-experimental designs or natural experiments may be an alternative when evaluating integrated care because they involve the application of experimental thinking to non-experimental situations. They widen the range of interventions beyond those that are amendable to planned experimentation, and they encourage a rigorous approach to use observational data (Craig et al. 2012). Natural experiments are applicable when control groups are identifiable and when groups are exposed to different levels of intervention. Natural experiments using regression adjustment and propensity score matching could reduce observed confounding between the comparators, while difference-in-differences, instrumental variables and regression discontinuity could reduce the unobserved confounding between the comparators (Craig et al. 2012). A combination of these techniques is also possible in the evaluation (Stuart et al. 2014). Figure 34.1 provides an overview of study designs to be considered in the evaluation depending on the availability of a control group and degree of experimenting.

Data availability and quality are other important factors to be considered when choosing a study design. Routine data from electronic medical records, existing patient registries and payers might be of good quality and comprehensiveness, but it can be costly or time consuming to access it, and lengthy procedures involving “trusted third parties” may be needed to merge data from different sources as confidentiality should be secured. In addition, researchers have lack of control of the type of outcome measures included in the routinely collected data. In the absence or inadequacy of routine data, survey data could be used in the economic evaluation. However, the quality of survey data depends on the validity of the questionnaire, the response rate, the amount of missing observations and data



		Individual level allocation	Group level allocation	Any level of allocation
Observational designs	No control group	• Cross-sectional study • Retrospective cohort study • Prospective cohort study • Pre-post comparison • Benchmarking • Statistically adjusted pre-post	• Interrupted time series • Cohort before and after • Ecological cross-sectional study	
	Control group	• Historically controlled trial • Case- control study	• Controlled cohort before and after	
Quasi experimental designs	Control group	• Predictive modelling • Nested case-control study • Propensity score matched cohorts • Quasi-RCT	• Controlled interrupted time series • Difference-in-difference • Cluster quasi-RCT	• Regression discontinuity design • Instrumental variables
Experimental designs	Control group	• Randomized controlled trial (RCT)	• Cluster RCT	

Fig. 34.1 Study designs by type and level of allocation. *Source* Adapted from a series of RAND reports (Mattke et al. 2006; Conklin and Nolte 2010; Nolte et al. 2012)

comprehensiveness (consider that lengthy surveys with many measures lead to low response rates). Ideally, routine data would be combined with survey data in the evaluation of integrated care and would be interpreted with the support of data collected from qualitative research. However, a complete economic evaluation based on different data sources requires substantial financial and human resources. Even when resources are not an issue, lack of evaluation culture and reluctance of payers or providers to engage in evaluation might challenge the evaluation of integrated care (Knai et al. 2013).

34.3.4 Evaluation Period

Most economic evaluation guidelines issued by health technology assessment agencies worldwide suggest to adopt a lifetime horizon in economic evaluation of medical innovations (Mathes et al. 2013). However, most evaluation studies of integrated care had an evaluation period of a year, and some were extended up to 3 years (Conklin et al. 2013). This short- to medium-term evaluation period may fail to capture the full effect of integrated care. This is because it takes at least 3–5 years for health management initiatives to identify true programme effectiveness due to lags in full implementation (Serxner et al. 2006). This may not even be long enough to study the effects of the preventive interventions in the integrated care package. However, adopting a follow-up period longer than 5 years would be problematic in attributing effects to integrated care because in the long-term, the intervention and eventually control groups are contaminated with other interventions and health policy reforms (Steuten et al. 2006b). Common sense would suggest to consider the start and end points of integrated care to determine an adequate evaluation period, but none of these points is clear-cut in integrated care. An exact baseline measurement for evaluation is often hard to determine because the preparation and development of some integrated care interventions may have occurred way before that point. Failing to capture these efforts would underestimate the development costs of integrated care (Tsiachristas et al. 2014b). Determining the end point of integrated care is challenging as well. Integrated care interventions may be delivered one-off (e.g. eight sessions of self-management support), repeatedly or continuously in case of a permanent change in the way care is delivered (e.g. monitoring of high-risk patients, establishment of multi-disciplinary teams and development of integrated ICT system). Thus, the (partial) effects of integrated care are expected to be recurrent in time.

One way to extend the evaluation period is to set up a continuous monitoring system that tracks a core set of outcomes over time, not as part of the research but as part of routine practice. This can guide managers, healthcare providers and payers and may even be used to motivate patients when they have access to their own outcome data via patient portals. The challenge is to choose this core set and to adequately adjust for differences in case mix when these data are used to compare groups.

34.3.5 Outcome Measures

Integrated care, as being a complex intervention, impacts many outcomes on different levels. These outcomes could be categorized in process indicators of the organization and delivery of care, patient's satisfaction with care, access to care, informal caregivers' satisfaction and quality of life, patients' lifestyle and risk factors, patients' ability to self-manage and cope with disease, clinical outcomes, functional status, quality of life, wellbeing and mortality (Nolte and Pitchforth 2014; Tsiachristas et al. 2013a; Steuten et al. 2006a). These outcomes encompass the argument of Huber et al. (2011) that health should be defined more dynamically and more positively, based on the resilience or capacity to cope and maintain and restore one's integrity, equilibrium and sense of wellbeing (Huber et al. 2011), as well as the capability approach of Amartya Sen including "empowerment" which can be viewed as a type of capability that measures the "ability of a person to function" (Coast et al. 2008a, b). Even advocates of QALYs as outcomes to support decision-making would argue that all of these outcomes cannot be captured in a single unit of measurement. Moreover, the literature suggests that the QALY may not be relevant for decision-making at the level of provider organizations and insurers, when decisions to include an intervention in the benefit package at national or regional level have already been made (Kind et al. 2009). In that case, the decision that needs to be taken is not whether to fund integrated care but which type of programme should be provided, to whom and how in day-to-day practice. Thus, a QALY is not a relevant measurement to be used in clinical decision support systems, which are primarily informed by changes in clinical outcomes, health risk factors, care processes and behaviour. To fully understand the impact of integrated care, multiple outcome measures, measured at multiple levels (e.g. patient, GP practice and community) and eventually from different perspectives (e.g. providers and patient), should be employed to assess whether the triple aim of integrated care has been reached.

Some of these outcome measures could be used to inform performance indicators to facilitate the provision of financial incentives for integrating care. This would go beyond the performance indicators currently used in pay-for-performance schemes [e.g. in England (Downing et al. 2007)] by informing integrated care-specific indicators and group-specific indicators (e.g. disadvantaged people or people with multi-morbidity). Examples of such measures have been issued by WHO and include, for example, care planning and coordination, shared decision-making and medication review in older adults (WHO 2015). Looking at the care continuum, performance indicators could be assigned with different importance in time. For example, indicators of physical improvements may be more important in the short term and indicators of psychological and social improvements in the long term for a patient who had a stroke. Furthermore, absolute and relative performance indicators could be combined to stimulate high-performing providers to maintain their performance levels and motivate low-performing providers to achieve relatively high performance (Tsiachristas 2015; van Herck et al. 2011).

34.3.6 Measurement and Valuation of Costs

Similar to outcomes, integrated care also impacts a broad range of costs, inside and outside the healthcare system. As a result, the societal perspective (i.e. considering all costs at societal level) is preferred to the narrower healthcare perspective when estimating the costs of integrated care. A full societal perspective would include the impact of integrated care on all sectors of the society (e.g. social care, workforce, education, security and justice). However, such a perspective would demand complex, time consuming, and costly data collection and cost calculation. Thus, health economists may want to restrict the societal perspective to include only those societal costs that are expected to be most impacted by the integrated care programme under evaluation. For example, costs in the education and justice sectors might be relevant for inclusion in an economic evaluation of integrated care programmes for adolescents with mental conditions but not for a programme targeting adults with diabetes. Costs of informal care are commonly important to include in an economic evaluation of integrated care for frail elderly or individuals with severe or multiple conditions that require a lot of support. Furthermore, integrate care programmes require substantial development costs (including but not limited to training costs, ICT costs and costs of redesigning the care delivery process) and implementation and operating costs (such as multi-disciplinary team meetings, the costs of coordination between caregivers, the costs of monitoring and feedback).

These costs are commonly carried by the organization that implements the programme and should be included in the economic evaluation.

A minimum set of cost categories relevant in the evaluation of integrated care may include (Vondeling 2004; Tsiachristas et al. 2013a): (1) the development costs of integrated care, (2) the implementation costs of integrated care, including process-oriented costs, (3) the costs of health and social care utilization (including long-term care), (4) the costs borne by the patient (and the informal caregiver), such as home adaptations, specific diets, particular assistive devices, travelling to receive care and (5) the costs of productivity loss due to the absence from paid work or reduced productivity while at work. But again, the selection or relevant cost categories depends on the context. For example, if an already developed integrated care programme was implemented in another setting, then the development costs would not be relevant for inclusion in the analysis.

Development and implementation costs of integrated care could be collected via surveys or interviews with managers or financial controllers of integrated care programmes. A study systematically collected these costs by using a template based on the CostIt instrument of the World Health Organization (WHO) (Tsiachristas et al. 2014b; Johns et al. 2003). This study could provide inspiration on how to treat overhead and capital costs as well as how to amortize development costs of integrated care.

Measuring and valuing various cost categories could follow the current practices and guidelines in health economic literature. The costs of health and social care utilization could be measured retrospectively by standardized questionnaires like the Client Service Receipt Inventory (CSRI) (Beecham and Knapp 1992) or based on routine or claims data. The CSRI also includes questions for residential care, criminal justice service and state benefits. Patient travelling costs and productivity costs could also be collected via standardized surveys (Bouwmans et al. 2015). Information to calculate costs of informal care could be collected with the *I*MTA Valuation of Informal Care Questionnaire (*i*VICQ) (Hoefman et al. 2011). Developing and applying questionnaires to measure resource use customized to a study would be an alternative for using the existing questionnaires, but this would require additional research time to validate them (Thorn et al. 2013). Unit costs could be gathered similar to traditional economic evaluations (Gray et al. 2011). When national average unit cost prices are not available or not precise enough, activity-based costing may be a useful alternative in estimating service costs of integrated care (Paulus et al. 2002, 2008). However, this approach is very costly and in many cases impractical to be performed in large-scale economic evaluations (Mogyorosy and Smith 2005).

34.3.7 Broader Economic Evaluation

Considering the broad range of health and non-health outcomes for inclusion in the evaluation of integrated care, the adoption of cost–benefit analysis (CBA)—in which all benefits are expressed in monetary terms— and cost-effectiveness analysis (CEA)—in which the effects are measured in natural units (e.g. life years gained)—is precluded because these methods have a single measure of outcome (Gray et al. 2011; Drummond et al. 2005). Even if all outcomes of integrated care could be expressed in monetary terms and included in CBA (Evers 2010), it would be very time consuming and costly to do so, and the objections against assigning monetary values to health would still remain (Coast et al. 2008b). Performing a cost–utility analysis (CUA), which is the most widely used evaluation method and believed to have a comprehensive outcome measure, might be problematic in the case of integrated care because as mentioned earlier, a QALY does not capture the non-health benefits of integrated care (e.g. patient satisfaction with the process of care delivery). Therefore, a cost-consequence analysis (CCA) seems an adequate alternative because it presents a range of outcomes alongside costs. CCA probably fits better with real-world decision-making, in which decisions are made based on other criteria besides cost-effectiveness, but it does not support a systematic ranking of alternative interventions based on their cost-effectiveness (Baltussen and Niessen 2006). Multi-criteria decision analysis (MCDA) could overcome this limitation of CCA by supporting a systematic comparison of different alternatives based on their performance on various pre-specified criteria (i.e. a range of outcomes and costs) (Baltussen and Niessen 2006). In this process, different criteria are weighted according to their relative importance to the decision by different stakeholders, including patients, allowing an aggregation of the performance on multiple criteria into an overall composite score. Hence, MCDA is a sophisticated method for comparing complex interventions, such as different types of integrated care programs, incorporating all relevant categories of outcomes and costs (Goetghebeur et al. 2012; Bots and Hulshof 2000).

A framework to evaluate integrated care based on MCDA is reported in the literature (Tsiachristas et al. 2013a). The challenge for performing MCDA in this context is to determine a set of criteria relevant for decision-making and assign weights based on the preferences of stakeholders in integrated care. Whether the new composite measure that results from an MCDA can include other criteria than health and non-health benefits (e.g. costs) is debated (Baltussen 2015; Claxton 2015). If the new composite measure only includes benefits, then a new incremental cost-effectiveness ratio (ICER) threshold value for one unit of additional benefit on this composite measure may need to be determined to support reimbursement decisions. However, MCDA may also be used alongside and as a supplement to the existing deliberate process, serving to structure the discussions and feedback to decision-makers the weights implicit in their decisions (Thokala et al. 2016). This may particularly apply when other criteria than benefits are included in the composite measure. Inter-sectoral costs and consequences may also be addressed by combining CCA and MCDA (Weatherly et al. 2009).

34.3.8 Determinants of Cost-Effectiveness

Whether a particular intervention is cost-effective depends on key contextual variables involving place and time. Sculpher et al. (2004) identified 26 such factors that may cause variability in cost-effectiveness across locations, including case mix, culture/attitudes, demography, and health professional's skillsets and experience. Welte et al. (2004) offer a similar list of 14 transferability factors to be considered when transferring economic evaluation results across country contexts. In some instances, interventions that are found to be presently cost-effective or cost-saving in a particular setting may not remain so if expanded or delivered under different circumstances. The transferability of economic evaluation results is highly challenging when integrated care is regarded because it interacts with the context in which it is provided. Thus, standardizing reporting of methods and results is necessary (see respective subsection below for further details).

Similar to many complex interventions, the cost-effectiveness of integrated care also depends on the provided interventions and their combination. There is evidence about the (cost-) effectiveness of most interventions included in integrated care (Tsai et al. 2005; Ouwens et al. 2005; Zwar et al. 2006; Weingarten et al. 2002; WHO 2015b). However, theoretical and conceptual studies on integrated care strongly suggest that the value of integrated care is in the combination of interventions. This is because integrated care is not a discrete and immediately replicable intervention and its elements should be treated as a totality (Coleman et al. 2009). Ham (2010) argues that the tenth characteristic of a high-performing chronic care system is the link between individual interventions that transforms them into a coherent whole and has an additional effect (Ham 2010). It is unclear whether this effect of combining different interventions is additive or multiplicative, but it surely is the synergy and interaction between interventions that contribute to the overall effect. Therefore, the evaluation of integrated care should be undertaken at an aggregated level (Hawe et al. 2004). Moreover, the complexity of integrated care in terms of intervention intensity (Nolte et al. 2012) and comprehensiveness (Tsiachristas et al. 2015) as well as its uptake and successful implementation (Boland et al. 2015) may impact outcomes and costs. Especially, the development and implementation costs would increase with complexity (Tsiachristas et al. 2014b). The target population is another determinant of integrated care cost-effectiveness (Tsiachristas et al. 2014a). This may largely be explained by the fact that integrated care involves behavioural aspects. The literature shows that behaviour interventions are highly cost-effective but not for everyone (McDaid et al. 2014). This notion is also shared by the National Institute for Health and Care Excellence (NICE) in England where thorough subgroup analysis is recommended when evaluating behavioural change interventions (NICE 2007). Finally, the existence of economies of scale and economies of scope may influence development and implementation costs of integrated care and therefore its cost-effectiveness (Tsiachristas et al. 2014b).

34.3.9 Policy Evaluation and Implementation Analysis

The implementation of integrated care in many countries was supported by new forms of financing and payments (Nolte et al. 2014; Tsiachristas et al. 2013b; Busse and Mays 2008). This is because adequate funding and payment systems with financial incentives that steer behaviour towards collaboration between professionals are prerequisites for the successful implementation of integrated care (Busse et al. 2010; Scheller-Kreinsen et al. 2009). Examples include the reduction in co-payments for patients participating in disease management programmes in France, the performance-based payment system in England that stimulates GP adherence to clinical guidelines, the bundled payment in The Netherlands where care groups receive a single annual payment for a patient to cover the (mostly primary) care for a particular chronic disease. Positive evidence from the implementation of such financial incentives and payment schemes is reported in the literature (Eijkenaar et al. 2013; Song et al. 2014; Rosenthal et al. 2004; de Bakker et al. 2012; Tsiachristas et al. 2016).

These incentives may either be considered as behavioural interventions that are part of an integrated care programme or they may be seen as part of the local context with which the integrated care programme interacts. In the former case, a broad policy evaluation may accommodate the implementation of integrated care and accompanying payment reforms simultaneously. In the latter case, payment reforms could be seen as strategies to successfully implement integrated care. As a result, the application of value of implementation analysis (Hoomans et al. 2009; Mason et al. 2001) may be employed to provide the overall cost-effectiveness of implementing integrated care with the support of financial incentives. However, it would be hard to disentangle the impact of the payment reform from the effect of the care reform on healthcare expenditure and care quality.

34.3.10 Standardized Reporting

Reporting of methods and results should be systematized to allow traceability and transferability of the health economic evidence in integrated care. A thorough description of the interventions provided as part of integrated care, and eventually in the control group, including their timing and intensity and the involved providers should provide a clear understanding of what was evaluated. The methods employed and the assumptions made in the economic evaluation should also be clearly stated regarding the how was it evaluated and the results of subgroup analysis should highlight for whom it was cost-effective. The existing statements such as the CHEERS statement (Husereau et al. 2013), the STROBE statement for observational studies (von Elm et al. 2007) and the disease management quality assessment instrument developed by Steuten et al. (2004) could be used to standardize reporting. Including a periodic evaluation and detailed documentation of the provided interventions (including the control group, if available) in the stream of integrated care interventions, could provide meaningful information about the full and sustainable cost-effectiveness of integrated care.

34.4 Conclusion

The complexity of integrated care and the substantial resources needed to collect reliable data appears to have challenged health economists to evaluate the cost-effectiveness of integrated care to date. Economic evaluations published in health economic journals mostly focus on single elements of integrated care (Gandjour 2010; Scott et al. 2009; Cuellar and Gertler 2006; Dusheiko et al. 2011; McCullough and Snir 2010). There is need for that to change and health economists to understand the peculiarities of integrated care as intervention under evaluation. On the health services research side, health economists were not involved in many evaluation studies so far, which presumably resulted in low-quality evidence on cost-effectiveness. Economic evaluations are frequently piggyback tailed in the effectiveness evaluation of integrated care, but this needs to be changed because there is a clear need for better understanding and communication between health economists, researchers from other disciplines, clinicians, payers and decision-makers during the set-up of an evaluation study.

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Integrated Care Through the Lens of a Complex Adaptive System

35

Aine Carroll

35.1 Introduction

Across the globe, health and social care systems are struggling. It is impossible to view any media, anywhere in the world, without seeing or hearing about local health and social care systems being in crisis. In 2016, the WHO identified a number of key challenges: inequity of access, fragmented services, poor care quality, system inefficiencies, unaffordability and complexity (World Health Organization 2016).

There have been a great many attempts at improving services over the last 50 years using techniques mainly adapted from industrial settings, yet these do not seem to have resulted in any meaningful sustained improvement (Dixon-Woods 2019; Dixon-Woods and Martin 2016; Walshe 2009). Health and social care have changed dramatically over those years. Life expectancy has increased, and our citizens and residents are living with the consequences of diseases from which previous generations would have died. This necessitates a change in how we plan and deliver health and social care, yet our healthcare models are still predominantly hospital orientated and episodic and curative in nature.

Continuity of care in the community across the continuum of care from primary prevention to end-of-life care that is coordinated and integrated is required. There are a great many national and international mandates in healthcare reform that require more integrated services across disciplines, organisations and domains. How best to do this however remains a bit of an enigma. People-centred and integrated health services have been shown to generate benefits for people and

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health systems in countries across the world (Robertson 2011). The evidence suggests that people-centred and integrated services are essential components of building universal health coverage (World Health Organization 2015) and can improve health status.

Most health and social care systems are made up of a broad range of eclectic organisations, both public and private, and professionals who work in organisational and disciplinary siloes providing health and social care that is fragmented and difficult to navigate. The task environment is dynamic, complex and, at times, uncertain, requiring healthcare professionals to practice according to evidence-based practice and standard protocols yet also maintain the flexibility to improvise and adapt when the situation calls for it (Roberts and Coghlan 2011). External stakeholders such as governmental agencies also exert significant pressure on providers to adhere to higher standards of quality while reducing costs (Ramanujam and Rousseau 2006). If our health and social care systems are to provide for the needs of our citizens, tinkering around the edges is not the solution. Dramatically different ways of viewing, designing and implementing solutions are required. In a quote attributed to Albert Einstein ‘a new type of thinking is essential if mankind is to survive and move toward higher levels’.

35.2 Complexity and Healthcare

There is a wide body of complexity literature in diverse scientific disciplines such as meteorology, biology, physics, chemistry and mathematics and in many different non-scientific fields. Helpfully, in 2009, Johnson, in an attempt to bring order to the chaos of complexity definitions across the literature, offered a description of complexity as ‘the study of phenomena which emerge from a collection of interacting objects’ (Johnson 2009, p. 1). Complexity science is a useful framework for studying dynamic, real-life systems (Arthur 1999; Boulton et al. 2015). It examines the messy unpredictable behaviour of diverse, interconnected agents and processes from a systems perspective [a system being a set of elements standing in interrelation Bertalanffy (1993)]. It has been applied to many different, diverse systems such as weather systems, water turbulence, manufacturing, hospitals and primary care. Simon in 2019 summarised the literature as being in three different waves: holism; cybernetics and general systems theory and chaos and adaptive systems (Simon 2019). Complexity theorists recognise that some common patterns of behaviour exist in these diverse systems. This thinking aligns well with more recent reflections and philosophies in health care, for example, collectivistic and distributed leadership and person-centeredness and also the recognition that many interventions in health care consist of a number of interacting components that require new behaviours by those delivering or receiving the intervention or have a variety of outcomes (Anderson 2008; O'Cathain 2019). Understanding the inherent complexity of human systems is essential if we are to solve the crisis in health and social care. Complex systems thinking is increasingly being embraced in health care. A recent systematic review by Rusoja and colleagues identified 3982 titles on systems thinking and complexity ideas in health across the search period 2002–2015 (Rusoja 2018) This has developed from an emerging appreciation that modern health care is complex and therefore needs to be viewed through a complexity lens with solutions that are complexity sensitive rather than more traditional industrially orientated linear and reductionist healthcare solutions (Rusoja 2018; Burns 2001; Fraser and Greenhalgh 2001; Greenhalgh and Papoutsi 2018; Plsek and Wilson 2001; Braithwaite et al. 2017; Sturmberg et al. 2012; Sturmberg and Martin 2013).

35.3 Complex Adaptive Systems (CAS)

In the literature, the word systems, complexity and CAS are often used interchangeably; however, they are not synonymous. There are two major subfields in theories of complexity; complex physical systems and complex adaptive systems with the latter referring to complex systems where agents learn and adapt 'in response to interactions with other agents' (Holland and Complexity 2014, p. 8).

Holland describes CAS as 'systems that have a large numbers of components, often called agents, that interact and adapt or learn' (Holland 2006, p. 24). Plsek and Greenhalgh define a CAS as 'a collection of individual agents with freedom to act in ways that are not always totally predictable, and whose actions are interconnected so that one agent's actions changes the context for other agents. Examples include the immune system, a colony of termites, the financial market, and just about any collection of humans (for example, a family, a committee, or a primary healthcare team)' (Plsek and Greenhalgh 2001, p. 625). Many papers confuse the terms complex systems and complex adaptive systems and also the terms properties, features and characteristics. Many publications make reference to the characteristics outlined in Paul Cilliers work which are themselves adapted from the work of Nicolis and Prigogine (1989), Serra and Zanarini (2013) and Jen and Holmes (1991). However, it is challenging to decide which of these features are the most important when choosing approaches and methods for studying CAS. Clarity around typology is important if we are to properly evaluate the utility of this approach to viewing health care. Braithwaite and colleagues acknowledge the challenge of describing a CAS but also acknowledge the need to delineate the characteristics (Braithwaite et al. 2017). In the absence of a universally accepted definition or unified theory of CAS, Preiser and colleagues in their evidence synthesis, acknowledging these challenges, have proposed a general typology of six organising principles that underlie the observable attributes [or conceptual components (Wallis 2008)] and features of CAS (Preiser 2018) that allows a discernment of complex systems Preiser (2019). These principles emerged from a synthesis of prominent authors' classifications of CAS features and characteristics and were developed as a heuristic framework to identify methods and approaches for studying social-ecological systems. They acknowledge that complex systems have certain distinguishable properties (features) and behaviours (dynamics) that challenge us to come up with new ways of studying and governing such systems. The six principles are: (1) CAS are constituted relationally; (2) CAS have adaptive capacities; (3) CAS behaviour comes about as a result of dynamic processes; (4) CAS are radically open; (5) CAS are determined contextually; and (6) novel qualities emerge through complex causality. These principles incorporate many concepts and attributes of authors included in the synthesis but can also be applied to other authors whose work was not included in the synthesis. This is summarised in Table 35.1 which is based on Preisers work but updated with more recent works having a specific focus on health care. This is not an exhaustive list but acts to facilitate a more coherent conceptualisation of complex systems that may help researchers and practitioners in the field of integrated care.

Adapted from Preiser et al. (2018)

35.4 Integrated Care

A fairly recent review of the literature on integrated care revealed some 175 definitions and concepts (Armitage 2009). Such diversity reflects what one commentator refers to as ‘the imprecise hodgepodge of integrated care’ (Kodner 2009). According to the WHO, ‘Integrated health services delivery is defined as an approach to strengthen people-centred health systems through the promotion of the comprehensive delivery of quality services across the life-course, designed according to the multidimensional needs of the population and the individual, and delivered by a coordinated multidisciplinary team of providers working across settings and levels of care. It should be effectively managed to ensure optimal outcomes and the appropriate use of resources based on the best available evidence, with feedback loops to continuously improve performance and to tackle upstream causes of ill health and to promote well-being through intersectoral and multisectoral actions’ (WHO 2016, p. 5). There are a number of well-described inter-related ‘building blocks’ or ‘system levers’ for the effective design and implementation of integrated care: understanding your ambition; creating an enabling environment; building common values and narrative; workforce development and competencies; supporting people’s empowerment and engagement and financial models and incentives, assessment and evaluation (tools and methodologies) (Union 2017).

Despite a large number of frameworks for the assessment and implementation of integrated care (Valentijn and Rainbow of Chaos 2015; Minkman 2012; WHO Regional Office for Europe 2016; Calciolari 2016; Leijten 2017; Harnett et al. 2019), in many analyses of integrated care interventions, despite the promise of such programmes, the results have often been disappointing (Georghiou and Keeble) with the suggestion therefore that integrated care does not work. However, these types of interventions tend to be highly complex, such as the implementation of models of integrated care and therefore pose considerable challenges for standard research methods and systematic review methods (Baxter 2018; Raus et al. 2020). Perhaps, it is more correct to say that the intervention design and evaluation did not take the view of health care as a complex system and that interventions need to be evaluated using an approach that takes into account the complexity of the context and the intervention itself. Although there are now a large number of integrated care frameworks, none explicitly include reference to CAS theory. The Rainbow model describes many features that are consistent with a CAS (Valentijn and Rainbow of Chaos 2015) and Harnett et al. make reference to CAS, but neither use a well-referenced definition or typology or comment how these principles may be utilised in practice (Harnett et al. 2019). Therefore in order to understand the value of integrated care, perhaps, there is a need to view such interventions through a complexity lens which will necessitate new research methods that will allow, as Greenhalgh states 'rich theorising, generative learning, and pragmatic adaptation to changing contexts' (Greenhalgh and Papoutsi 2018, p. 1). There have been various publications over recent years that have looked at various aspects of integrated care and complex systems (Edgren and Barnard 2009, 2012; Nugus 2010; Nurjono 2018) with agreement that this may a useful way to lead, manage and provide integrated care. So how might those of us involved in integrated care usefully apply the principles of CAS?

I propose applying Preiser's organising principles of a CAS and will use examples of successful integrated care programmes as illustrations of each principle.

35.5 Organising principles of CAS applied to Integrated Care

1. Principle 1: CAS are constituted relationally

   CAS are defined more by the interactions between their constituent parts (agents) rather than by the parts themselves. The nature and structure of relationships between the system components need to be understood.

   Integrated health services consist of a diverse range of actors or agents, patients and families/carers, health and social care professionals, managers and policy-makers. These actors/agents exist in a variety of organisations (government departments, hospitals or communities, mental health organisations, home care associations, etc.), and each of these organisations is made up of subgroups such as professional groupings, multidisciplinary teams and management teams and policy groups. These organisations are often part of a larger organisation structure or network of organisations, such as hospital trusts, community organisations or accountable care organisations.

Each agent is able to act autonomously, but their actions will have an effect on other teams and vice versa. As in a CAS, these interactions allow teams to self-organise and produce adaptive, dynamic and emergent behavioural patterns (Folke 2006). In successful integrated care projects, time has been spent building relationships and trust between different agents and subgroups. Many examples are collaborations of different, often diverse, organisations. The Buurtzorg project in the Netherlands is an interesting example of where relationships are important from an integrated care perspective. One of the key features of the Buutzorg model is relationship-based practice (Kreitzer 2015). In this model, small teams of nurses make all the clinical and operational decisions themselves within non-hierarchical entrepreneurial self-managed teams with excellent staff and patient satisfaction (Duncan 2019). Buurtzorg nurses are holistic in their approach to clients, taking into account their life circumstances, the environment and spiritual and social needs in addition to physical needs. The relationship between the nurse and the client is the core strategy of the organisation.

Buurtzorg is underpinned by an ethos of autonomous practice with community nurses forming effective inter-professional partnerships (Nandram and Koster 2014). Nurses work in partnership with community volunteers where appropriate, and link with community-based health and social care professionals as required depending on each client's needs. Although there is no centrally mandated model of joint working, it has emerged organically through the development of local relationships and through taking person-centred needs-based approach. Rather than top-down prescription, the model seeks to trust and free up staff to do what is right for clients and fosters collaborative teamwork, network building and allows for diversity of views and opinions in keeping with the principles of a CAS.

2. Principle 2: CAS have adaptive capacities.
   CAS have self-organising capacities and can adjust their behaviour as a response to change in their environment. Each of the broad range of actors or agents in an integrated health system has the ability to change. Agents do not stay the same. They adapt to their ever-changing surroundings, situations and experiences. No two patients are ever the same; therefore, a clinician has to adapt a treatment plan to the specific needs of a specific patient. In a hospital, the onset of a pandemic like COVID-19 can result in significant operational and clinical changes within the hospital but also wider changes as we have experienced in terms of curtailment of individual liberties and the impact of the pandemic globally.
   Clinicians regularly change their practice with the emergence of new evidence and the arrival of new protocols and procedures, environments or care models. Patients behaviour may change individually, based on financial situation, access

issues, health issues or positive or negative care experience. They may also change as a group, for example, through an advocacy group or lobbying for access to a particular treatment. Managers and policy-makers behaviours may change as a result of restructuring or change in government or policy. Whether at micro-, meso- or macro-levels within an integrated care system, the subgroups are able to learn, adapt and change when confronted with new situations which is commonplace in the ever-changing world of health care.

The Compassionate Inverclyde project in Scotland is an example of how different agents adapt through collaboration and iterative learning.

A key principle of the project is inclusion and empowerment; listening and responding to people as individuals. The project has created a community 'social lab' where citizens, local organisations, public institutions and other community work together to share experiences, understand each other's needs, create a common narrative of change and design actions for a better future through listening, co-creation, action and evaluation and communication (Hendry and Compassionate 2018). It is a social movement for palliative care provision that is a citizen-led collaboration that demonstrates needs-based evolution, with no blueprint for development (Bunce and Hendry 2019). The whole community accepts responsibility for the health of its citizens.

3. Principle 3: CAS behaviour comes about as a result of dynamic processes.

The model has two main components: naturally occurring networks (close connections, including family and friends) and supportive resources (those available within the community in the person lives. A compassionate community is the combination and activation of both of these elements to enhance the lives of individuals and create benefits to the local community. This process allows communities to utilise available support systems, problem solve, make decisions, and communicate and act more effectively, contribute to social capital within the community with carers and the cared for being part of a vibrant and growing and evolving network of relationships. This project is an excellent example of how shared learning can facilitate change and adaptation.

In a CAS, there are nonlinear dynamic processes that bring about the behavioural patterns. As a result of nonlinear feedback loops, perturbations can be dampened or amplified resulting in a phase shift, or whole system change. In integrated care systems, agents have a series of complex interdependencies and are constantly interacting with other agents, receiving feedback, within, between and across systems. These constant interactions result in changes to behaviour of individual agents or groups of agents resulting in co-evolutionary adaptation or exaption. These interactions between agents and groups of agents and their environment tend to be nonlinear, i.e. the outputs are greater than the sum of the inputs and may, in fact, be significantly disproportionate. For example, despite national policies and mandates and significant investment, an integrated care programme may not result in the desired outcomes and may fail. However, in another region of similar size and constitution, a small investment of seed funding may result in whole system change, sometimes referred to as a phase change. In an integrated care system, there are multiple groups and networks of multiple agents, which are working across boundaries (primary, secondary and social care), making decisions and responding in real time to changing needs and contexts. This dynamic behaviour can be dependent on a set of internalised rules, often based on professional training, that can change depending on the situation and the agents' ability to make sense of and respond to the situation. This fits well with the WHO description of integrated care which suggests that the use of evidence and feedback supports continuous learning within and across sectors.

The Nuka System of Care in Alaska is an example of this principle. Nuka is a partnership between Southcentral Foundation and the Alaska Native community, with the mission of 'working together to achieve wellness through health and related services'. In Nuka, citizens take greater control over their health services, transforming the community's role from 'recipients of services' to 'owners' of their health system and giving them a role in designing and implementing services (Gottlieb 2013). Local Alaskan Native and American Indian employees have active roles as members of Southcentral Foundation's 4 functional committees which were created to be responsive to customer–owner feedback and move improvement initiatives and work plans forward without having to take ideas to the executive leadership team. Among the core concepts is a commitment to understanding, to notice the dignity and value of everyone, to engage others with compassion and to share stories. The Nuka System has developed more than a dozen methods for gaining regular feedback from customer–owners on their experience of services. These include a simple online system for submitting feedback or raising concerns via Nuka's website, optional online satisfaction surveys after every visit to a primary care clinic, and focus groups on particular issues. Improvement staff review feedback within 24 h and work with the frontline teams to resolve and respond to complaints within five days. The results are shared through the customer feedback recording system and reviewed by its customer service committee on a monthly basis (Collins 2015).

4. Principle 4: CAS are radically open;

   Every system is part of a larger system and is made up of sub-systems. Interactions between the different systems and sub-systems generate effects that have impacts across scales and domains. In an integrated care system, the system boundary is often unclear as different agents work or journey across many different organisations and teams. Although individual agents and subgroups may have a strong professional and organisational identity, there is an understanding of interdependence and a need for co-operation across boundaries in integrated care, allowing exchange of information, movement and learning.

Indeed, some roles such as the key care coordination roles are often referred to as ‘boundary spanning’ with agents exerting influence in multiple systems (primary care team, older persons MDT, social care). It can sometimes be challenging to identify clearly what belongs to the healthcare system and what belongs to the wider environment, especially as many long-term conditions are as a result of the social determinants of health. Social prescribing is a useful example of this principle. There is no widely agreed definition of social prescribing but the Social Prescribing Network report in 2016 defined it as ‘enabling healthcare professionals to refer patients to a link worker, to co-design a nonclinical social prescription to improve their health and wellbeing' (Network 2016, p. 19). Such interventions frequently target people in socioeconomically deprived areas, increasing the options available to primary care practitioners when patients present with needs that are related to wider social determinants of health and not just healthcare per se, a clear example of blurred boundaries. In social prescribing, traditional clinical practice connects with activities and support services within the community. GPs, nurses and other primary care professionals refer people to a range of local, non-clinical services which are typically provided by voluntary and community sector organisations (Drinkwater et al. 2019).

In addition, different agents may have quite different perspectives on where a boundary exists depending on their point of view. Patients may be completely unaware of any boundaries whereas staff in a hospital or community setting may see very clear (and often impenetrable) boundaries existing at organisational level. In a truly integrated care system, roles span boundaries and information is exchanged and patients move seamlessly across them.

5. Principle 5: CAS are determined contextually

   In a CAS, the identity and function are defined by the context in which it exists. In an integrated care system, different agents interact, communicate, share information, boundary span and navigate the health and social care system. How they do that depends on a set of internal rules (set by professional training or values that may or may not be predictable) and organisational structures and processes that will in turn be analysed by individuals or teams (e.g. MDTs) in real time and decisions taken. These decisions may be influenced by external factors such as resource availability. If a decision has been taken, for example, that home care packages are no longer available, then the decision taken (such as home discharge) may change (to discharge to nursing home) which may have negative consequences for the patient, family and team. So, the function of an integrated health system can be changed by the changing environment and context in which it is situated. An example of context-driven change is the At-Risk Individuals (ARI) programme, Counties Manukau Health in Auckland, New Zealand, a complex multi-layered initiative aiming to achieve improvements in outcomes for patients. This programme grew from a recognition that people with long-term health conditions were not always well supported by proactive or coordinated services. They use a model of care that emphasises patients achieving long-term behaviour change and aims to keep people well in their homes. They learned through the evaluation of the previous projects that further improvements to the patient experience could be made by moving away from clinically managed care towards team-based processes that place the patient at the centre of the care (Middleton and Cumming 2016). At the heart of the change is the belief that small-scale changes in how those with long-term health conditions are cared for can accumulate into large effects. ARI is based around targeting patients with the highest risk, improving patient self-management and increasing care coordination between health professionals. Practice staff are resourced to spend more time with patients to facilitate; (1) making a more holistic assessment of patients' needs and (2) taking more responsibility for care coordination rather than merely referring patients on to others. ARI was a response to an emerging body of evidence that recommended a whole system approach to long-term condition management (Coulter et al. 2013).

This approach requires primary care to be proactive rather than reactive and encourages the use of community assets through the localities initiative and promotes the use of self-management approaches enabled by a new electronic infrastructure to share information. ARI is very context-specific but could be adapted for other ecosystems.

6. Principle 6: Novel qualities emerge through complex causality. (Emergence)

Through the interaction of agents, novel qualities and phenomena emerge. CAS are co-evolutionary as a result of multiple unfolding events, continuous learning and adaptation. This may result in the emergence of system outcomes that were not directly intended and are greater than the sum of the individual agent behaviours. From an integrated care perspective, providing person-centred, integrated care may have a positive impact on the health and wellbeing of the patient which will positively impact on the health and wellbeing of the family which will result in an improved staff experience which may improve recruitment and retention. Why that may be, is not directly attributable to or predictable from, the actions or behaviours of the individual agents. In the Integrated Care Programme for Older People (ICP OP) in Ireland, a 10-step framework was developed. This allowed all agents involved (locally and nationally) to share a common conceptual map of what 'good' looks like in integrating care for older persons. This facilitated an understanding of their respective clinical and organisational contributions and enabled innovative, flexible local design to be set within a national common context that included evaluation, technology and resource. In addition, it provided a means by which local leaders could mobilise service redesign. This facilitated a shared social construct around what a national 'model' might look like while allowing for local variation. In doing so, it recognised the complexity context and provided 'direction without dictat' (Harnett et al. 2019). The early findings suggest this approach holds promise as a means of mobilising systemic change.

35.6 Discussion

As can be seen from what has been presented, integrated care systems meet the criteria of a complex adaptive system as defined by Holland and Plsek and Greenhalgh. They also conform to Preiser's six organising principles of a CAS: (1) they are constituted relationally; (2) they have adaptive capacities; (3) behaviour comes about as a result of dynamic processes; (4) they are radically open; (5) they are determined contextually; and (6) novel qualities emerge through complex causality. These six organising principles distil the key concepts and capacities in complexity literature and provide a useful ontology for understanding the nature of integrated care and offers the possibility of gaining a deeper understanding of the features and patterns of behaviour in integrated care systems. By using these principles as a framework, it should allow those of us interested in integrated care to investigate the nature of integrated care systems and gain a deeper understanding of the underlying mechanisms that bring about CAS behaviour and identify the underlying causal explanations.

These principles can form the basis of both the understanding and evaluation of integrated care systems and also interventions to improve them. By recognising integrated care as a CAS, we can be more effective in the design and evaluation of our interventions when we realise that top-down and rigid management is not effective. Rather, creating an innovative adaptive environment supported by management will create the conditions for transformation and emergence.

By using these principles, we can design more appropriate approaches to the design of interventions, evaluation and research studies to investigate the properties, features and mechanisms of successful integrated care that embraces the nonlinearity and complexity of health care rather than traditional linear reductionist approaches. How we might combine these principles with the integrated care frameworks that have already been developed is an area that needs to be explored. Those of us involved in integrated care are already familiar with complexity but thus far, apart from a few publications, we have not related these phenomena to CAS characteristics.

35.7 Conclusion

Complexity theory has the potential to be an inspiring and invigorating contribution to the study of integrated care. I propose that using Preiser's six organising principles of a CAS provides a general typology around which we can design, evaluate and research integrated care interventions to develop a deeper, richer understanding of integrated care systems and interventions. We have already acknowledged that integrated care is complex and surely that behoves us to embrace complexity theory like many other disciplines have to unpack the black box of integrated care.

Table 35.1 A conceptual typology of the general underlying organising principles of complex adaptive systems (CAS) features

Underlying features and organising principles	Key features and attributes	Related concepts and capacities that characterise CAS features
Constituted relationally	Process-dependent interactions on multiple scales result in networks of interactive relations. CAS are defined more by the interactions among their constituent components than by the components themselves	Netlike structure, hierarchies, holarchic, diverse components, built-in redundancy, heterogeneity, connections, interconnections (Braithwaite et al. 2017)
Adaptive capacities	CAS have self-organising capacities and can adjust their behaviour as a response to changes in their environments	Self-generation, self-organisation, decentralised control, memory, history, evolutionary and concurrent persistence and change (resilience), co-evolution (Ellis and Herbert 2011) anticipatory capacities, learning, adaptation (Thompson 2016)
Dynamic processes	Nonlinear dynamic processes bring about the behavioural patterns of CAS As a result of nonlinear feedback loops that can dampen or amplify perturbations, small changes can have significant, cascading effects resulting in multiple modes of system-wide re-organisation or regime shifts	Far from equilibrium, equilibrium, disequilibrium (Thompson 2016), dissipative structures multiple trajectories possible, periods of fast and slow change (punctuated equilibria), nonlinear interactions, attractors, thresholds, tipping points, regime shifts, dynamic systems (Braithwaite et al. 2017) feedback loops (enabling and constraining), cross-scale interactions
Radically open	All systems exhibit hierarchy in that every system is part of a wider system and is made up of sub-systems How we describe (or identify) systems is a function of our individual points of view Systemic interactions generate effects that have impacts across scales and domains	Porous boundaries, embeddedness, nestedness, exchange of matter, information, energy, teleconnections, communication (Thompson 2016), diversity
Contextually determined	The identity and functions of CAS are defined by the context in which they exist	Function changes as system changes, components with multiple context-dependent identities

(continued)

Table 35.1 (continued)

Underlying features and organising principles	Key features and attributes	Related concepts and capacities that characterise CAS features
Novel qualities emerge through complex causality	Through the interaction of the individual components, novel qualities and phenomena emerge Hence, the whole is more than the sum of its parts, meaning that systems cannot be understood, nor their behaviour predicted based solely on information relating to the individual parts	Circular/recursive causality, large webs of causality, multiple pathways of causality, high levels of stochasticity, same starting conditions that produce different outcomes, emergent properties, emergence (Thompson 2016)

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Evaluating Complex Interventions

36

Apostolos Tsiachristas and Maureen P. M. H. Rutten-van Mölken

36.1 Definition of Complex Intervention

There is an increasing interest in evaluating complex interventions. This is because epidemiological changes increasingly call for composite interventions to address patients' needs and preferences. It is also because such interventions increasingly require explicit reimbursement decisions. That was not the case in the past, when these interventions often entered the benefit package automatically, once they were considered standard medical practice. Nowadays, payers as well as care providers are intrigued to know not just if a healthcare intervention works but also when, for whom, how, and under which circumstances. In addition, there is broad recognition in the research community that evaluating complex interventions is a challenging task that requires adequate methods and scientific approaches. One of the main points of discussion across all interested parties is what exactly a complex intervention is.

One of the first attempts to define complex interventions was undertaken by the Medical Research Council (MRC) in UK, which issued a guidance in 2000 for developing and evaluating complex interventions (Campbell et al. 2000). The guidance was updated and extended in 2008 to overcome limitations in the earlier guidance (Craig et al. 2008). The guidance was published in response to the challenges faced by those who develop complex interventions and evaluate their impact. MRC defines an intervention as being complex, if it includes one or more of the following characteristics:

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(a) various interacting components, (b) targeting groups or organizations rather than or in addition to individuals, (c) a variety of intended outcomes, (d) they are amendable to tailoring through adaptation and learning by feedback loops, and (e) effectiveness is impacted by behaviour of those delivering and receiving the intervention. In other words, the MRC argues that the greater the difficulty in defining precisely what exactly are the effective ingredients of an intervention and how they relate to each other, the greater the likelihood that a researcher is dealing with a complex intervention. Examples of complex interventions are presented in Box 36.1.

Box 36.1 Examples of complex interventions

Tele-health, e-health, and m-health interventions

Online portal for diabetes patients to support self-management

Home tele-monitoring.

Mobile phone-based system to facilitate management of heart failure Interventions directed at individual patients:

Cognitive behavioural therapy for depression

Cardiac or pulmonary rehabilitation programmes

Care pathways.

Motivational interviewing and lifestyle support to improve physical activity and a healthy diet.

Group interventions:

Group psychotherapies or behavioural change strategies.

School-based interventions to reduce smoking and teenage pregnancy Interventions directed at health professional behaviour:

Implementation strategies to improve guideline adherence

Computerized decision support systems.

Service delivery and organization:

Stroke units

Hospital at home

Community and primary care interventions:

Community-based programmes to prevent heart disease

Multi-disciplinary GP-based team to optimize health and social care for frail elderly.

Population and public health interventions

Strategies to increase uptake of cancer screening.

Public health programmes to reduce addiction to smoking, alcohol, and drugs Integrated care programmes for chronic diseases.

Could include all interventions above.

In the same line, other definitions also emphasize the degree of flexibility and non-standardization of complex interventions, which may have different forms in different contexts, while still conforming to specific theory-driven processes (Hawe

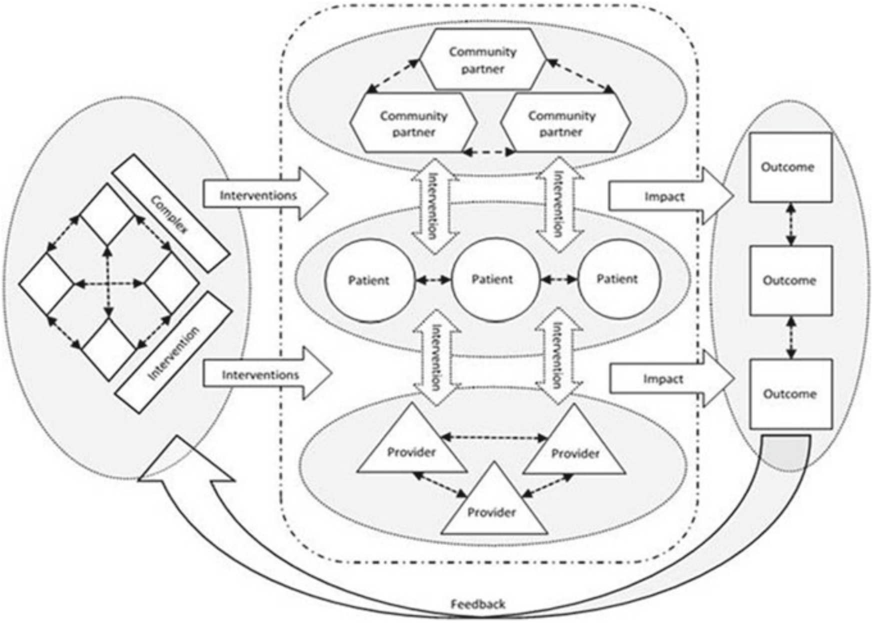

Fig. 36.1 Illustration of complex intervention

et al. 2004). Although there are many more definitions of complex interventions, they all tend to emphasize multiple interacting components and nonlinear causal pathways. Figure 36.1 illustrates how a complex intervention is diffused to different groups of recipients, interacts, and impacts different outcomes.

In contrast, health technologies such as medicines, diagnostic tests, medical devices, and surgical procedures are considered to be simple interventions because they are usually delivered by one care provider or provider organization and have mostly linear causal pathways linking the intervention with its outcome. However, the distinction between complex and simple interventions may be not entirely clear because after all simple interventions can also have a degree of complexity. Complexity is defined as ‘a scientific theory which asserts that some systems display behavioural phenomena that are completely inexplicable by any conventional analysis of the systems’ constituent parts (Hawe et al. 2004). Reducing a complex system to its components amounts to irretrievable loss of what makes it a system.

In has also been suggested that complexity is not necessarily a feature of an intervention but it is the complexity of the setting in which interventions are implemented. In other words, complexity is a property of the setting in which an intervention is being implemented not an inherent feature of the intervention itself (Shiell et al. 2008). For example, a vaccination programme for tuberculosis in a low-income country may be seen as a simple intervention implemented in a complex setting because its implementation requires the interaction between primary care, hospitals, local community, and schools.

It has also been argued that the research question and the perspective from which that question is answered define the complexity of an intervention. Researchers often treat interventions as simple because it is convenient to answer simple research questions (Petticrew 2011). Addressing complexity requires studying synergies between components, phase changes and feedback loops, interactions between multiple health and non-health outcomes as well as processes. Alternatively, focusing on the effectiveness of the single most-important component of an intervention simplifies the research question considerably. The intervention is the same but the research questions are different, and therefore, the adopted research methods are different. Based on this argument, not every complex intervention requires complex analysis unless the research question demands it.

In any of the above arguments to define complex interventions, integrated care is a brilliant example of a complex intervention. The World Health Organization (WHO) defines it as 'services that are managed and delivered in a way that ensures people receive a continuum of health promotion, disease prevention, diagnosis, treatment, disease management, rehabilitation and palliative care services, at the different levels and sites of care within the health system and according to their needs throughout their life course. It is an approach to care that consciously adopts the perspectives of individuals, families and communities and sees them as participants as well as beneficiaries of care' (WHO 2015). Similar definitions of integrated care can be found elsewhere (Kodner and Spreeuwenberg 2002; Nolte and McKee 2008). Based on this definition, integrated care may be considered an ultra-complex intervention or according to Shiell et al. (2008) a complex system (Shiell et al. 2008) because it is composed of multiple complex interventions (e.g. shared decision-making and self-management support); it behaves in a nonlinear fashion (i.e. change in output is not proportional to change in input), and the interventions interact with the context in which they are implemented, and involved decision-makers are merely interested in complex research questions.

36.2 The Rationale for Evaluation

Although research and service innovation have not been always aligned, service leaders and managers are increasingly keen to assess the effects of changes in such a way that they can be causally attributed to the complex intervention. Policy-makers are also keen to ensure that they allocate scarce healthcare resources only to services that have proven value for money (i.e. to increase allocative efficiency). Some healthcare systems, such as Germany, do not allow process innovations without proof of efficiency. This is mainly driven by the notion that we cannot afford to make poor investments in times of tight budgets. Investing in any new interventions requires an increase in taxes, premiums, patients' co-payments or takes away budget from other interventions. As a result, there is a rationale to evaluate complex interventions already during their development and implementation. However, there are some questions to be addressed by researchers before pursuing an evaluation of a complex intervention, including (Lamont et al. 2016):

(a) why is it important to address the aims of the evaluation and what is already known about the intervention, (b) who are the main stakeholders and users of research at outset, (c) how will the evaluation be performed in terms of study design and research methods, (d) what to measure and which data to be used, and (e) when is the perfect timing to maximize the impact of the evaluation results.

Similarly, policy-makers may want to assess its evaluability to support more systematic resource allocation decisions depending on the knowledge generated by an evaluation of a complex intervention. An assessment of evaluability may include the following questions (Ogilvie et al. 2011): (a) where is a particular intervention situated in the evolutionary flowchart of an overall intervention program?, (b) how will an evaluative study of this intervention affect policy decisions?, (c) what are the plausible sizes and distribution of the intervention's hypothesized impacts?, (d) how will the findings of an evaluative study add value to the existing scientific evidence?, and (e) is it practical to evaluate the intervention in the time available?

36.3 Challenges in Evaluating Complex Interventions

Key challenges in the evaluation of complex interventions were identified in a recent review of 207 studies (Datta and Petticrew 2013). One of the main challenges was related to the content and standardization of interventions due to variation in the delivery of services in terms of frequency of interventions and lack of precise definition of the start of the treatment and a wide range of patients' diagnoses, stage of diseases, needs, and preferences. Other challenges were related to the people (healthcare providers and patients) involved in the delivery of complex interventions. On the provider side, time and resource limitations may obscure data collection for evaluation purposes. Data collection may also be challenged due to issues related to patient's preferences, patient/provider interaction, and recruitment and retention to trials.

Furthermore, the organizational context of implementation, such as hierarchies, professional boundaries, staffing arrangements, social, geographical and environmental barriers, and the impact of other simultaneous organizational changes may affect the implementation of a complex intervention. A deterrent organizational context alongside with lack of support from healthcare providers poses another major challenge in evaluating complex interventions. Considering the plural, multi-dimensional (bio-psychosocial-clinical aspects), and multi-level (patient/organizational/local level) outcomes of complex interventions and their time spanning (i.e. short, medium, and long term), researchers face difficulties in establishing 'hard' outcomes that capture all effects. Combining quantitative with qualitative methods may ease part of this challenge. However, to do that sufficiently, more resources should be committed to the evaluation. Furthermore, we have seen an increase in the use of so-called composite endpoints (Hofman et al. 2014). Taking this step further, Datta and Petticrew suggested a departure from focusing on primary outcomes and a small number of secondary outcomes towards a much more multi-criteria form of assessment which acknowledges the multiple objectives of many complex interventions (Datta and Petticrew 2013).

Similar challenges were identified in a cross-national study that investigated barriers in the evaluation of chronic disease management programmes in Europe (Knai et al. 2013). The study found that lack of awareness for the need of evaluation and capacity to undertake sound evaluations, including experienced evaluators, deterred the development of an evaluation culture. Other reported barriers included the reluctance of payers to commit to evaluation in order to secure financial interests and the reluctance of providers to engage in evaluation due to perceived administrative burden and compromises their freedom. A more technical set of barriers to evaluate disease management programmes was related to low quality of routinely collected data, or the lack of, inaccessibility, fragmentation, and wide variety of information and communication technology (ICT). The authors argued that these barriers lie on the complexity of the intervention and current organizational, cultural, and political context.

The evaluation of a complex intervention may also be challenged at the policy-making level, where the decision to allocate substantial resources to implement and evaluate a complex intervention is often taken. Failing to convince policy-makers about the 'evaluability' of a complex intervention may hamper any action for evaluation.

36.4 Evaluation Frameworks

The increasing attention for complex interventions and urgent need to evaluate them boosted the development of evaluation frameworks in the last decade. One of these is May's rational model, which focuses on the normalization of complex interventions. Normalization is defined as the embedding of a technique, technology or organizational change as a routine and taken-for-granted element of clinical practice (May 2006). In this model, four constructs of normalizing a complex intervention are distinguished. The first is interactional workability, referring to the immediate conditions in which professionals and patients encounter each other, and in which complex interventions are operationalized. The second construct is relational integration, which is the network of relations in which clinical encounters between professionals and patients are located, and through which knowledge and practice relating to a complex intervention are defined and mediated. Skill-set workability is the third construct and includes the formal and informal divisions of labour in healthcare settings and to the mechanisms by which knowledge and practice about complex interventions are distributed. Finally, the fourth construct is the contextual integration and refers to the capacity of an organization to understand and agree on the allocation of control and infrastructure resources to implementing a complex intervention and to negotiating its integration into the existing patterns of activity. The model is argued to have face validity in assessing the potential of a complex intervention to be 'normalized' and evaluating the factors of its success of failure in practice.

The multiphase optimization strategy (MOST) is another framework for optimizing and evaluating complex interventions (Collins et al. 2005). It consists of the following three phases: (a) screening; in which randomized experimentation closely guided by theory is used to assess an array of programme and/or delivery components in order to select the components that merit further investigation; (b) refining; in which interactions among the identified set of components and their interrelationships with covariates are investigated in detail, again via randomized experiments. Optimal dosage levels and combinations of components are identified; and (c) confirming; in which the resulting optimized intervention is evaluated by means of a standard randomized intervention trial. To make the best use of available resources, MOST relies on design and analysis tools that help maximize efficiency, such as fractional factorial designs.

The MRC guidance is probably the most influential framework in developing and evaluating complex interventions. It is based on the following key elements (Craig et al. 2008): (a) development including the identification of evidence bases and theory as well as modelling of processes and outcome, (b) feasibility/piloting incorporating testing procedures, estimating recruitment, and determining sample size, (c) evaluation by assessing the effectiveness and cost-effectiveness as well as understanding the change processes, and (d) implementation including dissemination, surveillance and monitoring and long-term follow-up. Regarding evaluation, the MRC guidance is supportive of using experimental study designs when possible and combining process evaluation to understand process changes with formative and summative evaluation to estimate (cost-) effectiveness.

36.5 Process Evaluation

Process evaluation is as important as outcome evaluation, which can provide valuable insight not only within feasibility and pilot studies, but also within definitive evaluation studies and scale-up implementation studies. Process evaluations can examine how interventions are planned, delivered, and received by assessing fidelity and quality of implementation, clarifying causal mechanisms, and identifying contextual factors associated with variation in outcomes (Craig et al. 2008). It is particularly important in multi-site studies, where the 'same' intervention may be implemented and received in different ways (Datta and Petticrew 2013). The recognition that the MRC guidance elaborated poorly on guiding process evaluation (Moore et al. 2014) resulted into a separate MRC guidance on the process evaluation of complex interventions (Moore et al. 2015). This guidance provides key recommendations for planning, designing and conducting, analysing,

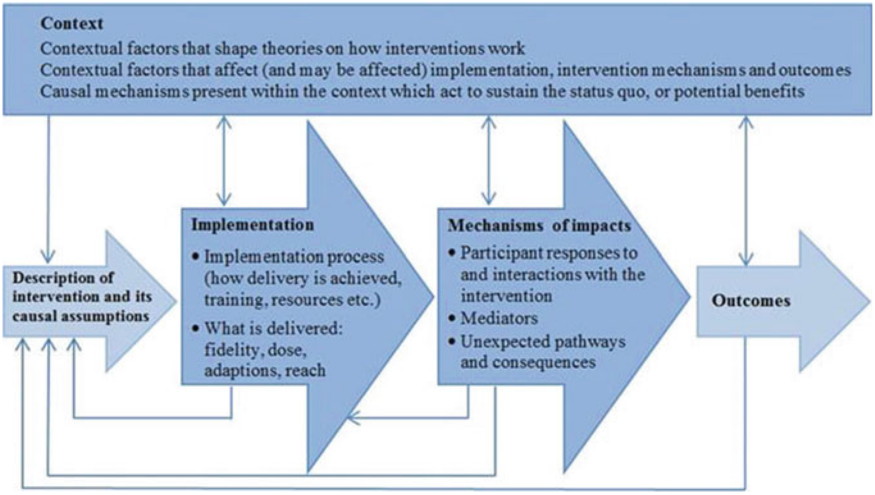

Fig. 36.2 Elements and relations of process evaluation. *Source* Moore et al. (2015)

and reporting process evaluations. Figure 36.2 shows the functions of process evaluation and relations among them as identified in the MRC guidance.

Following the MRC guidance and the earlier work of Steckler et al. (2002), the following subsections provide more details on the implementation, context, and causal mechanisms of complex interventions as the main components of their process evaluation. This is in accordance with an early case study of treating integrated care as complex intervention, Bradley et al. (1999) who suggested three levels of defining the intervention, including theory and evidence which inform the intervention, tasks, and processes involved in applying the theoretical principles, and people with whom and context within which the intervention is operationalized (Bradley et al. 1999).

36.5.1 Fidelity and Quality of Implementation

A complex intervention may be less effective as initially thought because of weak or incomplete implementation (Boland et al. 2015). This is because they often go through adaptations depending on the context, which might undermine intervention fidelity. Standardizing all components of an intervention to be the same in different sites would treat complex interventions as being simple interventions. According to Hawe et al. (2004), the function and process of a complex intervention should be standardized not the components themselves. This allows the intervention to be tailored to local conditions and could improve effectiveness. Intervention integrity would be defined as evidence of fit with the theory or principles of the hypothesized change process. However, others may argue otherwise and propose the standardization of the components, while allowing flexible operationalization of these components based on the context.

Hence, the first stage in process evaluation focuses on the fidelity (the extent to which the intervention is delivered as intended), reach (whether an intervention is received by all those it targeted), dose delivered (the amount or number of units of intervention offered to participants, and dose received (the extent of participants' active engagement in the scheme). Steckler and Linnan conceive of evaluating intervention reach and dose, and participants' responses to an intervention largely in quantitative terms (Steckler et al. 2002). Reach and dose are commonly examined quantitatively using methods such as questionnaire surveys exploring participants' exposure to and satisfaction with an intervention. However, receipt can also be seen in qualitative terms as exploring participants' reports of an intervention in their own terms. Qualitative research can be useful in examining how participants perceive an intervention in unexpected ways which may not be fully captured by researcher-developed quantitative constructs. Qualitative research can also explore how providers or participants exert 'agency' (willed action) in engaging with the intervention rather than merely receiving it passively.

At this stage of the process evaluation, the RE-AIM framework developed by Glasgow et al. (1999) may be used to assess the reach, efficacy, adoption, implementation, and maintenance of a complex intervention at individual and organizational level. This framework provides also specific metrics on each of these five dimensions (Glasgow et al. 2006a) and has been used in the process evaluation of many complex interventions including diabetes self-management interventions (Glasgow et al. 2006b) and community-based interventions for people with dementia (Altpeter et al. 2015).

36.5.2 Context

Context is a critical aspect of process evaluation. Although there is no consistent definition, context refers to the social, political, and/or organizational setting in which an intervention is implemented (Rychetnik et al. 2002). In broader terms, this could include factors such as the needs of participants, the infrastructure within which interventions will be delivered, the skills and attitudes of providers, and the attitudes and cultural norms of potential participants. The context in which a complex intervention is implemented usually influences the intervention's implementation by supporting or hindering it (Steckler et al. 2002). For example, an intervention may be delivered poorly in some areas, but well in others, because of better provider capacity or more receptive community norms in some areas. Context can be measured quantitatively in order to inform 'moderator' analyses, but this occurs rarely and inconsistently between studies (Bonell et al. 2012). Qualitative research allows for a different understanding of the importance of context, for example, examining how intervention providers or recipients describe the interaction between their context and their own agency in explaining their actions (Oakley et al. 2006).

Moreover, the context interacts with complex interventions and therefore influences outcomes. The interaction of context and interventions has two major implications (Rychetnik et al. 2002). Firstly, it is likely to affect the transferability of a complex intervention. Secondly, interactions greatly complicate attempts to pool the results of different interventions. Distinguishing between components of interventions that are highly context dependent (e.g. a self-management support programme) and those that may be less so (e.g. wearable health devices that support self-management) may be a way of scaling down these implications. A process evaluation should therefore determine whether interactions between the context and intervention have been sought, understood, and explained. Where such interactions seem to be strong, it may be preferred to explore and explain their effects, rather than pooling the findings. To do this, a combination of different qualitative methods, including interviews, focus groups, observations, and tick descriptions, should be used. Qualitative research can also enrich the understanding of intervention effects and guide systematic reviews. Standards for conducting qualitative investigations are widely available (Taylor et al. 2013).

36.5.3 Causal Mechanisms

Assessing an intervention's mechanisms of effects involves assessing whether the validity of the theory of change does indeed explain its operation. Such analysis can explain why an intervention is found to be effective or ineffective within an outcome evaluation. This might be critically important in refining an intervention found to be ineffective or in understanding the potential generalizability of interventions found to be effective. Quantitative data can be used to undertake mediator analyses to assess whether intervention outputs or intermediate outcomes appear to explain intervention effects on health outcomes (Rickles 2009). Qualitative data can be used to examine such pathways, and this is particularly useful when the pathways in question have not been comprehensively examined using quantitative data, as well as when pathways are too complex (e.g. using multiple steps or feedback loops) to be assessed adequately using quantitative analyses. However, such analyses can be challenging. First, quantitative analyses require evaluators to have correctly anticipated what data is needed to examine causal pathways and to have collected these. A second challenge involves using qualitative alongside quantitative data to understand causal pathways. If qualitative data is analysed in order to explain quantitative findings, this may introduce confirmation bias. This may occur because the qualitative analysis will be used to confirm hypothesis of the quantitative analysis and focus disproportionally less to alternative possibilities. Furthermore, quantitative and qualitative methods originate from different research paradigms. Qualitative research is inductive, and generalizations are made from particular circumstances making the external validity of the findings somewhat uncertain.

36.6 Formative and Summative Evaluation

In a formative evaluation, complex interventions are typically assessed during their development or early implementation to provide information about how best to revise and modify for improvement. For these purposes, a pilot study can be designed to test that both the intervention and the evaluation can be implemented as intended. If the pilot is successful and no changes are made, then data from it can be incorporated into the main study. Moreover, a feasibility study can be used to indicate whether or not a definitive study is feasible and to examine important areas of uncertainty such as possibility and willingness for randomization, response rates to questionnaires collecting outcome data, or the standard deviation of the primary outcome measure required for the sample size calculation.

In summative evaluation, complex interventions are assessed for their definitive effectiveness and cost-effectiveness to support decisions-making of whether an intervention should be adopted, continued, or modified for improvement. The key statistical design issues alongside formative and summative evaluations of complex interventions are related to the study design and outcomes (Lancaster et al. 2010).

36.6.1 Study Design

The MRC guidance advocates the adoption of an experimental study design when evaluating complex interventions because it is the most robust method of preventing selection bias (Craig et al. 2008). Experimental designs include randomized controlled trials where individuals are randomly allocated to an intervention or a control group. These trials are sometimes considered to be inapplicable to complex interventions, but there are many flexible variants that can overcome technical and ethical issues associated with randomization such as randomized stepped wedge designs (Brown and Lilford 2006), preference trials (Brewin and Bradley 1989) and randomized consent designs (Zelen 1979; Torgerson and Sibbald 1998), and N-of-1 designs (Guyatt et al. 1990). When there is a risk of contamination (i.e. the control group is affected by the intervention), cluster randomized trials, in which groups of individuals (e.g. patients in a GP practice) are randomized instead of single individuals, are preferred.

Realist RCTs have also been suggested as adequate design in evaluating complex intervention because they emphasize the understanding of the individual and combined effects of intervention components and examination of change mechanisms (Bonell et al. 2012). Realist RCTs should be based on ‘logic models’ that define the components and mechanisms of specific interventions and combine qualitative and quantitative research methods. However, Marchal et al. (2013) objected the ‘realist’ nature of RCTs and proposed that the term ‘realist RCT’ should be replaced by ‘theory informed RCT’, which could include the use of logic model and mediation analysis that are entirely consistent with a positivist philosophy of science. Such an approach would be based on theory-based impact evaluations for complex interventions and would be aligned with the approach suggested in the MRC guidelines. Irrespective of the terminology, both studies agree that experimental designs should be based on theories and incorporate methods adequate to evaluate complex interventions.

If an experimental approach is not feasible, for example, because the intervention is irreversible, necessarily applies to the whole population, or because large-scale implementation is already under way, non-experimental alternatives should be considered. Quasi-experimental designs or natural experiments may be the best alternatives when evaluating complex interventions because they involve the application of experimental thinking to non-experimental situations. They widen the range of interventions beyond those that are amendable to planned experimentation, and they encourage a rigorous approach to use observational data (Craig et al. 2012). Natural experiments are applicable when control groups are identifiable or when groups are exposed to different levels of intervention. Regression adjustment and propensity-score matching could reduce observed confounding between the comparators, while difference-in-differences, instrumental variables, and regression discontinuity could reduce the unobserved confounding between the comparators. A combination of these techniques is also possible in the evaluation (Stuart et al. 2014).

The selection of the study design could be informed by primary studies, literature reviews, and qualitative studies (Lancaster et al. 2010) and decided based on size and timing of the expected effects, the likelihood of the selection bias, the feasibility and acceptability of randomization, and the underlying costs (see Box 36.2).

Box 36.2 Choosing between randomised and non-randomised designs

Size and timing of effects: randomisation may be unnecessary if the effects of the intervention are so large or immediate that confounding or underlying trends are unlikely to explain differences in outcomes before and after exposure. Randomization may be inappropriate if the changes are very small, or take a very long time to appear. In these circumstances a non-randomised design may be the only feasible option, in which case firm conclusions about the impact of the intervention may be unattainable.

Likelihood of selection bias: randomisation is needed if exposure to the intervention is likely to be associated with other factors that influence outcomes. Post-hoc adjustment is a second-best solution, because it can only deal with known and measured confounders and its efficiency is limited by errors in the measurement of the confounding variables.

Feasibility and acceptability of experimentation: randomisation may be impractical if the intervention is already in widespread use, or if key decisions about how it will be implemented have already been taken, as is often the case with policy changes and interventions whose impact on health is secondary to their main purpose.

Cost: if an experimental study is feasible, and would provide more reliable information than an observational study, you need then to consider whether the additional cost would be justified by having better information.

Source Craig et al. (2008)

36.6.2 Outcomes

Given the nature of complex interventions, an appraisal of evidence should determine whether the outcome variables cover the interests of all the important stakeholders, not just those who conduct or appraise evaluative research. Important stakeholders include those with responsibility for implementation decisions as well as those affected by the intervention. Identification of the appropriate range of outcomes that should be included in a formative/summative evaluation requires a priori agreement about the relevant outcomes of an intervention from important stakeholders' perspectives, including agreement on the types of evidence deemed to be adequate to reach a conclusion on the value of an intervention, and the questions to be asked in evaluating the intervention (Rychetnik et al. 2002).

Outcomes can be measured using qualitative and quantitative research methods. Qualitative studies can also be used as a preliminary to a quantitative study to establish, for example, meaningful wording for a questionnaire. The selection of the outcome measures can be based on recommendations and evidence from the literature as well as practical issues in collecting or gathering the necessary data. The outcomes measures should extend over different dimensions (e.g. dimensions of quality of life), time scales (e.g. short, medium, and long term), and levels (e.g. patient, organizational, and local). For this reason, there is a need for a multi-criteria form of assessment which acknowledges the multiple objectives of many complex interventions (Datta and Petticrew 2013).

Costs should be included in an evaluation to make the results far more useful for decision-makers. Ideally, economic considerations should be taken fully into account in the design of the evaluation, to ensure that the cost of the study is justified by the potential benefit of the evidence it will generate, appropriate outcomes are measured, and the study has enough power to detect economically important differences.

36.7 Reporting and Reviewing Evaluation Results

It is of crucial importance to provide detailed reporting of the results from the process, formative, and summative evaluations for several reasons. First, information on the design, development, and delivery of interventions as well as its context is required to overcome the challenges of evaluating complex interventions (Datta and Petticrew 2013) and enable the transferability of the interventions to other settings (Rychetnik et al. 2002). Second, well-reported outcomes, knowledge of factors that influence the intervention's sustainability and dissemination, and information on the characteristics of people for whom the intervention was effective or less effective support evidence-based decision-making and practice. Third, poor reporting limits the ability to replicate interventions and synthesize evidence in systematic reviews.

The availability of such information from an evaluation study is a marker of the quality of evidence on a complex intervention. High-quality evidence should refer to evaluative research that was matched to the stage of development of the intervention; was able to detect important intervention effects; provided adequate process measures and contextual information, which are required for interpreting the findings; and addressed the needs of important stakeholders (Rychetnik et al. 2002).

Several instruments have been developed and reported in the literature to systematize the reporting of evaluation studies of complex interventions. Some of them are mentioned in the MRC guidance for developing and evaluating complex interventions (Craig et al. 2008) and included generic statements (i.e. not specifically applicable to complex interventions) such as the CONSORT statement for reporting clinical trials (Moher et al. 2010) and the STROBE statement for observational studies (von Elm et al. 2007). Extended versions of the CONSORT statement for cluster randomized trials (Campbell et al. 2012), pragmatic trial, (Zwarenstein et al. 2008) and complex social and psychological interventions have been issued (Montgomery et al. 2013a). Similarly, the Criteria for reporting the Development and Evaluation of Complex Interventions in healthcare (CReDECI 2) is a checklist based on the CONSORT statement and EQUATOR network to report 17 items related to the development, feasibility and piloting, and evaluation of complex interventions (Mohler et al. 2015).

Authors of systematic reviews are increasingly being asked to integrate assessments of the complexity of interventions into their reviews. The challenges involved are well recognized (Shepperd et al. 2009). Some studies attempted to contribute in overcoming these challenges by systematically classifying and describing complex interventions for a specific medical area (Lamb et al. 2011). A more comprehensive attempt towards that direction was the Oxford Implementation Index. This tool was developed to incorporate information in systematic literature reviews and meta-analyses about the intervention characteristics with regards to their design, delivery, and uptake as well as information about the contextual factors (Montgomery et al. 2013b). Furthermore, the Cochrane collaboration has published a series of methodological articles on how to consider complexity of interventions in systematic reviews (Anderson et al. 2013).

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Realist Research, Design and Evaluation for Integrated Care Initiatives

37

John G. Eastwood, Denise E. De Souza,
and Ferdinand C. Mukumbang

37.1 Introduction

There is increasing interest in realist-informed approaches to studying the health and social care needs of populations, systems of care and in the development and evaluation of appropriate interventions. Although the principles underpinning realist approaches are fundamental to many professional practices and fields including the medical and social welfare practices, these tenets are challenging to conceptualise. A classic example of the application of realist principles is the crime investigator Sherlock Holmes, in popular literature and television, who uses abductive reasoning to identify the best explanation of a complex crime from available visible [empirical] evidence. Physicians also apply realist principles by examining the patient's history (subjective), observing and measuring (objective), followed by the generation and appraisal (assessment) of theory to determine the best or most likely explanation.

A standout feature in the two examples above is that the investigator (crime investigator, clinician, social worker, etc.) draws conclusions or offers explanations based on observations that are obtained subjectively and objectively. Nevertheless, observing is only a piece of the puzzle. There is also the aspect of what happened

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(events) before the observations occur and what are the causal elements (usually hidden) driving the events. To this end, reality is considered to consist of the visible (observations and sometimes events) and the hidden (mechanisms), and to have multiple layers and domains that need to be examined to arrive at the best explanation of the observed events. When conducting an investigation in complex health and social systems, the realist approach is similar and must first consist of investigation of the observed and reported phenomena, followed by the generation of theories, and finally the appraisal of the theories to infer the best explanation (aka inference to best explanation). This is analogous to the development of a differential diagnosis in a medical investigation.

It is usually the purpose of the investigation, whether epidemiological, criminal, medical, or health and social system related, to apply an intervention that will alter the outcome of interest to a more favourable state. Thus having identified the most likely explanation (theory), the practitioner will use a combination of knowledge and logic to propose an intervention that will most likely result in the intended outcome sought. Following the prescription of a treatment, or design and implementation of another type of intervention, the practitioner evaluates whether the intervention worked (or not), how, for whom and why. The aim of this chapter is to introduce the tenets of critical realist methodology and its application to research, design and evaluation of complex health and social integrated care interventions.

37.2 The Nature of Reality (Ontology)

The critical realist's view of the form and nature of reality (ontology) is that a reality within and beyond our sense experiences exists and that it is possible to conceptualise and make theories that describe (aspects of) it. This view is in contrast to the empirical view that knowledge cannot extend beyond sense experiences and observations. What makes critical realism "critical" is the view that all knowledge and theoretical claims are fallible. Thus, critical realists argue that all knowledge claims should be continually critiqued, challenged and revised as both culture and practice of science shape the lens through which the world is viewed.

There are two dimensions to how realist researchers consider the nature of reality and the different entities and categories within that reality. The first dimension concerns the distinction between the empirical, actual and real, and the second concerns the stratification or layering of reality. The empirical domain comprises our experiences of what actually happens, and the actual is constituted by the things that happened independently of whether we observed them or not (i.e. events). The last ontological domain is the deepest level of reality and is constituted by structures with generative powers that under certain conditions activate mechanisms (Collier 1994). The *Real* domain of reality exists independently of our perception or knowledge of it and consists of both natural and social objects. Importantly at this level, at a point in time, these objects and their latent powers remain in stasis until a certain condition or

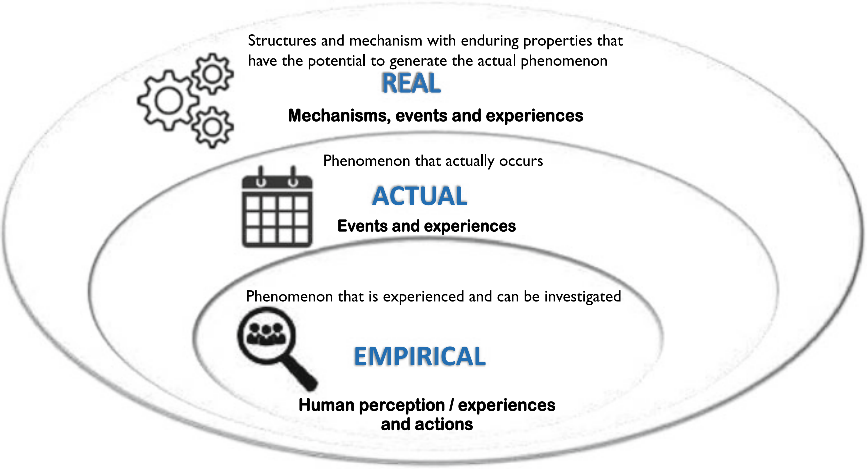


Fig. 37.1 Stratified ontology of critical realism (Bhaskar 1975; Mukumbang et al. 2019a)

intervention is introduced. Critical realism posits that this *Real* domain (reality) is stratified, and that it consists of structures and mechanisms (Fig. 37.1).

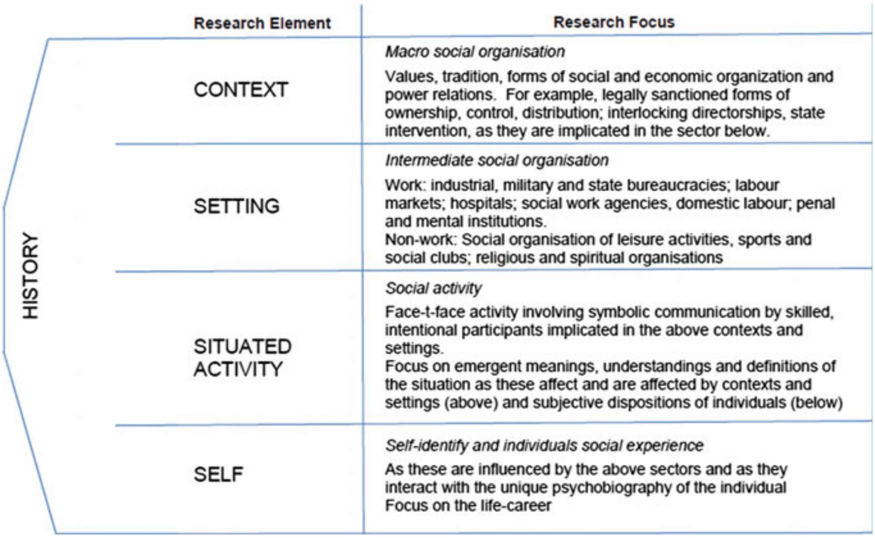
A second critical realist ontological dimension is that mechanisms in reality are stratified, where mechanisms at a lower level create conditions for the unfolding of mechanisms at a higher level. Mechanisms exist at each different stratum, with the stratification being variably described as including the: physical, chemical, biological, psychological, psychosocial, behavioural, social, cultural and economic layers (Sayer 2000; Bhaskar 1998; Danermark 2002; Danermark and Gellerstedt 2004; Layder 1993; McGuire 2006). The existence of a level's specific generative mechanisms is what constitutes or defines that level or stratum (Danermark 2002), and the ability of mechanisms to combine to create something new is called *emergence* (McGuire 2006; Danermark 2002; Bhaskar 1998). An implication of this stratification and emergence is that it is not possible to reduce the causes of what occurs on one level to those on another level (whether lower or higher) (Danermark 2002). Collier (1994) describes this stratification as a one-way hierarchy of inclusion. Sayer (2000) illustrates this idea by highlighting that "social phenomena are emergent from biological phenomena, which are in turn emergent from chemical and physical strata. Thus, the social practice of conversing is dependent on one's physiological state, including the signals sent and received around our brain cells, but conversing is not reducible to those physiological processes".

Table 37.1 from McGuire (2006) depicts the two realist ontological dimensions with examples across the body, the self and society.

Layder (1993) has also illustrated this layering of reality in his Research Map (Fig. 37.2) which importantly includes a historical element. In critical realism, structures exist in the domain of the real. In social reality, historical pre-existing structures and mechanisms are important aspects to be considered when

Table 37.1 Determinants of health and layers of reality (McGuire 2006)

	Body	Self	Society
Empirical (observable)	Biological determinants, diagnosis or illness, treatment	Individual determinants (e.g. lifestyle), experience and meaning of illness, coping	Social determinants (e.g. poverty), disruption of social participation, health and social costs
Actual (objects/events)	Normal and pathological processes, signs and symptoms	Cognition, emotion, development, behaviour	Political, economic, social welfare, health care systems, social behaviours, norms, relations
Real (mechanisms)	Biological, physical, chemical, genetic mechanisms	Psychological, emotional, cognitive, spiritual mechanisms	Social, cultural, political, economic, religious mechanisms



Research Element	Research Focus
CONTEXT	*Macro social organisation* Values, tradition, forms of social and economic organization and power relations. For example, legally sanctioned forms of ownership, control, distribution; interlocking directorships, state intervention, as they are implicated in the sector below.
SETTING	*Intermediate social organisation* Work: industrial, military and state bureaucracies; labour markets; hospitals; social work agencies, domestic labour; penal and mental institutions. Non-work: Social organisation of leisure activities, sports and social clubs; religious and spiritual organisations
SITUATED ACTIVITY	*Social activity* Face-t-face activity involving symbolic communication by skilled, intentional participants implicated in the above contexts and settings. Focus on emergent meanings, understandings and definitions of the situation as these affect and are affected by contexts and settings (above) and subjective dispositions of individuals (below)
SELF	*Self-identify and individuals social experience* As these are influenced by the above sectors and as they interact with the unique psychobiography of the individual Focus on the life-career

Fig. 37.2 Research Map (Layder 1993, p. 72)

undertaking the research, design and evaluation approaches described in this chapter. This is because structures and mechanisms have a conditioning effect on individuals and contribute to the socially conditioned nature of their reasoning and behaviour as they make decisions within social programmes. This framework was previously used for translation of causal theory arising from a critical realist theory building social epidemiology study (Eastwood et al. 2016), to the collaborative design of an integrated health and social care initiative for families experiencing adversity (Eastwood et al. 2019b).

37.2.1 Causal Inference

For realists, natural or social objects are, or form, a part of structures. A structure (e.g. water molecule), in turn, comprises related parts (hydrogen and oxygen atoms) with causal powers. When combined, the causal powers are said to be emergent from the components. In contrast to positivism, causation is not understood based on a model of regular succession or association of events (Sayer 2000). Rather, explanations depend on understanding the structure of natural and social objects, "identifying causal mechanisms and how they work, and discovering if they have been activated and under what conditions" (Sayer 2000, p. 14). Figure 37.3 provides a framework for understanding how causality is conceptualised in critical realism with structures having causal powers that activate causal mechanisms under certain conditions to produce events.

Related to the above is *tendency*. The structure and its generative mechanisms may produce an outcome or regularity, but its empirical manifestation is contingent upon certain conditions or context. Therefore, this empirical manifestation must be considered as tendencies of the structure rather than empirical regularities. Because of the potential modifying effect of contextual elements, critical realists consider any observed outcome as—"demi-regularities". Realist causal propositions are usually expressed in terms of mechanisms (M), context (C) and outcomes (O). For critical realist research, the MCO propositions are proposed by Danermark and colleagues (2002) (Fig. 37.4a), while for evaluation studies, Pawson and Tilley (1997) propose a CMO configuration as in Fig. 37.4b. For a more complete causal proposition, structure (S) may be added as CSMO (Bhaskar 2014).

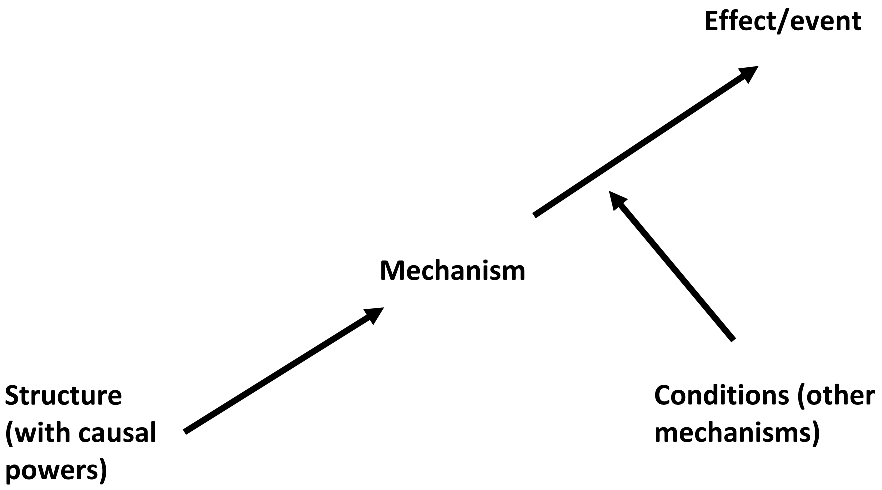


Fig. 37.3 Critical realist view of causation (Sayer 2000)

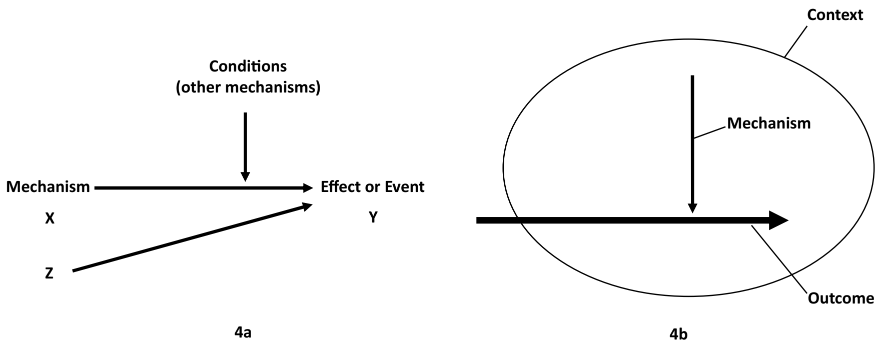


Fig. 37.4 CMO propositions: **a** Danermark et al. (2002); **b** Pawson and Tilley (1997)

37.2.2 Mechanisms

The concept of mechanisms is central to critical realist ontology. As previously stated, structures have causal powers with potential to produce events given certain conditions. In critical realism, the term mechanism is used when we talk about the effects that structures can potentially produce under certain conditions. Danermark et al. (2002, p. 55) describe a mechanism as “that which can cause something in the world to happen, and in this respect mechanisms can be of many different kinds”. Mechanisms are typically not directly observable. Based on observed phenomenon, the task may be to mine the “underlying mechanisms” that produce the “phenomenon and to understand the interplay between them and how they shape the outcome”. The task of critical realist research and evaluation is to make explicit the mechanisms orchestrating the observed phenomenon and to understand their interplay in a specified organisational/institutional/social structure. Some mechanisms may not produce empirically manifest expected outcomes because they may not have been activated, or their effects have been mitigated by other counteracting mechanisms (Danermark 2002).

The identification of generative mechanisms and counteracting mechanisms requires consideration of *context*. Under certain contextual conditions, the existing mechanisms can be activated to cause the observed outcome. The outcome resulting from activated mechanisms is therefore always dependent on context. Thus, *context* determines how a mechanism is empirically manifested (Danermark 2002). A mechanism does not always produce the same outcome in different contexts, a notion described by Smith (2010) as *contingent causality*, a feature of open systems. De Souza (2013), drawing on realist social theory, and Archer’s proposition that the theory is amenable to being adopted for smaller-scaled human interactions and activities (Archer 1996), has conceptualised *context*, in a social programme, as consisting of aspects of structure, culture, agency and relations. Insofar as an integrated care setting is interested in modifying the organisation of its services, it is possible to suggest that social programmes—introduced in public institutions as interventions—tend to implicate structural, cultural, agential and relational mechanisms (Table 37.2).

Critical realists tend to use the term "mechanism" in relation to effects and "powers" in relation to structures. Collier (1994, p 60) highlights this relationship by stating that "effects are ascribed to causal powers, causal powers to inner structure (and place in larger structures) of the causal agent".

However, what constitutes a mechanism has received much debate and critique, leading to various constructs of a mechanism when applied in realist review and evaluation practice. Westhorp (2018) has argued that different constructs of mechanisms are required if they align with the principles of critical realism and identified five constructs of mechanisms (Table 37.3) giving examples beyond social programmes.

Table 37.2 Context, mechanisms and outcomes, modified from (De Souza 2013)

Context	Mechanisms related to	Outcomes
Structure—institutional/organisational	Roles, practices, resources, processes	(T), (I) or (R) of institutional/organisational structure
Culture—institutional/organisational	Group ideas and propositional formulations about the institution/organisation	(T), (I) or (R) of institutional/organisational culture
Agency	Individual beliefs and reasons for actions or non-action	(T), (I) or (R) of individual agency within the institution/organisation
Relations	Maintaining, adjusting or redistributing power/duties/responsibilities	(T), (I) or (R) of institutional/organisational relations

Note Transformation (T), invariance (I) or reproduction (R)

Table 37.3 Five constructs of mechanism in critical realism (Westhorp 2018, p. 49)

Construct of mechanism	Material	Psychological/cognitive	Social—groups	Social—institutional
Powers and liabilities	Trees can grow, e.g. photosynthesis	Humans can learn, e.g. sensitisation; motivation	Groups can make agreements	States can make laws
Forces	Gravity	Love	Peer pressure	Laws, regulations
Interactions	Gun powder explosion	Reasoning and resources	Contracts	New technologies and market systems
Feedback or feedforward processes	Genetic inheritance	Developing attachment styles	Negotiation	Stock market crash
Reasoning and resources	Neurons firing: electrical signals	Logic-in-use; affective response	"Group link"	Cultural assumption

37.3 Understanding Reality (Epistemology)

As noted above, critical realists consider that reality exists independently of us and is not merely a social construction. Realists have been challenged to answer the question that “if the social world is socially constructed and significantly concept-dependent, how can it be treated as independent of the researchers’ knowledge?” (Sayer 2000, p. 32). In response to this, Bhaskar (1975) drew the distinction between *intransitive* and *transitive* knowledge. Things that are studied such as physical and social phenomena form the intransitive dimension of science, while theories and discourse form part of a *transitive* dimension (Sayer 2000, p. 11).

Causal inference is the process of drawing conclusions regarding causation by applying forms of reasoning or logic. Danermark and colleagues (2002) define inference as “a way of reasoning towards an answer to questions such as: What does this mean? What follows from this? What must exist for this to be possible?” They distinguish between four modes of inference (deduction, induction, abduction and retroduction) which they define as follows:

Deduction: To derive logically valid conclusions from given premises. To derive knowledge of individual phenomena from universal laws.

Induction: From several observations to draw universally valid conclusion about a whole population. To see similarities in several observations and draw the conclusion that these similarities also apply to non-studied cases. From observed co-variates to draw conclusions about law-like relations.

Abduction: To interpret and recontexualised individual phenomena within a conceptual framework or a set of ideas. To be able to understand something in a new way by observing and interpreting this something in a new conceptual framework.

Retroduction: From a description and analysis of concrete phenomena to reconstruct the basic conditions for these phenomena to be what they are. By way of thought operations and counterfactual thinking to argue toward transfactual conditions.

Retrodiction is another form of reasoning used by realists. It is applied to construct in-case explanatory models; retrodiction is used to examine the similarities and differences between various cases.

A full discussion of these modes of reasoning is not possible here, but an understanding of abduction is essential to discover the “hidden” generative mechanisms in the domain of the real. Eco’s typology of abduction includes over-coded, under-coded and creative types of abduction (Eco 1984 as cited by (Danermark et al. 2002, p 23). Over-coded abduction is a mode of inference consisting of spontaneous interpretations based on cultural and social prejudging. Thus, all observations involve some form of interpretive abductive process being a precondition for the observed phenomenon having any meaning at all. This interpretive abduction occurs naturally during realist interviews, initial coding of qualitative data and visualisation of quantitative data.

By contrast, under-coded abduction is where we choose between several possible frames of interpretation of theories. This process of abductive inference often occurs during the second phase of coding and during the quantitative interpretation of an exploratory factor analysis (EFA) or its variants (e.g. exploratory structural equation modelling ESEM). It is also the mode of reasoning used for medical differential diagnosis and epidemiological use of the Bradford Hill Criteria (Hill 1965).

The third type of abduction, creative abduction, is characterised by being unique and innovative and moving to a frame of interpretation that nobody has used before, or which "at least opposes conventional interpretations (i.e. the "eureka" moment).

37.4 Intensive and Extensive Methodology

The epistemological aim of critical realism is to explain the relationship between experiences, events and underlying mechanisms. The emphasis is on explaining the "how and why" of particular phenomenon. To undertake this task, it is necessary to use different kinds of reasoning: inductive, deductive, abductive and retroductive, with an emphasis on linking the abstract to the concrete. Sayer (1992) emphasises the importance of different methods of data collection and analysis. He proposes four types of research: intensive or concrete (empirical and theoretical analysis); generalisation (empirical), abstract (theoretical) and synthesis (interdisciplinary analysis).

Sayer (2000) further outlines two different kinds of research design relevant to this study. The "intensive research design" is used in research where we wish to obtain in-depth knowledge of a specific phenomenon for the purpose of causal explanation. "Intensive research design" mainly applies to qualitative methods. "Extensive research" typically uses more quantitative methods that seek to identify regularities and patterns. The "extensive" study typically identifies regularities and has limited explanatory power (i.e. of how and why).

Jeppesen (2005) identified the requirement to sometimes supplement the "intensive" and "extensive" designs described by Sayer (2000), with a third "explorative design" aimed at establishing an understanding of the area of investigation according to involved parties. This involvement of citizens, practitioners and other parties is central to the collaborative and person-centred approaches used in integrated care (Table 37.4).

Realist research, design and evaluation, could be qualitative, employ mixed methods or, to a lesser extent, entirely quantitative. Realists have argued that both may be used (Porpora 2005). Drawing on Haig (2005b), Eastwood (2014a) proposed their use for both phenomenon description and explanatory theory generation. It is important to note, however, that intensive research and extensive research can be both qualitative and quantitative. This possibility of intensive quantitative and extensive qualitative studies has not been fully examined.

Table 37.4 Intensive and extensive research (Sayer 2010)

	Intensive	Extensive
Research question	How does a process work in a particular or small number of cases? What produced a certain change? What did agents do?	What are regularities, common patterns, distinguishing features of a population? How widely are certain characteristics or processes distributed/represented?
Relations	Substantial relations of connection	Formal relations of similarity
Types of groups studied	Causal groups	Taxonomic groups
Type of account produced	Causal explanation of production of certain objects/events, though not representative ones	Descriptive "representative" generalisations, lacking explanatory penetration
Typical methods	Study of individual agents in their causal contexts, interactive interviews, ethnography Qualitative analysis	Large-scale survey of population or representative sample, formal questionnaires, standardised interviews Statistical analysis
Limitations	Actual concrete patterns and contingent relations are unlikely to be "representative", "average" or generalisable Necessary relations discovered will exist wherever their relata are present, e.g. causal powers of objects are generalisable to other contexts as they are necessary features of these objects	Although representative of a whole population, they are unlikely to be generalisable to other populations at different times and places Problem of ecological fallacy in making inferences about individuals Limited explanatory power
Appropriate tests	Corroboration	Replication

A full exploration of mixed-method designs is not possible here. Case study (Mukumbang et al. 2018b) grounded theory (Haig and Evers 2015) and multi-level concurrent triangulated (Eastwood et al. 2014a) mixed-method designs might be used. Mixed-method pragmatic realist randomised control trials (RCTs) have also been controversially proposed (Bonell et al. 2012). Other approaches might include mixed-method social network analysis (Domínguez and Hollstein 2014) and mixed-method structural equational modelling approaches (Ford et al. 2018).

37.5 Critical Realist Research, Design and Evaluation Cycles

We will consider here critical realist research, design and evaluation methods. A critical realist research approach looks at concrete phenomenon and events and asks "What structures are fundamental for this phenomenon to exist and be what it is?" (Danermark et al. 2002, p. 147). In doing so, explanatory models and causal theories about the phenomenon are constructed and may subsequently be used to inform the design of an intervention. By contrast, the realist evaluation approach seeks to confirm and refine a programme theory about an intervention (Pawson and Tilley 1997). The intervention may have arisen from a realist design process (Eastwood et al. 2019c), but often, the researcher's first task is to determine the intended programme theory. Both approaches consist of similar elements albeit with a focus on theory building and theory testing, respectively (Fig. 37.5).

37.5.1 Realist Explanatory Research

The purpose of the realist research is primarily to *explain* an observed phenomenon and only secondarily prediction. There is no single approach to undertaking realist research, but several leaders in the field have provided guidance that incorporates elements of ethnography (Porter 1993; Porter and Ryan 1996), emergent and grounded theory (Oliver 2012), and comparative case studies (Mukumbang et al. 2018a, 2019b).

Bazeley (2013), who describes herself as a pragmatic critical realist with a transformative perspective, observes that realists argue that it is necessary to explain events, not just to document regularities in them—to identify the physical or mental mechanisms, processes, structures and other contextual forces that account for events or observed regularities. Bazeley (2013, p. 21) cites Miles and Huberman (1994, p. 11) who describe analysis as progressing naturally from telling a first story

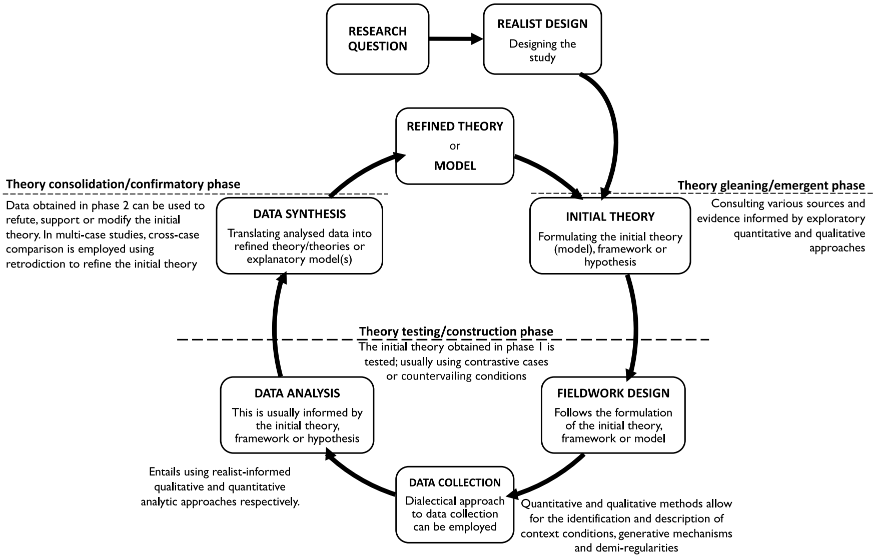


Fig. 37.5 Realist research cycles

about a specified situation (what happened, and then what happened), to constructing a map (formalising the elements of the story, locating key variables), to building a theory or model (how variables are connected how they influence each other). This emergent explanatory approach is also described by Bhaskar (2014) and Danermark (2002). Bhaskar describes such an approach to theoretical inquiry (DREIC) where:

1. D stands for the description of pattern of events or phenomenon;
2. R for retroduction of possible explanatory mechanisms or structures;
3. E for elimination of competing alternatives;
4. I for the identification of the causal generative mechanisms and
5. C for the iterative correction of earlier findings.

Maxwell (2012) advances a realist research design framework that explicitly rejects the idea of cyclical or linear sequencing of the research elements. He proposes an interconnected and flexible structure (Fig. 37.6) where the first three components (goals, conceptual framework and research questions) are real phenomenon that exist in the researcher's mind and represent the researcher's thoughts about the phenomena. The fourth component (methods) exists as actual behaviours as well as ideas, and the fifth component (validity) "concerns the relationship of the conclusions and inferences drawn from the study to the actual phenomena studied" (Maxwell 2012) (Fig. 37.7).

Drawing on the work of Haig (2005a) and Danermark et al. (2002), Eastwood and Colleagues (2014a) propose an *Explanatory Theory Building Method*

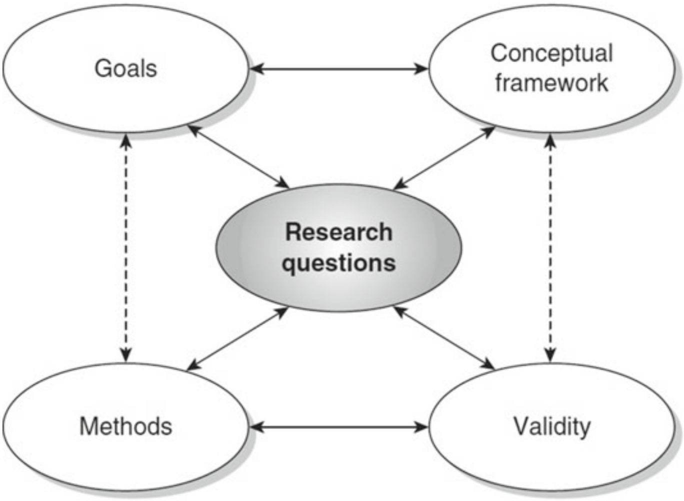


Fig. 37.6 An interactive model of research design. *Note* From qualitative research design: an interactive approach, by Maxwell (2005). Copyright by SAGE

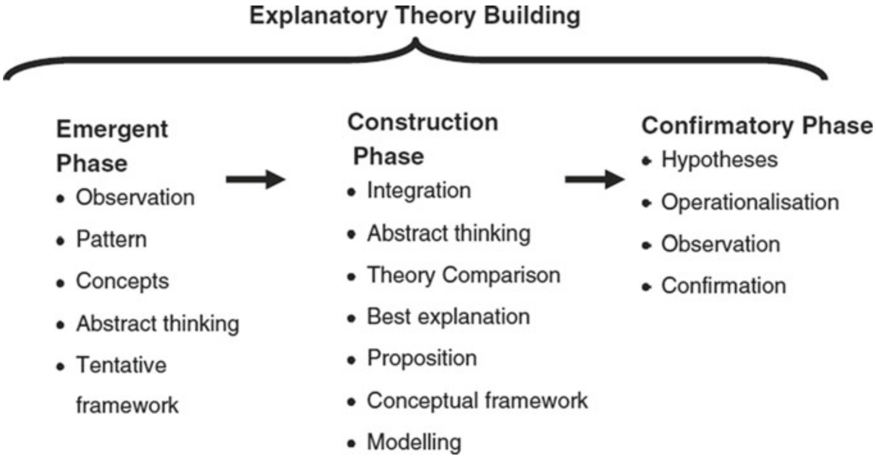


Fig. 37.7 Explanatory Theory Building Method (Eastwood et al. 2014a)

(Fig. 37.5) for their mixed-method study. The *Emergent Phase* uses methods such as factor analysis, regression, interviews, focus groups and grounded theory for both phenomena detection and theory generation (Fig. 37.8).

A similar approach is described below for mixed-method data analysis and synthesis with abstraction of conceptual themes during data analysis followed by the development and testing of theories and models in the data synthesis stage.

Haig and Evers (2015, p. 96) argue that exploratory factor analysis (EFA) is most fundamentally an abductive method of theory generation. The results of an EFA postulate the existence of latent variables but say little about their nature and function. The analyst, using abductive reasoning, may offer the beginning of a theory about a phenomenon. Eastwood and colleagues (2012b), in their concurrent triangulated mixed-method multi-level study, report on the use of nonlinear principal component analysis, regression and multi-level exploratory spatial data analysis to generate theory of postnatal depression and neighbourhood context.

Case study designs (Yin 2014) are also suitable for realist explanatory research. The case study approach is appropriate for teasing out structural entities, contextual conditions and mechanisms that interact to generate a given set of (Løkke and Sørensen 2014). It also allows for the use of multiple methods of data collection (Westhorp 2014) and is usually accommodating of mixed quantitative and qualitative methods. Danermark et al. (2002) argue that the "closeness" offered by the cases enhances the ability of the realist researchers to use hermeneutic methods to generate theories.

The realist approach to interviewing is explored by Smith and Elgar (2014)who argue that the "critical realism approach suggests theories should be developed "in process" during data collection as this allows for the development of theoretically informed data and is less likely create divisions and disconnect between the

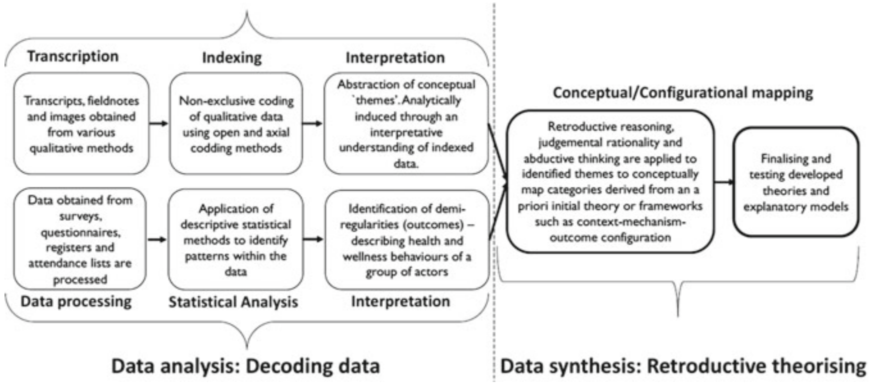


Fig. 37.8 Realist-informed mixed-method data analysis and synthesis

empirical data and later theoretical analysis". In a similar way, emergent and grounded theory should use abductive reasoning in the search for the best explanation of the studied phenomenon (Haig and Evers 2015, pp. 71–92).

The purpose of the *Theory Construction Phase* is to undertake abductive triangulation of findings from the *Emergent Phase* to construct a conceptual framework, theory and model as proposed by Miles and Huberman (1994). The methods used in the *Theory Construction Phase* include: (1) defining stratified levels; (2) analytic resolution; (3) abductive reasoning; (4) comparative analysis (triangulation); (5) retroduction; (6) postulate and proposition development; (7) comparison and assessment of theories; and 8) conceptual frameworks and model development (Eastwood et al. 2014a, 2016).

The Emergent and Theory Construction approaches described above can also be used where there is a prior conceptual framework (Miles and Huberman 1994). As discussed later, they can also be used to evaluate both causal and programme theory. Drawing on the work of Bygstad and Munkvold (2011), an abductive reasoning approach with five iterative steps for theory building and evaluation is described at Fig. 37.9. The approach begins with a suitable analytical framework and proceeds as follows (Bhaskar and Danermark 2006; Danermark et al. 2002): (1) identifying a suitable analytic framework; (2) identification of candidate mechanisms; (3) linking of key components; (4) judgemental rationality; and (5) theoretical abstraction—retrodiction.

Box 1: Realist Research Case Study of Neighbourhood Context and Postnatal Depression (Sydney)

Eastwood and colleagues undertook a critical realist mixed-method study that aimed to build a theory of neighbourhood context and postnatal depression. The study used a critical realist Explanatory Theory Building Method comprising of an: (1) emergent phase, (2) construction phase and (3) confirmatory

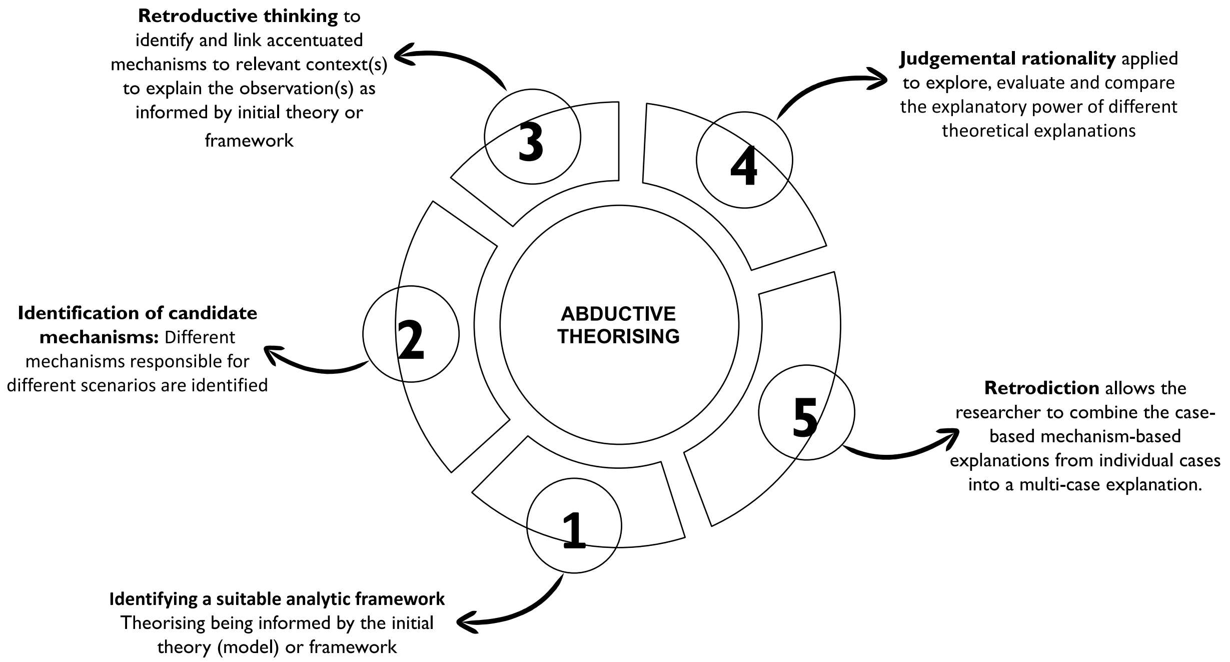


Fig. 37.9 Iterative processes involved in abductive theorising

phase. A concurrent triangulated mixed-method multi-level cross-sectional study design was used. Emergent Phase used a constant comparative analysis of the qualitative (intensive) and quantitative (extensive) arms of the study. The methods used to detect and describe the phenomena included: interviews, focus groups, exploratory data analysis, exploratory factor analysis, regression and exploratory ecological and multi-level spatial data analysis (Eastwood et al. 2012a, 2013, 2014b; b).

Theory generation was undertaken in both the qualitative and quantitative arms of the Emergent Phase, to develop tentative conceptual frameworks. This analysis used: categorical principal component analysis, exploratory factor analysis, exploratory confirmatory factor analysis, coding of concepts and categories, constant comparative analysis, drawing of conceptual networks, and situational analysis, to move from the "concrete to the abstract" (Danermark al. 2002, p. 109) (Fig. 37.10).

The construction phase undertook abductive and retroductive triangulation of the reported empirical findings and emergent theory development (Eastwood et al. 2016). Global, economic, social and cultural mechanisms were identified that explain maternal stress and depression within family and neighbourhood contexts. Critical realist causal propositions were proposed to explain the complex intertwining of historical, spatial, cultural, material and relational elements that contribute to the experiences of loss and nurturing. Emerging was the centrality of social isolation and "expectation lost" as possible triggers of stress and depression not only for mothers but possibly also for others who have their dreams shattered during life's transitions (Eastwood et al. 2018).

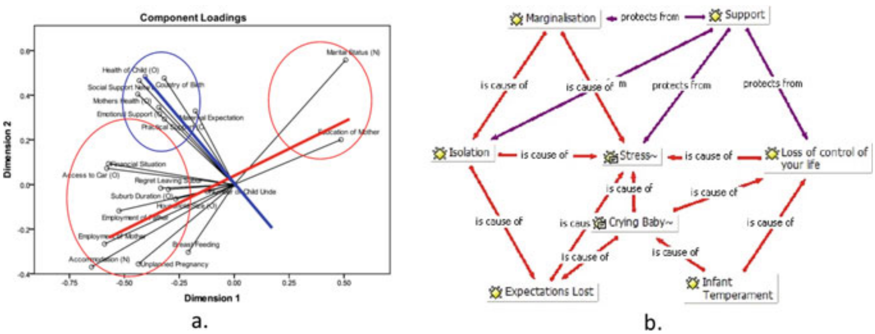


Fig. 37.10 Theory generation—**a** principal component analysis, **b** conceptual networks

37.5.2 Realist Design

The process of designing a programme intervention using critical realist causal and programme theory is not well explicated. Keller and Colleagues (2010) present a realist design evaluation framework that combines design theory and realist evaluation. Jeppesen (2005) argues that consumers and partner agencies should be included in the design process. Muntaner (1999) also argued for the use of a realist methodology that seeks to generate social interventions in partnership with the affected populations, thus moving from the study of causal mechanisms (i.e. realist causal theory) towards the applied development of implementation and programme theories.

As part of the design process, it is usual to review available and relevant causal and programme-related theory. For this purpose, a realist synthesis may be undertaken to review the available evidence on potential interventions. The review purpose is to explain explicitly how an intervention works, for whom, in which setting and why. In doing so, it helps make sense of the circumstances of interest and the interventions intended for implementation (Pawson et al. 2005). Five stages are undertaken in conducting a realist synthesis (Pawson et al. 2004, 2005). An additional sixth stage involving stakeholder engagement for theory refinement is included by some reviews (Power et al. 2019). The six stages are nonlinear and can be carried out in an iterative fashion with theory refinement occurring throughout (Fig. 37.11).

Blamey and Mackenzie (2007) propose that the Theory of Change (Connell et al. 1995; Fulbright-Anderson et al. 1998) approach can be used as a means of explicating implementation (intervention) theory for the purpose of programme planning, improvement and the development of robust monitoring systems at a whole programme level, while realist evaluation approaches can be used to examine, in detail, aspects of the most promising programme (mechanism) theories. Those programme theories describe mechanisms that reside in the “Real Domain” (Fig. 37.12).

The design process considers the historical and current context of the situation, literature on what has worked in similar situation and why, and the views of consumers and stakeholders. Consequently, a critical realist collaborative design approach might include the following five elements:

1. A historical analysis of the context to theorise the pre-existing social structures and mechanisms (De Souza 2013);
2. The proposed design elements of an intervention, stemming from inputs from consultation forums, realist syntheses, systematic reviews, consumer and key informant interviews;
3. The development of a programme theory hypothesising the pre-existing situational conditions and causal mechanisms, and specifying how the proposed intervention would trigger desired psychological, motivational and behavioural responses to bring about change (Blamey and Mackenzie 2007);

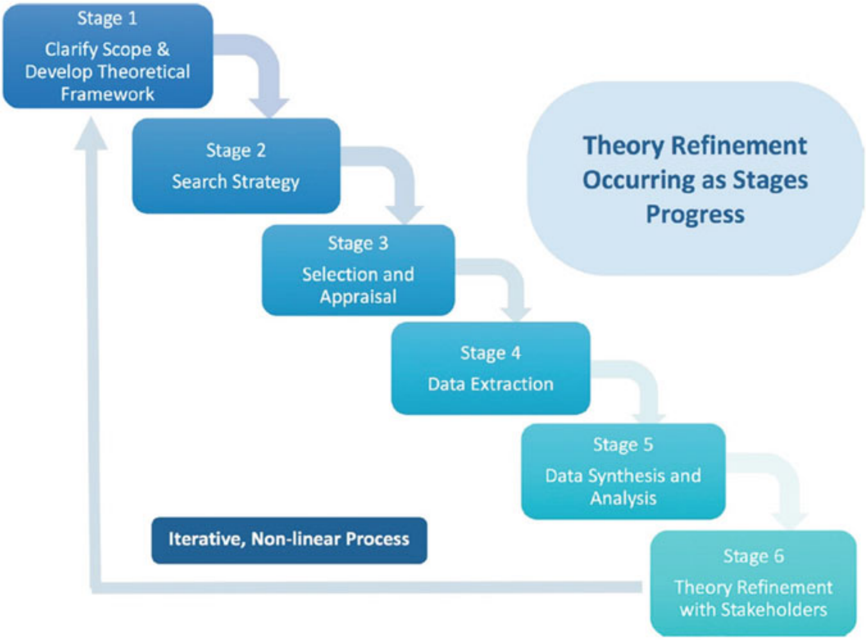


Fig. 37.11 Overview of stages of the realist review (Power et al. 2019)

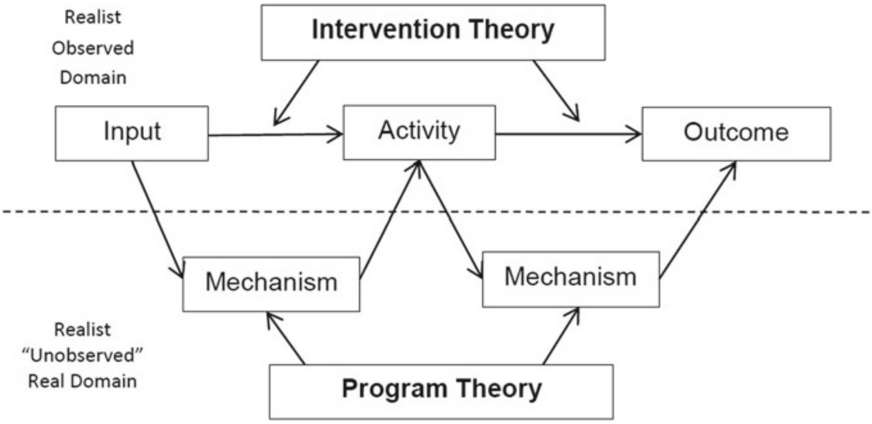


Fig. 37.12 Intervention and programme theory (Eastwood et. al. 2019d)

4. The construction of a Theory of Change (ToC) logic model explicating a proposed implementation theory (Blamey and Mackenzie 2007).

Integrated care interventions are usually “targeted” at different layers, dimensions or structures within a complex system. Consequently, it is appropriate to define hypothesised causal, intervention and programme theory for each layer (Table 37.5).

Table 37.5 CIMO propositions

Theorised contextual conditions (Fig. 37.2) [C]	Present contextual mechanisms activated [C_M]	Proposed intervention Design elements (Table 37.1) [I]	Postulated intervention Programme mechanisms (Table 37.1) [M_P]	Postulated psychological, motivational and behavioural outcomes [O]
Self—self-identity and individuals experience				
Lack of partner and family support, distrust of services, limited treatment access	Stress mechanism activated causing anxiety and depression	Friendship and family support, professional support, medication, treatment	Activate mediating mechanisms of family, peer and professional support to strengthen and build trusting relationships with peers, family and clinicians through SHV and FCISD design components	Decreased depression and anxiety
Lifetime trauma, loss, being alone, Isolation	Stress mechanism activated arising from mismatched expectations and loneliness	Family and peer support, home visiting, telephone support		Increased perceived support
Situated activity—face-to-face activity				
Services unavailable or poor access, services not trusted, services not skilled	Absence of trusted professional support mechanism	“Wrap around” services, family conferences, workforce training	Activate services mechanisms that are client, peer and neighbourhood focused, and trauma and evidence informed through FCISD and IS design components	Improved perceived access to skilled and trusted services
Community distrust, low social capital and cohesion, crime, unemployment	Absence of trusted neighbourhood and community support mechanism	“Wrap around” services, Family conferences, public health, social work services		Improved perceived support from neighbours and community
Intermediate-level social and service organisation				
Unhelpful intake and referral practices, lack of service,	Absence of specialist service support mechanism for	Strengthened pathways and design	Activate mechanisms related to trust and confidence	Improved perceived access to services that are

(continued)

Table 37.5 (continued)

knowledge and trust	front-line professionals	collocation of services	with service network, increased local social capital, community trust and community safety	"wrapped" around front-line workers
Weak social networks, community trust, community safety, available social services, access to information	Social-level stress mechanisms relating to class, position, racism, segregation, crime and neighbourhood decay are activated tending to increase psychological stress	Population and community-level interventions in neighbourhoods and communities	Activate mechanisms relating to improved coordination and access to services and information through FCISD and IS design components	Decrease in psychological stress of individuals and families
Macro-level social and service organisation				
Migration, mega-malls pull service activity away from neighbourhoods, urban development1	Activation of social-level stress mechanisms tend to hinder the activation of social-level buffer mechanisms	Population and community-level interventions in neighbourhoods and communities	Activate mechanisms related to increased social-level activities in deprived neighbourhoods	Increase in perceived social-level buffers
Immigration policy, racism, media policy, global market, settlement patterns, Ethnic bonding networks, access to services	Migrant-related social-level mechanisms including acculturation, cultural practices and integration tend to decrease social-level stress	Ethnic and cultural specific community and population-level interventions	Activate mechanisms related to increased migrant-related social activities among ethnic populations through FCISD and IS design components	Increase in perceived migrant social-level buffers

37.5.3 Realist Explanatory Evaluation

A critical realist evaluation of an integrated care intervention or programme seeks to explain, what works, for whom and under what circumstances (Pawson and Tilley 1997). The three principal phases for conducting a critical realist explanatory evaluation study are: (1) development or eliciting the initial programme theory (IPT) for the intervention under study; (2) testing the initial programme theory using empirical data and 3) building a more refined programme theory based on the empirical findings.

The approach is theory-driven, but in most other respects is similar to that undertaken with other modes of critical realist research. The main difference is that the focus is on programme theory rather than causal inference. For both purposes, theorised contextual conditions and contextual mechanisms are important, including the historical and layered context as illustrated by Layder (1993, p. 72) in his Research Map (Fig. 37.2). As noted earlier, programme theory is illustrated using context, mechanism and outcome (CMO) configurations (Fig. 4b). That diagram is expanded below (Fig. 37.13) to also illustrate:

1. The importance of the macro-context (K) (including historical context);
2. That a new mechanism is introduced (M2) or the original mechanisms (M1) is subverted by the intervention;
3. That the outcome (O) is a change demi-regularity R1 to R2; and
4. That there has been an alteration in context C1 to C2 which has led to an alteration in the balance of mechanisms triggering, or modifying, the demi-regularity.

Integrated care policy, programme and practice interventions are designed to impact on a layered set of mechanisms (Westhorp 2018; De Souza 2013). Interventions (I) may influence institutional and social structural (S) mechanisms, or the reasoning (mechanism) of targeted actors or agents (A). The inclusion of these elements into the formulation of critical realist theories can be conceptualised as: intervention-context-actor-mechanism-outcome (ICAMO) (Mukumbang et al. 2018b); context-structure-mechanism-outcome (CSMO) (Bhaskar 2014); or context-intervention-mechanism-outcome (CIMO) (Eastwood et al. 2019c) configurations.

As noted above, critical realist empirical data can be both quantitative and qualitative and with both an intensive and extensive focus. The study designs used are many but usually are mixed methods in nature.

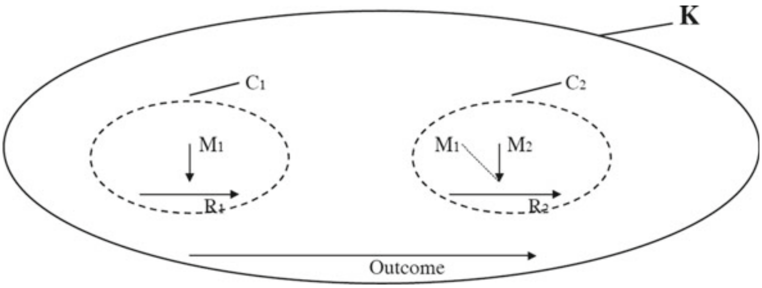


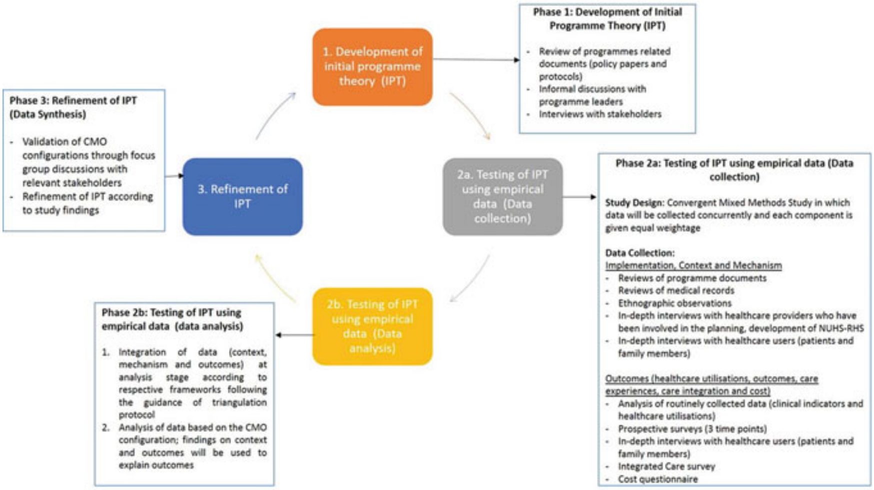
Fig. 37.13 Programme theory of change in demi-regulatory within context (Tilley 2000)

Box 2: Case Study of Realist Evaluation of an Integrated Care Network (Singapore)

Nurjono and colleagues (2018) describe a protocol for a proposed evaluation of an integrated care network, the National University Health System (NUHS) Regional Health System (RHS), Singapore, consisting of acute hospitals, step-down care, primary care providers, social services and community partners using a theory-driven realist evaluation approach. This study aims to examine how and for whom the NUHSRHS works to improve healthcare utilisations, outcomes, care experiences and reduce healthcare costs. IPT was elicited and developed through reviews of programme documents, informal discussions and in-depth interviews with relevant stakeholders. A convergent parallel mixed-method study was proposed using both quantitative and qualitative data with both data sources given equal weight (Fig. 37.14).

Box 3: Realist Evaluation Case study of an Antiretroviral Treatment (ART) Intervention (South Africa)

Mukumbang and Colleagues (2018b) describe a realist evaluation study of an antiretroviral treatment (ART) intervention in South Africa. The intervention was an adherence club designed to enhance the retention in care of patients on ART and their adherence to medication. The study design was a cross-case explanatory analysis of three contrastive sites. First, we selected three contrastive cases. (1) Typical case—the most representative of the phenomenon



Phase 1: Development of Initial Programme Theory (IPT)
- Review of programmes related documents (policy papers and protocols)
- Informal discussions with programme leaders
- Interviews with stakeholders

Phase 2a: Testing of IPT using empirical data (Data collection)

Study Design: Convergent Mixed Methods Study in which data will be collected concurrently and each component is given equal weightage

Data Collection:
Implementation, Context and Mechanism
- Reviews of programme documents
- Reviews of medical records
- Ethnographic observations
- In-depth interviews with healthcare providers who have been involved in the planning, development of NUHS-RHS
- In-depth interviews with healthcare users (patients and family members)

Outcomes (healthcare utilisations, outcomes, care experiences, care integration and cost)
- Analysis of routinely collected data (clinical indicators and healthcare utilisations)
- Prospective surveys (3 time points)
- In-depth interviews with healthcare users (patients and family members)
- Integrated Care survey
- Cost questionnaire

Phase 2b: Testing of IPT using empirical data (data analysis)
1. Integration of data (context, mechanism and outcomes) at analysis stage according to respective frameworks following the guidance of triangulation protocol
2. Analysis of data based on the CMO configuration; findings on context and outcomes will be used to explain outcomes

Phase 3: Refinement of IPT (Data Synthesis)
- Validation of CMO configurations through focus group discussions with relevant stakeholders
- Refinement of IPT according to study findings

Fig. 37.14 Realist evaluation processes and research phases (Nurjono et al. 2019) being explored; (2) deviant case—most likely case to be negative regarding the phenomenon under consideration and; (3) crucial case—a case that is critical in understanding the phenomenon. The three phases were (1) eliciting the initial programme theory; (2) testing the initial programme theory in contrastive sites; and (3) building a more refined programme theory based on the findings from the contrastive case studies Fig. 37.15.

The study initially explored a typical case, a well-performing facility as representing an ideal implementation and outcome of the intervention. The first case was used to refine the initial programme theory (Mukumbang et al. 2019c). The study then assessed a deviant case, an underperforming facility regarding the implementation of the intervention and formulated ICAMO-based theories based on the initial programme theory (Mukumbang et al. 2018a). The third case studied was an average performing facility (a crucial case) as it offered an alternative context to further refine the developing programme theory (Mukumbang et al. 2019c). Cross-case analysis was achieved by placing different within-case theories in a juxtaposition allowing for the differences and similarities to become apparent. Finally, the researchers searched for variation in the contexts accounting for the

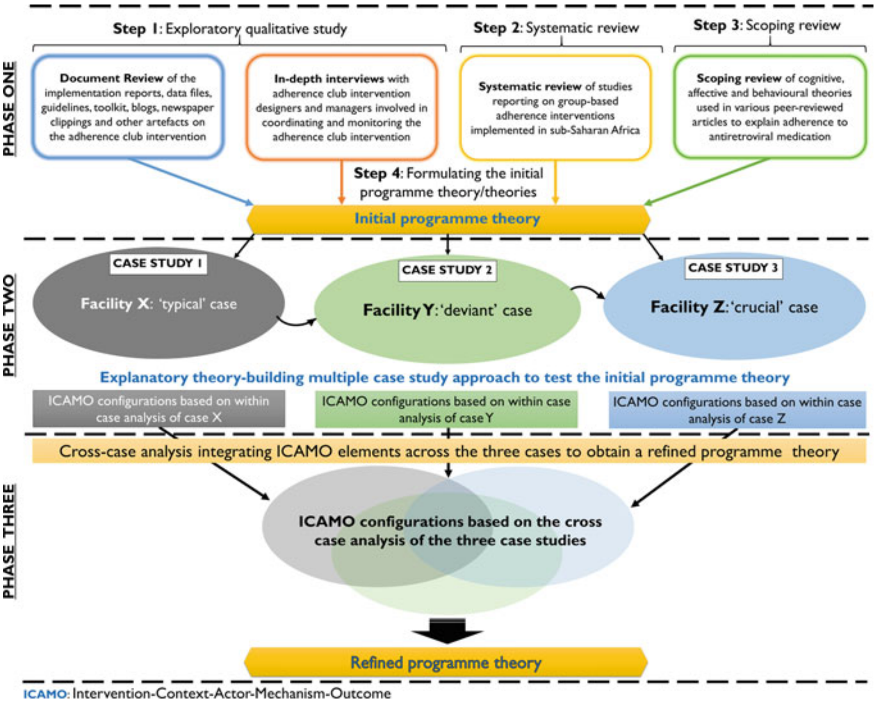


Fig. 37.15 Three phases of realist enquiry (Mukumbang et al. 2018b)

differences (if any) to generalise across cases and assessing how the most important outcomes might have been achieved.

37.6 Realist Evaluation of Complex Interventions

Campbell and colleagues described the original UK Medical Research Council (MRC) framework for evaluating complex interventions, which included sequential phases of development, feasibility testing and evaluation followed by estimation of effect size using a randomised control trial and finally full implementation (Campbell et al. 2000). The 2008 MRC guidance placed greater emphasis on the use of evaluation to build theory and understand causal mechanisms. The guidance proposed a four-phase, cyclical framework of development, feasibility/piloting, evaluation and implementation (Craig et al. 2008b). The double arrows are intentional and denote the iterative nature of the development, testing, evaluation and implementation cycle. The integration of realist principles into those MRC frameworks was described by (Fletcher et al. 2016), and realist methods are included a 2019 revision.

Box 4: Realist Evaluation Case study for a Vulnerable Families Integrated Care Initiative (Sydney)

Drawing on earlier critical realist research, Eastwood and colleagues used realist causal and programme theory to inform the collaborative design of a complex integrated care initiative for vulnerable families (Eastwood et al. 2019b). The design elements included: identification of vulnerable family cohorts; care coordination; evidence-informed intervention(s); general practice engagement and support; family health improvement; placed-based neighbourhood initiatives; interagency system change and collaborative planning; monitoring of individual and family outcomes; and evaluation.

The 2008 MRC framework for evaluating complex interventions was used to inform the realist evaluation (Fig. 37.16) (Eastwood et al. 2019a; d).

37.7 Conclusion

This chapter provides a synopsis of the empirical inquiries guided by the critical realist research paradigm. It reflects on how research designs and methods are influenced by the critical realist ontological and epistemological stance. The material presented here is meant to introduce the reader to other possible research

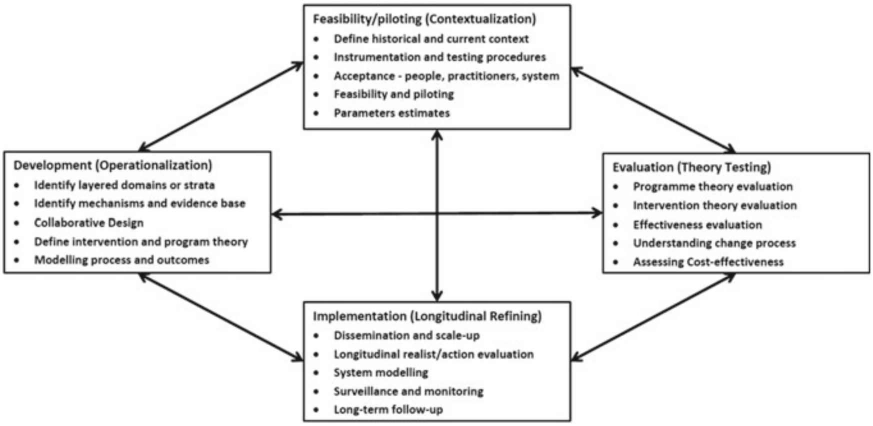


Fig. 37.16 Key elements of the development and evaluation process, adapted from (Craig et al. 2008a)

methods and what can be achieved by employing these research methods. The material is presented as a supplement to what they already know, with an aim to extend their knowledge of alternative, if not more appropriate, approaches to achieve their research and practice goals. This chapter has introduced the basic concepts governing realist-informed inquiries and practice, and we have provided references, throughout the chapter, that readers can use to inform a deeper understanding of different aspects of realist inquiries.

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Part V
Selected Client Groups

Integrating Perinatal and Infant Care

38

John Eastwood, Teresa Anderson, Nicolette Roman,
and Mariji van der Hulst

38.1 Introduction

> That “children are our future” is becoming increasingly evident as science comes to better understand the intergenerational, epi-genetic, and developmental origins of health and disease. The complex nature of child development, family, school and community environments, and the interplay of social, psychological and biological mechanisms, makes the provision of nurturing and protective services across the age ranges difficult. Approaches required during pregnancy, for example, will be very different to those provided for young people in transition to adulthood (Eastwood 2018).

It has been well established that evidence-informed health and social care during pregnancy, childbirth and the early years plays a significant role in lowering maternal and infant mortality, improving the health and wellbeing of women and promoting long-term physical, psychological and social wellbeing for the child. Despite decades of research into bio-medical, psychological, health education, organisational and policy interventions, there remains substantial evidence that

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those efforts are not achieving their full potential in either resource-poor or wealthy healthcare settings. While some of the challenges are related to equitable distribution of resources, many of the other difficulties relate to organisational and system issues. It is here that integrated perinatal and infant health and social care can make a significant impact on mortality, long-term chronic disease and the psychosocial and mental health and wellbeing of children, adults, families and communities more generally.

Much of the published research and guidance in the area of perinatal and infant care is focused on epidemiology, clinical assessment and care with a dominant focus on care in facilities. The importance of the role played by individuals, families and communities is acknowledged but often not fully elaborated. Similarly, the importance of the mental health and social protection of women, infants and their families, is often overlooked. It is in these areas that integrated care, beyond the walls of the facility, can play an important role.

38.2 Significance of Perinatal and Infant Care

Sustainable Development Goals

At the heart of achieving the 17 Sustainable Development Goals is the “Global Strategy for Women’s, Children’s and Adolescents’ Health (2016–2030)” (Every Women Every Child 2015). That strategy “envisions a world in which every woman, child and adolescent realises their rights to physical and mental health and wellbeing, has social and economic opportunities, and is able to participate fully in shaping prosperous and sustainable societies”. Building on the “Global Strategy for Women’s, Children’s and Adolescents’ Health (2016–2030)”, the “Nurturing Care for Early Childhood Development Framework” was launched at the 71st World Assembly (World Health Organization, 2018). That Framework contains five guiding principles: (1) the child’s right to survive and thrive (a Child Rights principal); (2) leave no child behind (an equity principal); (3) family-centred care; (4) whole-of-government action; and (5) a whole-of-society approach.

Maternal and Infant Survival

The development of high-quality and safe midwifery, obstetric and infant health services are arguably some of the most significant public health interventions of the twentieth century resulting in dramatic declines in both maternal and infant mortality. Despite these advances, significant challenges exist in low and middle income communities and among impoverished and marginalised communities affected by discrimination, migration and war. There also remain significant challenges in high-income countries in relation to stillbirth, prematurity, and sudden unexpected death infancy (SUDI), all of which may be associated with the social determinants of health and inequitable delivery of preventive health and social care programmes.

Life-course approach

The Barker hypothesis (Barker 1992) proposed that adverse nutrition in early life, including prenatally as measured by birth weight, increases susceptibility to the metabolic syndrome which includes obesity, diabetes, insulin insensitivity, hypertension, and hyperlipidaemia and complications that include coronary heart disease and stroke. While the hypothesis has not subsequently been supported by evidence from low-income countries, it has led to a significant scientific effort related to perinatal programming and the long-term effects of peri-pregnancy experiences on mother, foetus and infant. It is now known from both animal and human studies that prenatal stress can have adverse effects manifesting in prematurity, stillbirth, low-birth weight at term, as well as metabolic and behavioural effects across the life course.

Metabolic impact of perinatal adversity

Metabolic syndrome is a cluster of conditions that occur together, increasing an individual's risk of heart disease, stroke and type 2 diabetes. These conditions include increased blood pressure, high blood sugar, excess body fat around the waist, and abnormal cholesterol or triglyceride levels. As noted above there is increasing evidence that a person's life-course risk of metabolic syndrome may be related to the experience of perinatal foetal stress (Grieger et al. 2018). Women with metabolic syndrome in early pregnancy are at increased risk for gestational diabetes and pre-eclampsia and this in turn places the women and their infants at greater risk for cardiovascular and metabolic diseases in later life. The significance of this is that pregnancy may offer an opportunity to identify women with metabolic syndrome and increased risk of poor pregnancy and later life outcomes. There is also an opportunity to intervene in the infant's life-course trajectory. There are other metabolic impacts on the foetus that have been implicated in poor foetal and infant outcomes including: opioids, alcohol, tobacco smoke metabolites and environmental lead. All of these substances are associated with environmental and behavioural adversity and intergenerational effects.

Psychological impacts of perinatal adversity

There is a significant body of prospective research that has shown that if a mother is depressed, anxious or stressed while pregnant that this increases the risk of her infant having adverse behavioural and mental health problems across the life course. The causal pathways may be antenatal or postnatal with postnatal attachment and maternal ongoing mental health status playing a substantial role. Prenatal depression, anxiety and stress may contribute 10–15% of the attribution for emotional and behavioural outcomes (Glover 2015). The mechanisms contributing to these changes are beginning to be explored with a current focus on the role of hormones such as cortisol and serotonin (Glover 2015).

Perinatal mental health and child protection research has drawn attention to the negative impact of social exclusion, homelessness, poverty, interpersonal violence, depression, anxiety, personality disorders, addictive behaviours and intergenerational patters of harsh and inconsistent parenting on the pregnant woman, infant, father and other family members. This “toxic” home and neighbourhood environment is now understood to have a key influence on the hypothalamic–pituitary–adrenal axis (HPA axis) and intergenerational epigenetic transmission. Thus, a bio-psychosocial twin generation (even triple) approach is now considered an appropriate theoretical framework for considering early interventions. Such an approach involves concurrent interventions for children, parents and family elders.

Intergenerational approach

Thus, the life-course approach is not limited to individuals within a single generation but “should intertwine biological and social transmission of risk across generations” (Ben-Shlomo and Kuh 2002). This includes the potential role of household, neighbourhood and national influences acting across time and individuals (see Fig. 38.1). The life-course developmental approach implies that the biological, psychological and social experiences of a child’s parents, extended family, and others in their world will have an impact on the child’s life course. Parental experience of psychological trauma, poverty, malnutrition, and other adverse experiences will have both biological and psychological impacts on their child, and their own life-course health and wellbeing. Consequently, perinatal and infant interventions must address this historical context through family, neighbourhood and broader social approaches that are sustained across generations.

It is, therefore, of critical importance to identify current and previous parental adverse life experiences early in pregnancy and utilise family-focused, multigenerational approaches to optimise the child and family life course. The use of a

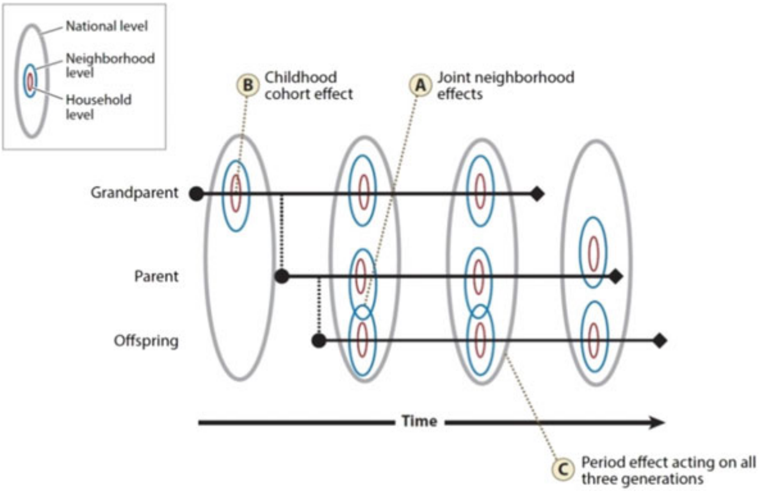

Fig. 38.1 Multigenerational schema of possible influences of hierarchical and life-course exposures on disease risk (Power et al. 2013) adapted from (Ben-Shlomo and Kuh 2002)

life-course framework is of considerable advantage for health and social interventions, as it incorporates interdisciplinary knowledge and activities, and allows both social and biological factors across the lifespan to be considered in the explanation of health, wellbeing and disease.

38.3 Challenges

The Lancet 2016 series on Maternal Health (McDougall et al. 2016) drew attention to the challenges facing women when they receive care that is either not timely or sufficient, or too much, too soon with unnecessary interventions. It noted that the challenges are evident not only in low and middle income countries but also in high-income countries. The Lancet series proposed a five-point action plan detailing steps that local, national and global communities must take to ensure good maternal health (Box 1).

Box 1: Five Point Action Plan to realise the vision of the Global Strategy for Women's, Children's, and Adolescents' Health (McDougall et al. 2016)

The Lancet Maternal Health Series proposes the following five-point action plan for all stakeholders, working in partnership to realise the vision of the Global Strategy for Women's, Children's, and Adolescents' Health:

- **Quality**: Partners must prioritise good quality, evidence-based maternal health services that respond to local needs and are capable of meeting emerging challenges. It is essential that maternal health services start with prevention (e.g., family planning, and safe abortion where legal), are context-appropriate, interlinked along the continuum of care, and capable of addressing the increasing diversity in the burden of poor maternal health.
- **Equity**: Partners must promote equity, for example through investments in Universal Health Coverage—a mechanism for achieving the 2030 Sustainable Development Goals (SDGs)—that should include a strong maternal health service core that reaches every woman, everywhere with good quality care, and without causing financial hardship and pushing families into poverty.
- **Health systems**: Partners must invest in strengthening entire health systems, including data and surveillance systems, facility capability, linked emergency medical services, and a skilled health workforce—so that they can respond to the changing contexts of women's lives and are made resilient in the face of shocks and environmental threats to maternal and newborn health.

- **Financing**: Sustainable financing for maternal health is necessary to maintaining maternal health gains and accelerating progress. With recent economic growth in low- and middle-income countries, the case for investing in health as a catalyst to both social development and economic growth is crucial to securing political attention and support.
- **Better evidence**: Better local evidence from routine audits and strengthened health management information systems is essential to improving quality of care locally—at the very frontline where women receive care. Smarter metrics are needed to capture the true burden of poor maternal health, to inform evidence-based maternal care and policy, and improve the ability of health systems to provide good quality maternal care for all. Better evidence from research will also help build a platform upon which all partners—local and global, public and private—can advocate for the mobilisation of resources, learn from programmatic successes and failures, strengthen laws and policies, and promote mutual accountability.

Universal access to services

Access to safe, high-quality and universal pregnancy and childbirth services is essential for ensuring that all women and infants have the best possible outcomes and developmental trajectory. The World Health Organisation as part of the 2030 Sustainable Development Goals (SDGs) Goal 3, Target 3.8 “universal health coverage”, recommends that every pregnant women and newborn receives quality care during pregnancy, childbirth and the postnatal period (Tunçalp et al. 2015). The provision of integrated high-quality antenatal care services is a critical part of achieving equitable, person-centred universal coverage.

In the Lancet 2016 review of the global burden of poor maternal health, Graham and Colleagues (2016) noted that SDG Goal 3 will not be achieved without reducing the burden of poor maternal health in all populations. They observed that the “highest burden of maternal mortality and severe morbidity clusters where health systems are weakest and where the broader context is challenging, such as in fragile states”. But they further observed that “in all countries, the burden falls disproportionately on the most vulnerable groups of women” (Graham et al. 2016).

Person-centered care

Freedman (2016) in her commentary on the above Lancet series argues that while “global strategies, evidence-based guidelines, or high-level monitoring and accountability initiatives are inherently wrong … they consume most of the oxygen in the room, drowning out voices and signals coming from the ground, [and] they distort both understanding and action”. In concluding she argues that the true engine of change will be “the determination of people at the front-lines of health systems—patients, providers, and managers—to find or take the power to transform their own lived reality" (Freedman 2016).

Psycho-social and social care

Most of the global and state orientated perinatal and infant health service focus is on reductions in maternal and infant mortality and dominant causes of physical morbidity, such as, diabetes, hypertension, haemorrhage, disease of prematurity and communicable diseases. Beyond these important causes of mortality and morbidity, there are significant psychological and social stresses on women and families that, in addition to their often unrecognised impact on the above physical health outcomes, also impact on matters of access, equity, person centred care, and maternal and family wellbeing.

The burden of poor maternal and infant health is concentrated among vulnerable populations; especially those who experience interpersonal violence, gender and other discrimination, financial stress, unstable housing, and humanitarian crises such as war and displacement. There is substantial evidence that exposure to adverse social determinants of health are associated with increased levels of stress, anxiety and depression.

The global response to integrating perinatal and infant health and social care continues to omit an emphasis on the psychological and social needs of women and their families. This is evident for example in the recently released WHO guidelines for antenatal care (World Health Organization 2016) and in the Every Woman Every Child strategy (Every Women Every Child 2015) documents which remain silent on the impact of behavioural and mental health, and psychosocial stress on perinatal and infant outcomes.

A failure to consider the psychological and social needs of women during pregnancy is evident in published studies on perinatal coordination. The systematic review of 33 observations studies of maternity care coordination, undertaken by Kroll-Desrosiers and Colleagues (2016) did not report on mental health outcomes. Most of the studies included in that review used a team approach to shared decision making and the review observed that social service referrals to outside organisations were common. However, neither of these approaches would be considered integrated care.

Intervention failure

A significant body of empirical research has identified interventions that are efficacious in study conditions (National Research Council and Institute of Medicine 2000; Center on the Developing Child at Harvard University 2007). But when those interventions are taken to scale, there is often a failure to achieve expected outcomes and the interventions may not have been tested with those most in need (Eapen et al. 2017; Overs et al. 2016). This may be because the intervention, when implemented in real-world settings, is not delivered with the appropriate quality, reach and uptake by end users. The interventions can be classified as universal, selected or indicated and are intended to be used based on some form of assessment of risk or need. Antenatal Care (Molloy et al.), Early Childhood Education and Care

(ECEC) (Molly et al. 2018) and Developmental Surveillance (Eapen et al. 2017; Overs et al. 2016) are "universal" interventions, while Sustained Nurse Home Visiting (SNHV) and parenting programmes are "selected" and "indicated" interventions, respectively. These interventions have demonstrated inequitable delivery (Eapen et al. 2017; Overs et al. 2016), thus identifying the need for system approaches (Garg et al. 2019; Goldfeld et al. 2003).

38.4 Goals of Integrated Perinatal and Infant Care

Based on the above, it is apparent that that perinatal and infant care should provide for the health and wellbeing of pregnant women, their infants and arguably also their partner and family members. So often the focus has been only on the obstetric and bio-medical aspects of pregnancy and childbirth. Increasingly it is clear that the psychological and social wellbeing of the pregnant woman, her husband and family are critically important to all pregnancy outcomes, including progress in labour and infant development.

The intention would not only to be to secure a safe start for women and their infants, but to also use the opportunity to support the wider family group who have supported her during her pregnancy. These family members will be important for nurturing and protecting the woman and her infant following the birth. Such an approach has inherent in it population, person-centred, and life-course elements.

Pregnancy and childbirth provide a unique opportunity for services to offer health promotion and protection to women and their family groups. For the most vulnerable women in our societies, it is often the only opportunity that health and social services have to offer person-centred support that could potentially alter the life-course of both the woman and her infant.

A structurally integrated approach to the delivery of integrated perinatal psychosocial care would go beyond a focus on pregnancy and childbirth, and the associated clinical services. It would include individual families and communities, shared intersectoral responsibility for population health and the determinants of health and empowerment of people and communities as co-producers of care at individual, organisational and policy levels (Goodwin et al. 2017, p. 5).

Box 2: Possible Goals of an Integrated Perinatal and Infant Care System

Whole of System Care

A whole of system governance system to support structural integration of health and social care:

- Collaborative planning and commissioning to ensure all women and their families receive support and protection across the continuum of health and social care

- Care coordination within the health sector (i.e. between hospital services and community health services), and within the broader interagency context
- Shared care-pathways, standards of clinical practice and streamlined communication across health, education, social welfare, housing, and criminal justice sectors to ensure vulnerable women and families receive high quality coordinated care

Population Health and Wellbeing

A universal population-based system for identifying all pregnant women.

- Identification before 20 weeks gestation
- Enrolment in a universal antenatal care system and place of delivery
- Ensure support from primary health and social care providers as required

A Universal population-based system of assessing obstetric and metabolic risks.

- Screening
- Interventions

A Universal population-based system for assessing psychosocial risks.

- Psychosocial risk questions—income, support, housing, food security
- Interpersonal violence screening
- Behavioural health assessment—tobacco, alcohol and substance use
- Mental health assessment—anxiety, depression, distress and previous mental health history of the woman and her family.

Life-course Interventions

Offer Universal evidence-based preventative and health promotion interventions to all families.

- Universal provision of antenatal and postnatal immunisation and chemical prophylaxis
- Universal provision of advice concerning nutrition, life skills, and parenting skills.

Offer selected intervention to those families who will benefit most.

- Based on risk stratification offer evidence-based interventions, including group and home visiting programmes
- Implement a process for monitoring the identification of eligible families and uptake of the programmes by families.

Person, family and community-centred approaches

- Use individual, family and community orientated approaches to encourage all pregnant women, and their families, to engage early in antenatal and postnatal services
- Contact all eligible families, invite participation, and provide where necessary pro-active assertive follow-up and engagement contacts.

38.5 Approaches to Integrating Perinatal and Infant Care

Global health perspectives

Policy frameworks and technical advice provided by WHO and UNICEF have an important impact on the delivery of maternal and child health. In 2016, WHO also released the evidence informed “WHO recommendations on antenatal care for a positive pregnancy experience” (World Health Organization 2016). In a related commentary, De Masi and Colleagues (2017) observe that “integrated high-quality antenatal care (ANC) services are a critical part of the global agenda of achieving equitable, people-centered universal health coverage”. While on first reading the guidelines seem to offer little guidance of relevance to integrated care, there are recommendations related to community-based interventions and the shifting of promotion of health-related behaviours for maternal and newborn health to a broader range of cadres, including lay health workers, auxiliary nurses, nurses, midwives, and doctors. While not explicit, this guidance encourages a multidisciplinary approach to antenatal care with involvement of a lay and un-registered workforce.

Previous WHO guidance, released in 2010, had called for person-centred, integrated care, in the report “Working with Individuals, Families and Communities to Improve Maternal and Newborn Health” (2010). The aims were to be achieved through strategies of education, community action for health, partnerships, institutional strengthening and local advocacy, implemented largely in the settings of household, community and health services (Fig. 38.2).

The application of these integrated perinatal and infant approaches is exemplified by the Zoe Project in Western Cape, South Africa (Box 3).

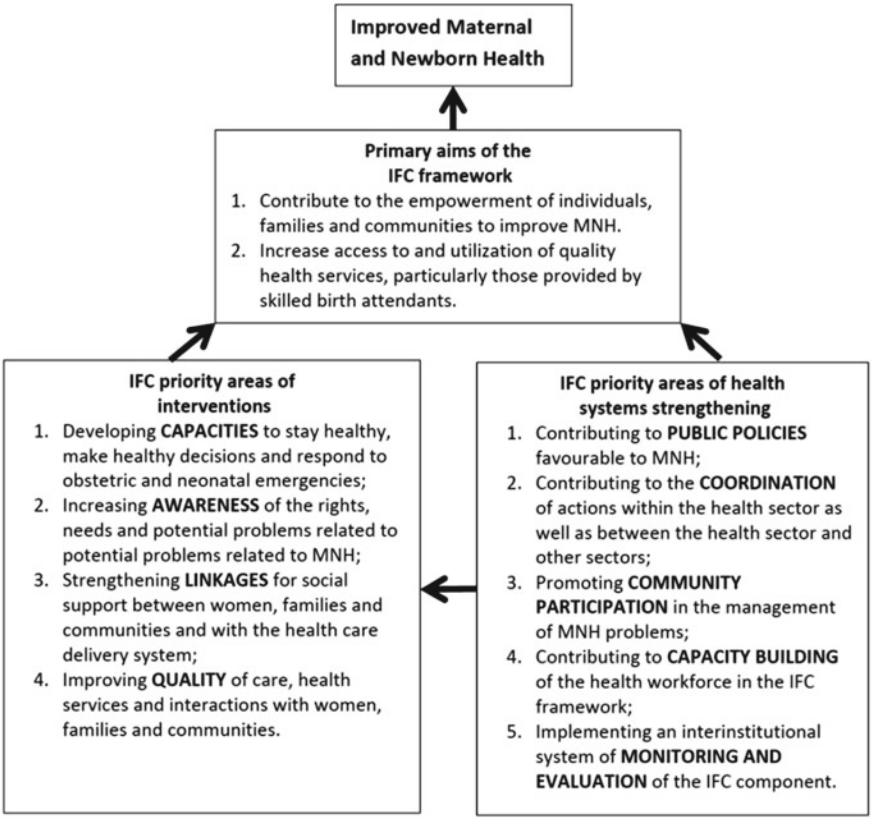

Fig. 38.2 Individual, Family, Community (IFC) framework objectives and priority areas, adapted from (World Health Organization 2017)

Box 3: The Zoe Project—Western Cape, South Africa

https://thezoeproject.co.za/

The guidelines for maternal health care in South Africa (2015) place maternal care as a priority and a free service in South Africa. Furthermore, the focus of the guidelines is to provide key medical approaches and strategies to reduce the risk of maternal death, and to improve the quality of perinatal care for both mother and baby. Concurrent to these national guidelines, the Western Cape Department of Health also provides a booklet for pregnant mothers "Caring for Mothers: Caring for You—Information, suggestions and support for mothers and their carers". This booklet highlights the importance of both health and social care for a healthy and safe pregnancy, and addresses a range of subjects including the role of fathers, mental health, substance abuse, violence, and infant mental health. In South Africa, the strength of care is found in a community approach to health care, with the government and private sector aligning with community-based organisations to provide a holistic approach to maternal care. The Zoe Project is one such example.

> *The Zoe Project believes that healthy, educated and empowered women can support healthy babies – breaking the cycle of poverty and abuse.*

The Zoe project was founded in 2002 by Tracey Aitkin, who is the current Director of the project. The project is linked to a Maternity Obstetric Unit

(MOU), providing holistic care to mothers in a low socio-economic community often at risk of psychosocial challenges. These challenges include poverty, unemployment, food insecurity, substance abuse, violence, and limited access to health care. The vision of the Zoe project is to strive for the health and wellbeing of mothers and babies. To achieve this, the Zoe project (1) educates pregnant women and new mothers not solely about health and wellbeing, but also about their rights to inform good decision-making; and (2) empowers women through counselling and support; and (3) nurtures women through provision of basic resources and perinatal support. Thus, while the health needs of mothers are monitored and cared for by staff at the MOU, the Zoe project focuses on the provision of social services such as adoption, counselling and substance abuse support.

Targeted Approaches

The review of integrated perinatal care undertaken by Rodriguez and Rivieres-Pigeon (2007) identified three main groups of studies: management of normal pregnancies by physicians; management of normal pregnancies by midwives; and management of high-risk-pregnancies. For this third group, they identified three strategies that seemed useful for adapting services and making them more accessible:

1. Ensuring continuity of care with personalised continued management that encouraged a “bond of trust”
2. Working in multidisciplinary teams mainly within the same institution but with an increasing use of care coordinators to put women in contact with social providers
3. Clientele-adapted services where services were adapted the health, culture and living conditions.

Again those three approaches would not by themselves be considered integrated care. Rodriguez and Rivieres-Pigeon (2007) observed that for women living in conditions of severe poverty they were sometimes difficult to reach. In those situations, home visits were used to reduce access obstacles and to offer both psychosocial support and personalised assistance in accessing various organisations and services (Buescher et al. 1991). In concluding their review of integrated perinatal care Rodriguez and Rivieres-Pigeon (2007) argued that “improvements in perinatal health care delivery appear related not to structurally integrated health care delivery systems, but to organizing modalities that aim to support woman-centred care and cooperative clinical practice”.

Rodriguez and Rivieres-Pigeon noted an exception to this among the studies they reviewed was the North Carolina Baby Love Program for Medicaid-covered women (Box 4). In Rotterdam, a holistic programme, The Mothers of Rotterdam, was developed in close collaboration between the university hospital, the local government and a non-profit organisation with the aim of organising health and social care from pregnancy until the second birthday of the child (Van Der Hulst et al. 2018) (Box 5).

Box 4: North Carolina Baby Love Program (Buescher et al. 1991).

North Carolina Baby Love Program

Maternal Support Services in North Carolina, USA, also known as the “Baby Love Program,” are available to Medicaid-eligible pregnant women during and after pregnancy (60-day postpartum period).

- Childbirth Education is a series of classes to help pregnant women and their support person to understand the changes experienced during pregnancy, to prepare for the labour and delivery experience, and to understand the postpartum period.
- Health and Behaviour Intervention provides counselling and emotional support when you are stressed.
- Medical Home Visits for mother and baby are conducted by qualified staff, and include referrals to other programs like nutrition and dietary evaluation, dental care, counselling and family planning.

https://medicaid.ncdhhs.gov/medicaid/get-started/find-programs-and-services/maternal-support-services

Buescher and Colleagues (1991) described the background to the “Baby Love Program” which involves the employment of maternity care coordinators to work with vulnerable populations of pregnant women and their families.

“In October 1987, in response to concerns over North Carolina's high infant mortality rate, the state Medicaid program was expanded to improve access to health care and support services for low-income pregnant women and young children. This expansion, referred to in North Carolina as the Baby Love Program, was developed and implemented by the Division of Maternal and Child Health and the Division of Medical Assistance, in cooperation with the Office of Rural Health and Resource Development. Two key elements of the Baby Love Program were the expansion of Medicaid eligibility to 100% of the federal poverty level and reimbursement for maternity care coordination (case management) services for Medicaid-eligible pregnant women” (Buescher et al. 1991).

“Maternity care coordination is the cornerstone of the Baby Love Program in that it is aimed directly at eliminating barriers to client use of services. Maternity care coordinators help eligible women receive services that address not only medical but also nutritional, psychosocial, and resource needs. Coordinators also provide emotional support, which may lead to stress reduction and the adoption of healthful behaviours during pregnancy.

In North Carolina, all pregnant women certified for Medicaid are eligible for maternity care coordination services. This entire population is considered to be at high risk for poor pregnancy outcomes, owing to either medical or psychosocial risk factors, or a combination of the two" (Buescher et al. 1991).

The results of an evaluation published in 1991 suggested that maternity care coordination can be effective in reducing low birth weight, infant mortality, and newborn medical care costs among babies born to women in poverty (Buescher et al. 1991). Subsequent studies published in 2018 confirmed those earlier findings and found increases in antenatal care visits, family planning attendances and participation in the Women Infant and Children (WIC) programme (Hillemeier et al. 2018).

Box 5: Mothers of Rotterdam

Mothers of Rotterdam

https://bmjopen.bmj.com/content/8/3/e020199.abstract

Having a low socioeconomic status is known to be related to ill-health, and individuals in these circumstances are more vulnerable to adverse health and economic outcomes. In the case of pregnancy, this vulnerability does not only affect the health of the mother, but also influences the growth and development of the (unborn) child. Vulnerable populations are usually hard to reach and known to be hesitant to seek care. Pregnancy can be seen as a window of opportunity to reach these vulnerable women, since pregnancy is a pivotal time when women are more motivated to improve or optimize the situation they are living in. To optimize care for highly vulnerable pregnant women in Rotterdam, a holistic care program was developed in which the social and medical care domains joined forces. This program provides a holistic care approach in which adult and child issues are targeted simultaneously, through integration of medical and social care for highly vulnerable pregnant women and their families. Care is provided from pregnancy until the second birthday of the child.

The program is divided into three main phases:

1. Reducing acute stress by taking over pressing actions from the mother, such as preventing home evictions and arranging health insurance.
2. Creating a calm and more structured environment, in collaboration with the mother, to enable the development of a secure mother–child relationship and to promote healthy infant development. This is achieved by implementing a daily structure, a healthier lifestyle, and allocating specific time for positive mother-infant interactions.

3. Enhancing parenting skills and sensitivity of the mother to the needs of her infant, through specific parenting advice and training. Simultaneously, the program seeks to promote the mother's autonomy, encouraging her to actively participate in society through (volunteer) work or education.

The intensity of the Mothers of Rotterdam program is initially high, with two home visits a week, decreasing gradually over time to one home visit every two weeks. Social workers employ an approachable and non-authoritarian communication style to gain mothers' trust, which is vital for those who have experienced negative interactions with condescending and judgmental care professionals. By close collaboration with the social worker, a mother can expand and practice her skills in a safe environment that builds her self-esteem and self-sufficiency, to make care and support of the program no longer necessary.

While the emphasis is on social care in the home environment, compliance to medical care is strongly encouraged. Care providers promote a healthy lifestyle and regular visits to the community midwifery during pregnancy, in addition to visits to a general practitioner or medical specialist when indicated, and regular visits to the preventive child healthcare centers (to monitor children's health and development after birth and to get immunisations). By doing so, the program aims to reduce avoidance of care and to promote preventive health behavior.

The Mothers of Rotterdam program was developed in close collaboration between the Erasmus MC University Medical Centre Rotterdam, the municipality of Rotterdam, and the Stichting de Verre Bergen (a non-profit organisation). The effectiveness of the program is currently being investigated by the Erasmus MC.

Universal Whole-of-System Approaches

The importance of perinatal and early childhood interventions was increasingly recognised during the 1990s by policy makers across governments in high-income countries (Eastwood et al. 2019a). The policy response acknowledged a requirement to intervene across government sectors and civil society utilising both evidence-informed interventions and integrated structural and process strategies within complex public sector systems (Eastwood et al. 2019a). Those early initiatives included Healthy Families America, Strengthening Families and Family

Start in New Zealand, Sure Start in the UK, and Families First and Best Start in Australia (Schmied et al. 2010).

In their literature review of collaboration and integration of service delivery for pregnant women, children and their families, Schmied and Colleagues (2010) noted that where services were well coordinated or integrated at a local level, there was a positive impact on families. The types of approaches reviewed included:

1. **Shared Antenatal Care**: responsibility for care is shared between different health professionals;
2. **Liaison positions**: the primary purpose of liaison positions is as “a communicator”, establishing and maintaining communication between services and different professionals;
3. **Multidisciplinary teams**: teams of different professionals working together with common goal of improving outcomes for a pregnant woman and her family;
4. **Care coordination**: one person identified as the coordinator/case manager of services for the family. This is most often an extension of the multidisciplinary team; and
5. **Co-location of services**: related services are physically located within the same or neighbouring facilities.

Schmied and colleagues identified that “biggest challenge to collaboration and integration is for agencies/services to overcome the underlying tensions arising from their pre-existing assumptions about other services and issues of trust between services/professional groups”. They argued that “these challenges underpin the importance of developing a shared framework and philosophy at the outset” (Schmied et al. 2010).

Schmied and colleagues also noted that the key elements of successful collaboration included: (1) shared vision and values; (2) inspirational and energetic leadership; (3) sound governance, clarity of leadership and assessment of risks; (4) capacity to address issues of power and achieve an equitable distribution of resources; (5) a willingness to share risks and problems as well as any positive outcomes; (6) evaluations to assess effectiveness and cost-effectiveness; (7) the need for frequent and effective communication; (8) mechanisms to facilitate sharing of information and administrative data as appropriate; and (9) understanding of participants’ practice, philosophy, culture, ideas and beliefs. An example of the application of whole of system collaboration in Sydney, Australia, is described in Box 6 below.

Box 6: Healthy Family Healthy Children, Sydney Local Health District, Australia

https://www.slhd.nsw.gov.au/hfhc/welcome.html

The Australian state of New South Wales (NSW) implemented an early childhood (0–8 years) and family focused interagency response, called *Families First,* in 1998 (Churchill and Fawcett 2016). The NSW interagency response attempted to improve health, development and wellbeing outcomes through the implementation of a wide range of multi-faceted elements in health, education, local government and social care sectors.

The Sydney Local Health District, responsible for delivering health services in inner west Sydney NSW, was established in 2011 and the following year the District commenced a program of collaborative interagency work to address the unique needs of children, young people and their families. An early focus of that work was on the special needs of families living with increased psychological and social stress (Eastwood et al. 2019b; c). A whole of system approach was utilised to integrate care during pregnancy and the early years.

The three main interagency and interdisciplinary outputs were: (1) an Inner West Sydney Child Health and Wellbeing Plan; (2) the Healthy Homes and Neighbourhoods Integrated Care Initiative; and the (3) Healthy Families Healthy Children Initiative. The key design elements and activities are shown below:

Design element	Key activities
Maternal child and family services	• Antenatal screening, risk stratification, perinatal pathways and coordination • Person-centred sustained nurse home visiting commencing before birth • Second tier allied health and medical services, pathways and coordination, including interagency education, justice and social care providers • Universal maternal, child and family health services with proportionate support according to need
Family and community integrated service development	• Integrated interagency service models including wrap-around and family group conference models • Targeted antenatal and postnatal transdisciplinary parent support programmes • Antenatal substance use and domestic violence early intervention • Interagency shared-care support for socially high risk families • "Hub" and "place-based" community building and service coordination • Universal family and community capacity building (health and wellbeing promotion)
System infrastructure support	• Perinatal, child and family public health (epidemiology, programming, research and evaluation) • Interagency system change strategies • Interagency service capacity building • Shared leadership, governance, collaborative commissioning and project management

38.6 Conclusion

We have drawn attention in this chapter to the importance of creating a nurturing start to a child's life and the role that families, neighbourhoods and society as a whole play in creating this "nest". Often the care that is provided is focused solely on the physical health (medical) domain with neglect of the psychological, material and social needs. The focus is often on only one aspect of the mother's needs, or is ignoring an important contribution that can be made by fathers and other family members. We have sought, therefore, to stress the importance here of focusing on the whole family as partners in the care of mothers and their infants.

It is here, also, that a multidisciplinary and multi-agency approach is helpful. As noted earlier a structurally integrated approach to perinatal and infant health and wellbeing should go beyond a focus on pregnancy and childbirth, and associated clinical disciplines. Integrated care should strive to include individuals, families and communities, to share intersectoral responsibility for population health and the determinants of health, and to empower people and communities as co-producers of care at individual, organisational and policy levels.

Therefore, a shared understanding that supporting, protecting and nurturing pregnant women and their infants is a shared responsibility of everyone is required. The biggest challenge, as observed by Schmeid and colleagues, is to overcome the tensions that arise from pre-existing assumptions about the contribution that can be made by other services and professional groups.

Society values the start of a new life, but often fails to provide a supportive "nest" that will protect and nurture. It is here that integrated care can play an important role in providing a policy response to the provision of appropriate housing, nutrition, emotional support and clinical care at a time of transition when families are perhaps their most vulnerable.

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Children

39

Ingrid Wolfe and Rose-Marie Satherley

39.1 Challenges in Providing Care for Infants, Children and Young People

The epidemiological transition towards chronic conditions applies to children[1] just as it does to adults and the elderly. Health systems need to adapt to provide more and better quality planned care, health promotion, disease prevention, and health policies that address the upstream determinants of chronic disease. Yet countries struggle to shift the focus of healthcare away from acute and urgent reactive care, so the hospital-centric health model continues to dominate. A wide variety of government and non-governmental strategies are focused on developing integrated care services as a way for health systems to adapt to meet current and evolving needs more effectively and efficiently. However, the majority of these initiatives are tailored to the needs of adults or the elderly, with scarce consideration for the distinct needs of children and young people.

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[1] The term children will be used for brevity and convenience, but all the stages of early years from birth, including infants, children, and young people should be understood unless otherwise specified.

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There is convincing evidence that the greatest long-term population health gains come from improving health at the earliest stages of the life course (Marmot 2012; Waldfogel 2004). Child health differs in important and sometimes subtle ways from the rest of the population. The relative importance of health, education, political, and economic systems varies with age and developmental stage and they also interact to shape and influence health differently across the stages of the life course.

More narrowly, paediatric medicine, which was once considered a subset of adult medicine, has evolved into a sophisticated specialty with different knowledge and skills required for different stages. Preterm and term newborns, infants and toddlers, children, adolescents, and young people are increasingly recognised as having distinct and often different health needs (Forrest et al. 1997). There are specific diseases of childhood, and in addition children may manifest illness symptoms and signs differently from older children and adults. The trajectory of acute illness often differs too, rapid decline and recovery being common features. While older adults and the elderly population frequently suffer from multiple co-morbidities and may be dependent on social care, these are rare circumstances among children (Wolfe et al. 2016). The demography of early life differs from later years too. For example, children are especially sensitive to the effects of social and economic conditions and in many countries more children live in poverty and social disadvantage than adults and the elderly (Eurostat 2013). Children, especially at younger ages, are dependent on their parents or care-givers to seek health care, to communicate their health needs and experience of care, and to administer medicines and other interventions. Finally, all the factors described here differ according to developmental stage.

The distinct health and healthcare needs of children merit different service, system, and policy responses. For example, a good balance between access and expertise in primary care may require different conditions for children reflecting the different skills required by generalists and specialists in caring for children. Furthermore, while the policy drivers for integrated care among the elderly reflects the interdependence between health and social care, most children do not require social care support, so their integration needs are different. A child-centred approach to integrated care is needed.

39.2 Goals of Integrated Care for Children

Children's health needs are changing as a result of the transition to chronic disease. These changes are reflected in trend data showing that an increasingly large proportion of deaths and the majority of the burden of disease in early years are caused by chronic and non-communicable conditions (Wolfe et al. 2013). This is similar to what is happening in the rest of the population, but there are important differences that mean different policy responses are needed. Most children are healthy and well, and have occasional acute illnesses and simple chronic conditions; so cure or support to enable the best possible quality of life and development are the goals. Therefore, integration between primary and secondary care, and between health and

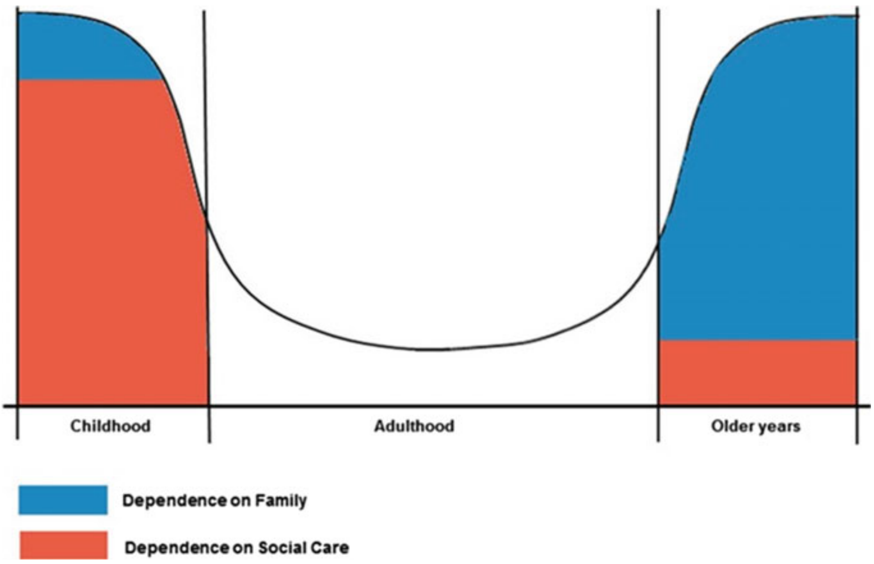

Fig. 39.1 Differences in integrated service needs and policy drivers between children and older people (Wolfe et al. 2016b)

education services, including services that promote early childhood development, is important to the majority of children and young people. By contrast, integration between health and social care services which is an important need for older adults is required by only a small proportion of children who have complex conditions, as most children are dependent on their families for care, as illustrated in Fig. 39.1 (Wolfe et al. 2016).

Family-friendly services are important in the early years, to ensure the context of care is appropriate to need (British Association for Child and Adolescent Public Health and British Association for Community Child Health 2014). But there are similarities between the young and the old too. Children's health is shaped partly by healthcare, but wider social and economic factors are very important determinants. Therefore, integrated healthcare in the context of a strong health system and healthy policy is important for the early years' population.

39.3 Value Proposition of Integrated Care for Children

The United Nations Convention on the Rights of the Child (UNCRC) specifies the right to the highest standard of healthcare, and to a standard of living and social security that enables their physical, mental, and social development (United Nations Convention on the Rights of the Child 1990). The value of integrated care for children and young people lies in securing some of the conditions towards realising the rights articulated in the UNCRC. The ultimate goal of integrated care should be about improved health and care services to ensure optimal health development for each child, and delivering maximal health gain at the population level. From the child and family's perspective this simply means the right care, at the right time, and in the right place (British Association for Child and Adolescent Public Health and British Association for Community Child Health 2014). The value proposition of integrated care can be more specifically articulated by considering how children and their families need and use services in the real world: when they are well, have acute illnesses, or chronic conditions. Moreover, children at each life stage within the early years will have different requirements for each scenario, and vulnerable children need special consideration towards achieving equity of access and outcome.

Children who are well need services that help keep them well, promote health and development and prevent disease. Integrated care for this group of children means population and individual level public health services delivered as conveniently as possible in school, home, and community settings where healthy children spend most of their lives. It also means healthy public policy and a strong health system. A life-course approach to planning and providing holistic and integrated services for children, to keep children well, is important. For example, promoting social, emotional, and speech and language development for infants is quite a different service from youth worker support for adolescents who may be engaging in excessively risky health-harming behaviour. Integrated services for well children means population health and policies providing a strong foundation for health and development, in concert with health systems and services when needed.

All children develop acute illnesses from time to time. While most illnesses are minor and self-limiting, universal access to urgent care delivered by professionals who are competent in differentiating between minor and serious illness in children is important. Children's acute healthcare is often considered especially challenging, partly because of the differences between adults and children described previously, but also because the changing family structures in many cultures mean fewer children are raised in extended families, so parents may lack the close support of experienced relatives to help them manage minor childhood illness. These factors, together with the rising public expectations of medicine and an increasingly risk-averse society, may help explain why normal childhood conditions and complaints are increasingly medicalised, reflected in more frequent care-seeking behaviour for minor problems.

Integrated care for children with acute illnesses means achieving a balance in first contact care between access and expertise in child health. In practice, this means primary and secondary care (or generalists and specialists) working well together in community and hospital settings. Because first-contact care performs a gate-keeping role in health services, effective integration between primary and secondary care for children is also important for enabling the rest of the health service to function optimally. This is an example of vertical integration, between tiers of healthcare providers. Different professionals will need to work in integrated child health teams depending on the developmental stage. Nurses and doctors who provide care for infants may require different skills from those looking after children in their middle years, and different again in adolescence and early adulthood.

Children with usually simple chronic conditions, such as asthma and diabetes, need preventive, proactive, and coordinated healthcare, and accessible urgent care to manage problems and exacerbations if they occur. Ensuring proactive care, prevention, and early intervention, for children with chronic conditions can be challenging, and the resultant exacerbations of diseases such as asthma, may be one explanation for the continual rise in demand for urgent hospital care (Cecil et al. 2018). School staff should be able to assist with administering daily medicines. Children with complex and multiple chronic conditions form a small part of the child population, but they have high needs. For example, a child with epilepsy who has neurodevelopmental delay and difficulties with feeding and toileting may need several medical and therapeutic specialties to be involved and may need extra help at school. Multiple agencies, organisations, and professionals may be involved in providing care for children with complex needs, and coordinating services can be a major undertaking, described by many parents as a full time occupation. Integrated care for children with chronic conditions means vertical integration between healthcare providers, and horizontal integration between health and education for many children, and for those with complex conditions, horizontal integration with social care too. For children living with any chronic condition, integration between health and education is crucial, and means schools playing a meaningful role in child health and wellbeing.

The health and care needs of children with chronic conditions may evolve as the child develops, and adolescents who may be used to child-centred care suddenly find that there are different expectations in adults' healthcare. The transition between children's and adults' services, for adolescents with chronic conditions, is a particularly a vulnerable time. For example, older adolescents with diabetes may develop complications of their disease reflecting less effective management during the transition to adulthood and adult healthcare. Children with chronic conditions need integration in a longitudinal dimension, across stages of the life course so that services are coordinated and evolve according to the child's development (Halfon et al. 2007).

Integration is truly comprehensive when it links public health, population-based and patient-centred approaches to children's health care, when it serves the needs of whole populations. Integrated care for children is complex; indeed four dimensions of integrated care may be described, as shown in Fig. 39.2: vertical, between tiers of healthcare; horizontal, between health and education or social care sectors; longitudinal, across the life course; and population integration between health, public health, and wider policy. The diagram shows also the different ways these four dimensions might be needed at different stages within the early years of life.

Comprehensive integration would require policy coherence to produce an integrated delivery system, alignment of functions and activities including payment and incentive systems, information technology, and regulatory systems, and cultural change among professionals and families (Nolte and McKee 2008; Curry and Ham 2010). Whole systems thinking underpins such a comprehensive approach to

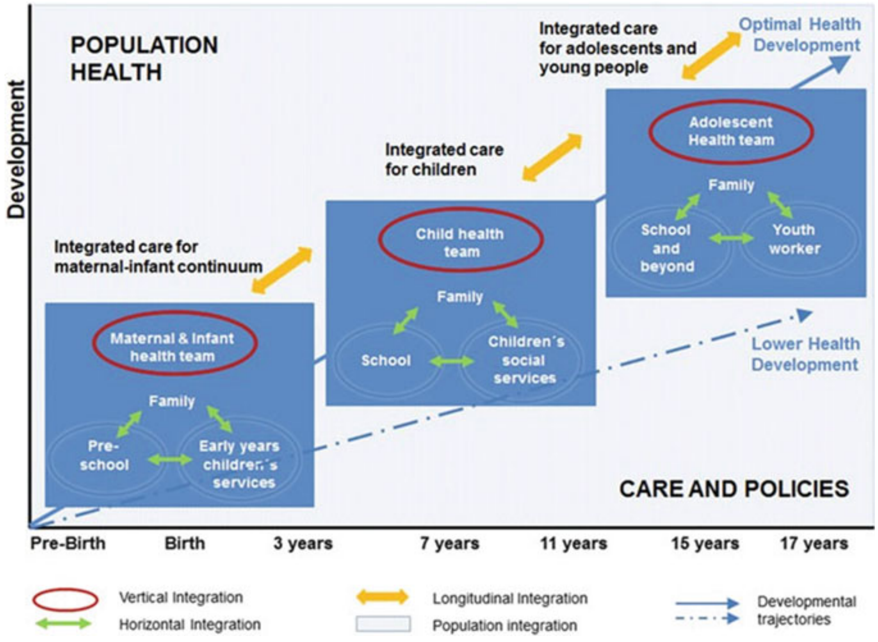

Fig. 39.2 Four dimensions of integration for a comprehensive approach towards strengthening health systems for children to achieve optimal health development. (Wolfe et al. 2016b)

integrating care (de Savigny and Adam 2009) and may be delivered through. Population. Health approaches to systems, as described in the next section.

Achieving an appropriate balance between all four dimensions of integrated care for children begins by considering health at the population level. Child health can be described along a normal distribution curve. The middle part of the bell-shaped curve describes the majority of children, who are healthy and well most of the time and have occasional acute illnesses. Increasing numbers of children in this group also have chronic conditions. The two tail ends of the curve describe the smaller proportions of children who are either very healthy, or very unhealthy. This distribution of child population health is different from elderly people who often have multiple chronic conditions and high social care dependence. A population health curve for older people would be skewed to the right, since a larger proportion of the population has ongoing illnesses, and fewer people are healthy and well. The need for integrated care between young and older populations varies, as described earlier, and not surprisingly the policy drivers are different too. Integrated care for the elderly is much more about cooperation between health and social care than it is for children. If social and health care fail to work smoothly together, elderly people end up staying in hospital longer than necessary waiting for social care interventions to be put in place so they can safely go home. Hospitals therefore have a strong incentive to ensure social care services are efficient and effective and that care packages are planned together. A similar scenario applies only to a small proportion of children with complex conditions.

Minor acute illnesses are common in children, but it can be challenging to distinguish between minor and serious illness, and a wide range of care may be required. These points are highlighted by two contrasting conditions. First, a child with fever and rash could have a common self-resolving childhood illness, or life-threatening meningococcal disease. A highly accessible front-line service is needed, with expertise and experience to distinguish common from rare. Secondly, childhood constipation, which is usually not caused by an underlying serious problem, but can be, does often result in significant distress. Moreover, common constipation requires an approach to care that goes beyond medicine and includes advice and sometimes support for nutrition and physical activity, which acute care services are typically not designed to provide. These scenarios emphasise the fact that unscheduled care services necessarily take precedence over planned proactive care, because of the risks involved in caring for acutely and potentially seriously ill children. However if first contact primary care is not as effective and efficient as it should be, and if primary and secondary care services do not cooperate closely, the inevitable consequences are excessive and avoidable use of hospital and secondary care services through high referral rates or parents bypassing primary care, resulting in unnecessary expense, and suboptimal quality and experience of care. With limited resources, the ineluctable result of excessive use of unscheduled care for children is that human and financial resources are directed away from planned proactive care. This failure-demand cycle is one reason why health systems are struggling to adapt to the epidemiological transition to chronic conditions. For the majority of children, the value proposition of integrated care for children is different from the elderly population; integrated primary and secondary health care, and effective integration with education are the key features to achieve for improving healthcare for children.

Comprehensive integrated services for children should improve care compared with the traditional service models, solving problems of imbalances between access and expertise in first contact care to improve effectiveness and efficiency and redirect resources to planned proactive care for children with chronic conditions. Fully integrated care should improve population and individual level services and ultimately improve child health.

39.4 From Services to Systems: Integrated Care and Population Health Management for children

Population health management (PHM) is about improving the health of the entire population, through data-driven planning, provision of services and the ways in which individuals interact with those services, which should improve both equity and quality of care. Integrated care systems can be a means towards achieving PHM.

The rise in chronic disease and long-term conditions among children and young people mean that it is vital that health services engage with social, political, and commercial determinants of health. A third of children in England are obese by the time they leave primary school (NHS), and the rise in obesity-related disease is already causing a significant strain on health systems. By 2022/23, we also expect to treat up to a further 1000 children a year for severe complications related to their obesity, such as diabetes, cardiovascular conditions, sleep apnoea and poor mental health. These services will prevent children needing more invasive treatment. The risk of developing type 2 diabetes is up to six times higher in certain Black, Asian and Minority Ethnic (BAME) groups. Expanding the Diabetes Prevention Programme By 2022/23 in England, the NHS is preparing to treat an additional 1000 children with severe obesity-related complications including diabetes, cardiovascular disease, sleep apnoea, and mental ill health. Many chronic conditions among children and young people (CYP) are socially patterned; they affect CYP in poor communities much more than those living in wealthier areas (Strategic Review of Health Inequalities in England). So access to healthcare is often even more challenging, and the social determinants of health may be experienced more strongly too. This is the case for conditions ranging from asthma to obesity. Poor children are more likely to be affected by either condition, than richer children, more likely to struggle with accessing care, and live in an environment that affects their condition—polluted air or obesogenic environments, both of which are clustered in deprived areas (Pillas et al. 2014; Dixon et al. 2005; Marmot 2010).

What are the essential ingredients for population health management? Broadly, data for understanding population needs, and a means of improving the conditions for health, from structural determinants to health care. Integrated care systems should enable effective collective action to improve health. An inter- and intra-sectoral governance mechanism is needed for decision-making and accountability (Schröder-Bäck et al 2019). And an integrated care system should deliver comprehensive or holistic care for individual patients, provide joined up pathways and networks of care, improve health of the population, and facilitate a cycle of translating data to action that serves continuous improvement.

The asthma scenario exemplar used in the previous section can help illustrate some of the challenges which a population health management system can help address. A proportionate universalist approach to healthcare exemplifies a PHM approach, balancing the needs of the individual with the population. This is effectively delivered in many countries in preventive and primary care services such as immunisation and screening. These public health principles can be applied to develop a PHM system for integrated healthcare too. For example, a novel PHM system is currently being tested in England. The aim is to use data to and integrated delivery systems to improve access by reaching out to children before they present for health care in order to deliver early intervention (Newham et al. 2019). Primary care patient lists are used to identify children, for example with asthma, then by adapting the primary care call–recall system used in immunisation and screening, invite them to participate in early intervention. Parents use a cloud-based portal to complete a biopsychosocial preassessment, and the data can be used to triage and tailor care, so that clinicians understand the physical, psychological, and social needs of the family. Multidisciplinary care can then be delivered according to need, and closer to home, avoiding the need for children to travel to hospitals. Early results from the parallel service evaluation [run alongside the cRCT due to report in 2021 (Newham et al. 2019)] suggest improved health, quality of care, and reduced dependence on acute care (Wolfe et al. 2019), and also improving access to care and early intervention. A high proportion of children in a sample of over 4000 children being reached through the PHM system have unmet health needs: 60% of children with asthma have poorly controlled symptoms that require clinical intervention. Early evidence and feasibility testing also suggests that the PHM system may be reducing socio-economic inequities in access to care: the system is reaching high proportions of children from the lower quintile of socio-economic groups and Black and Minority Ethnic populations who access care, closely matching the resident local population.

Population health management may be a useful means of delivering integrated care systems that improve outcomes for patients and populations. However, these concepts are only beginning to be applied in practice for the child population, and evidence remains preliminary.

39.5 The Integrated Treatment Path: Examples and Outcomes

The policy drivers for integrating children's care are different from the elderly and gain much less attention from policy-makers, researchers, and the public. This makes achieving integrated care for children particularly challenging. However, there are commonalities between the young and the elderly. For example, primary care staff shortages, increasing demand, and pressure to reduce hospital use in many countries have increased interest in developing new models of care that cross the boundaries between generalism and specialism, enhancing the best features of primary care and increasing the access to specialist expertise in the community. Several countries have made progress in developing integrated care services that are appropriate for children's needs and there are numerous examples that illustrate interesting and useful points about integrated care for children. However, health systems, services, and policy research for children and young people are less advanced than for the adult and elderly population, and there has been little evaluation of the impact of integrated care for children. A recent meta-analysis suggests that compared with treatment as usual, integrated care delivers improved quality of life for children and young people with chronic conditions (Wolfe et al. 2020). Furthermore, integrated care may offer cost savings; however, the effects of integrated care on service use is unclear. However, the evidence base remains limited, with interventions often limited to single conditions, and variable quality of research. Despite this, there are useful lessons to be learned through examining the breadth of experience from worldwide examples of integrated care for child health.

The Medical Home model in the USA is an integrated healthcare model for children. The aim is to deliver coordinated personalised and high-quality care (Cooley et al. 2009). The key features are that each child has a personal physician or other key worker who provides first-contact, continuous and comprehensive care, backed up by comprehensive teams including primary care and specialist doctors, nurses, and other professionals. Importantly, the Medical Home model incorporates preventive care, ambulatory and inpatient care for acute illnesses, coordinated continuity of care for chronic conditions, and access to specialists when needed (American Academy of Pediatrics 1992). A study of medical home services for children with chronic conditions including asthma, diabetes, attention-deficit hyperactivity disorder, cerebral palsy, and epilepsy, reported a significant association between a strong medical home model (measured by an index of implementation) and reduced hospital admissions but a non-significant association with reduced emergency department visits (Cooley et al. 2009). There are a few individual studies that suggest beneficial outcomes for specific diseases in children. For example, a pre- and post-intervention comparison of patients receiving integrated asthma services, with matched controls at non-participating sites, found that clinically important processes of care, health-related quality of life, and asthma-specific quality of life improved significantly in the intervention group (Mangione-Smith et al. 2005). A US study comparing quality of care between specialists and generalists for children with asthma found significantly more compliance with national guidelines for children looked after by specialists (Diette et al. 2001). These are important, if indicative, results since under-treatment is an important element in poor outcomes for children with asthma (Asthma 2007). Children and young people who receive multi-professional and intensive medical management together with psychosocial support, and whose families receive tailored education, have improved glycaemic control and diabetes outcomes (Diabetes Control and Complications Trial Research Group 1994; White et al. 2001). Additionally, there is weak evidence that medical homes may achieve improved health outcomes, timeliness of care, family-centred care, and better family functioning among children with special healthcare needs (Cooley 2004; Homer et al. 2008).

Australia has a reputation for improving care through innovative new models of services. However, primary care in Australia is a mix of public and private provision, and efforts to integrate care have been variable. Although there have been policy changes to enable supportive financing for coordinated chronic condition care and integration is viewed as important to enable the coordinating role of primary care, there are significant reported challenges including fragmented policy and responsibility for primary and community care, incompatible funding and accountability mechanisms, and difficulties in planning and accessing coordinated multidisciplinary care (Davies et al. 2009). Integrated primary care centres are being developed across the country, and Australia's version of integrated care for children is a broadly comprehensive rights-based approach to child and family services with a stated focus on health and wellbeing, learning and development. Services vary across the country but typically encompass education, day care, maternal and child health services, early childhood intervention, parenting, play groups and community activity space, and occasionally include other social services such as housing support services and employment advice (Press et al. 2012). The governance and organisational structures of Australia's integrated child health centres and services range from independent single or multiple employing organisations to government backed non-profit organisations managed by a governing council. Primary Care Partnerships are considered the most well-established integrated care systems, and they include primary and community health, local government, hospitals, and voluntary sector organisations. Service innovations are fostered through such partnerships, which are voluntary and based on memoranda of understanding (Davies et al. 2009; Department of Health 2010). Sweden's multiprofessional primary care and child health centres have GPs, paediatricians, and children's nurses working closely together, supplementing chains of care designed to improve integration of services and quality of care for children with chronic conditions. Children's health centres are staffed by general practitioners and children's nurses working closely together with paediatricians. Preventing disease and promoting health and development are the aims of children's health centres. Acute and minor illnesses are managed through primary care centres where GPs and children's nurses manage most problems, while paediatricians are close on hand if needed. A system called Chains of Care was developed for integrating services for chronic conditions as a response to the increasingly fragmented uncoordinated care that happened concurrent with growing decentralisation of service planning. Implementation was improved by involving patients as active participants in developing care, devising supportive financing and other policy tools, and fostering culture change through maintaining focus on quality improvement as the aim to the change process (Åhgren 2003). Specific aspects of services for children with chronic conditions include having a named physician who coordinates care, and specialist nurses who provide a point of contact for urgent problems. In addition, there are family education programmes to encourage supported self-management. A complementary system of integration in Sweden is known as Local Health Care, a system of primary and community care that incorporates some specialist services (Åhgren 2010). Although there has been a deal written about the implementation of integrated healthcare in Sweden, there are as yet insufficient reports of measurable outcomes for children (Åhgren and Axelsson 2011).

France has a general practitioner system, with mandated registration, providing gatekeeping and navigation roles (Nolte and McKee 2008). However, parents are entitled to choose any doctor for acute illnesses, and it is usual for parents to seek specialist care for young children. Routine care for children with chronic conditions is provided by specialists, such as paediatric pneumologists. The system for coordinating and integrating care for children with specified chronic conditions, or affections de longue duree´, is intended to ensure that children receive personal treatment plans. There are lists of investigations and interventions covered by health insurance for specific conditions, and a system of financial incentives for using evidence-based guidelines and national standards for management of chronic conditions. Coordinated planned care is achieved through multidisciplinary appointments in specialist centres. This system focuses on specialist aspects of the child's health and development, and is not thought to integrate care between generalists and specialists (Wolfe 2013).

The Netherlands has a General Practitioner-based primary care system supplemented by a youth-only primary and preventive healthcare system. The Trans-Mural system is a series of policies and practices to promote integration between primary and secondary care and between multiple insurers and providers of care. Health professionals have defined responsibilities at the individual and team level. Specialist nurses have a central role in organising and coordinating care. GPs and nurses provide everyday management for chronic conditions such as asthma, and paediatricians in hospitals provide care for children with complex conditions or where management is particularly challenging. Urgent advice is available through either the primary care or hospital system depending on the severity of the child's needs. Guidelines are shared between primary and secondary care, designed to reinforce shared practice and teamwork (van der Linden et al. 2001; Zwar et al. 2006). Evaluations of transmural care have demonstrated persistent discontinuity between primary and secondary care, emphasising the point that organisational integration did not necessarily produce clinical and service integration (van der Linden 2001). The Netherlands' provision of mental health care is divided between sectors, and there has been a small-scale attempt to test an integrated approach to delivering mental healthcare in primary care settings. The Eureka project comprised an incentive payment to GPs to perform a comprehensive assessment of children and parents with possible mental health problems, consult with specialists as needed, and deliver treatment in primary care. A study evaluating outcomes using a before-after design suggested some increase in the number of children identified as having mental health problems, but this effect seems not to have been sustained (Verhaak et al. 2015).

The UK universal primary care system is led by GPs, with a strong role in gatekeeping and navigation. There is a national drive towards developing new models of integrated health care, and a growing realisation in national policy that children and young people have distinct needs that must be factored into health system reform (NHS 2014, 2019). Various aspects of an integrated or chronic care model have been implemented or are being developed in the UK, but the emphasis on integrated care for children thus far has been largely about education and other children's services but without mainstream primary, community, and hospital-based services. The Sure Start programme was developed in the late 1990s to improve and promote health and development for children under 5 years and their families, particularly in disadvantaged areas (Eisenstadt 2011). The intention originally was to bring together local services and integrate staffing and management to include early learning and child care, family support, child and family health services, and advice and information on children's services and parental employment, to improve health and development outcomes. Sure Start evaluations demonstrated variable success in delivering its aims (SQW 2005). The programme evolved and became a national network of Children's Centres, but has more recently contracted with the financial crisis. Children's Centres have, however, enabled co-location of some services for children under 5 years, for example community and family support workers, and some health workers such as health visitors. Although there is a statutory requirement for partnership working between Children's Centres and the health sector, in practice this has been variable, with little involvement by GPs (Government UK 2009). The Every Child Matters (ECM) policy was introduced in 2003 following the death of a vulnerable child. ECM described five key outcomes for children: being healthy, staying safe, enjoying and achieving, making a positive contribution, and economic wellbeing. It aimed to bring together many children's services within the local government and education sectors and included some specific health services but excluded primary healthcare and other mainstream health services. Similarly, the Team around the Child concept is about fostering horizontal integration and is particularly suited for children with additional needs, usually complex social and educational needs, and there is relatively little health sector input (Jones 2006). Getting it Right for Every Child (GIRFEC), introduced in Scotland in 2004 and enshrined in law in 2014, is a rights-based approach to care which emphasises an integrated approach to care for children with multiple needs. There are some encouraging signs of changing practice associated with GIRFEC, and some indication of changes in outcomes (Stradling et al. 2009). Children with chronic illnesses in the UK may not have a specific professional who coordinates care and this function is often the responsibility of the parents. A variety of formal and informal integrated healthcare services and networks have been or are being set up. Although there is generally limited evaluation of outcomes to date, some implementation evaluation has been attempted. Difficulties in establishing coordinated services and networks include cultural resistance to change; lack of evidence to demonstrate benefits; financial disincentives to cooperate (promoting competition instead of collaboration); and organisational boundaries preventing cooperation between providers (Royal College of Paediatrics and Child Health 2012). New models of care that focus more on medical aspects of child health are being developed in several centres throughout the UK (Nuffield Foundation 2015). Four types of services have been described that attempt to integrate primary and secondary care: multidisciplinary teams with telephone links, hospital at home, GP outreach clinics, and decision support or advice and guidance (Woodman et al. 2015). Specific aspects of integrated care have been implemented to varying degrees, though not all of them have been described by the term. For example, an RCT investigating the effects of a Hospital at Home service for children with acute asthma found that home care was as effective as hospital care, and more acceptable to parents and children (Sartain et al. 2002). A randomised controlled trial of a clinical pathway for asthma in general practice in New Zealand (which has a similar system to the UK) achieved reduced numbers of hospital admissions and emergency department attendances; however, the positive results were demonstrated in both intervention and control groups (Mitchell et al. 2005). There are currently novel healthcare improvement and/or research programmes in both Australia and England which include elements of vertical integration through co-locating paediatricians and GPs for co-consultations and better sharing of skills and experience (Kossarova et al. 2016; Montgomery-Tayor et al. 2016; Newham et al. 2019).

In Italy, children's health care is delivered nearly exclusively by paediatricians who are the first point of access for urgent advice and consultations and assume responsibility for monitoring and managing children with long-term conditions. Children with very severe or complex conditions who require specialist paediatric management are often followed up in hospitals rather than by primary care paediatricians in community settings. Assistenza Domiciliare Pediatrica is a system joining specialist health centres with primary care paediatricians and other community services. The aim is to provide as much care as possible at home for children with complex chronic conditions who need specific interventions such as parenteral nutrition, oxygen therapy, physiotherapy, or frequent blood sampling, for example, rather than on integrating primary and secondary for the population (Tamburlini 2012).

Germany has primary care paediatricians, and paediatricians with a particular expertise in chronic conditions, for example pneumologists, working in community-based offices and hospitals. Specialised paediatricians act as care coordinators working in teams with nurses and therapists. Coordinated multidisciplinary care in Germany is facilitated by funding packages of care with a single provider organisation rather than the usual fee for service model (Strassburg 2011). In addition, for children with complex chronic conditions such as neurodevelopmental disorders, there is a specific location-based multidisciplinary service known as Social Paediatric Centres (SPZs) supplemented with a teaching programme, ModuS, to foster self-management for children with chronic conditions and their families (Szczepanski 2010). SPZs are usually co-located with hospitals.

Norway's health system has a strong universal primary care focus. Children with chronic illnesses have a local key health worker who acts as coordinator, guiding care according to individualised written plans which describe roles and responsibilities for all professionals involved. Hospital-based paediatricians provide most of the specialist medical care, and parents are able to telephone them directly for advice. All hospitals have educational centres that provide information and training for families after their child has been diagnosed with a chronic disorder, also providing a connecting function with other families who have similar problems. Mental healthcare services for children in Norway are beset by similar problems as in other countries, fragmented and complex services that often fail to deliver coordinated care (Manikam 2002; Walker 2001; Hudson 2005). There has been a national drive towards improving care and developing new services, backed by a ten-year national mental health escalation plan (Ådnanes and Halsteinli 2008). Fostering interprofessional collaboration between health and social care has been an important feature of Norway's mental healthcare improvement plan (Odegard 2006).

39.6 Lessons Learned and Outlook

Integrated care for children is in early stages in most countries, but there are promising signs that children's distinctive health needs are beginning to be recognised. Policy translation is the next goal in realising integrated care for children, and it is helpful to look again at the ultimate goals.

> Comprehensive integrated services for children should improve care compared with the traditional service models, solving problems such imbalances between access and expertise in first contact care to improve effectiveness and efficiency and redirect resources to planned proactive care for children with chronic conditions. Child health services evaluation research will be needed to establish the evidence to support new and integrated models of care.
>
> *Fully integrated care should improve population and individual level services and ultimately improve child health.*

Optimising child health requires health system strengthening, and integrated care is one aspect of this endeavour. It is widely accepted that we should now be evolving towards an era of population health and health systems, having progressed through earlier periods dominated by medical and public health models, and more recently healthcare systems. A new era of health systems responds to the understanding that a life-course health development approach to optimising health of individuals and populations is needed. Integrating care will be one important aspect of strengthening health systems for children. To achieve these things will require community-based organisations that are accountable to the communities they serve, better use of data to understand and provide for population health, flexible financing instruments that promote cooperation, and families as active participants and co-designers of health.

A community integrated health system aims to optimise health across the life course. Services and networks between healthcare organisations and public health and other community services are needed to prevent risk factors, promote health, treat disease and manage conditions. Care processes will focus also on optimising health and wellbeing and promoting development. Sophisticated payment systems and information connectivity will be needed. Embedding a community integrated health system for children in a learning healthcare system ensures continuous improvement of quality of care, and services that respond to population need. Finally, population level health improvement will come from a comprehensive approach ensuring that vertical, horizontal, longitudinal, and population integration are part of an overall programme of population health management and health systems strengthening.

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Integrated Care for Older Patients: Geriatrics

40

Sofia Duque, Marco Inzitari, Armagan Albayrak,
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40.1 Introduction

Since the 1st edition of the Handbook of Integrated Care in 2017 (Handbook of Integrated Care 2017), the focus and the literature on Integrated Care have increased considerably.

For this chapter, we have used the WHO definition of i*ntegrated care*: 'Integrated care is a concept bringing together inputs, delivery, management and organization of services related to diagnosis, treatment, care, rehabilitation and health promotion. Integration is a means to improve services in relation to access, quality, user satisfaction and efficiency' (Gröne and Garcia-Barbero 2002), as well

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as elements from the Commonwealth Fund Report (Commonwealth Fund International Experts Working Group on Patients with Complex Needs 2017).

An overall working definition of *integrated service delivery* is ‘The management and delivery of health services so that clients receive a continuum of preventive and curative services, according to their needs over time and across different levels of the health system.’ (Waddington and Egger 2008).

In the Report of the WHO Regional Office for Europe of October 2016 (WHO Regional Office for Europe 2016 *A*), *integrated care models for the elderly and frail* are discussed as a specific group of initiatives. This group of integrated care models is distinguished due to the high specificity of service individual needs that guide the design of care models and the extent to which care requires integration between health and social services. We discuss some of these models in Sect. 40.3.1 of this chapter.

Older people are more than the sum of their conditions, and their complex needs frequently consist of health and social needs, as well as the need for both physical and mental health care. This is well-addressed in the Commonwealth Fund Report (Commonwealth Fund International Experts Working Group on Patients with Complex Needs 2017), in which the authors recommend a holistic approach to integrated care, and emphasize the need of designing a high-performing healthcare system for patients with complex needs.

Recommendation number 8 addresses the need to integrate health and social services, and physical and mental health care.

The authors state that the separation of health and social care fails to recognize some patients’ closely related needs for both types of care; and that constrained social service spending may also lead to inefficient use of health care resources—for example, when patients are unable to be discharged from the hospital because of a lack of support available in the community.

They argue that care for patients with complex needs therefore requires close cooperation between the two sectors, and that care for mental health must be integrated with physical health care, with multidisciplinary teams ensuring that physical and mental health problems are addressed together in a timely fashion.

Finally, we believe that the care for older people should address more than their health conditions, that they rely a lot on social and leisure resources, services providers, commerce, home and public environment, and that networking and communication between the several stakeholders are crucial to deliver a coherent intervention (which can include healthcare interventions or not). This leads us to reason that the ultimate form of integrated care is the concept of integrated governance. *Integrated governance* is defined as ‘Systems, processes and behaviours by which an organisation leads, directs and controls its functions in order to achieve organisational objectives, safety and quality of services’. Integrated governance provides a framework for all governance approaches, it combines the principles of corporate and financial accountability with clinical and management accountability and enables a risk-sensitive approach which will enable the delivery of all objectives, functions and duties (NHS Halton Clinical Commissioning Group 2017).

For example, New Zealand's policymakers and healthcare providers have concluded that it is no longer acceptable nor sustainable to operate a health system with parallel structures that lack coordination or a governance model that supports this.

In response, from mid-2013 New Zealand moved to implement a governance model across the entire country, aimed at integration by requiring an alliance between each District Health Board and corresponding Primary Health Organisation (Gauld 2014).

40.2 Challenges for Providing Care for the Geriatric Patient

In humans, ageing refers to a multidimensional process of physical, psychological and social change, leading to functional decline. However, we must keep in mind that ageing is not a uniform process, and that there is a large inter-individual variety.

In old age, usually defined as from age 75 onwards, there is an accumulation of diseases and risk factors, the so-called cumulative complexity (Inouye et al. 2007), and an age-related increase in functional decline (Hebert 1997).

Factors that lead to complexity in older patients are the presence of multiple chronic diseases; multiple healthcare providers and facilities; geriatric syndromes; polypharmacy (leading to adverse drug reactions and events, drug-drug interactions); functional impairment; cognitive impairment; loneliness; being homebound; lack of caregivers; poor social support; poverty; lack of knowledge and training about older patient specificities among healthcare providers; inter-individual heterogeneity.

This complexity makes the care of the geriatric patient a challenge.

40.2.1 Multimorbidity and Geriatric Syndromes

Multimorbidity, the co-occurrence of two or more chronic medical conditions in one person, correlates with age, and currently represents the most common 'disease pattern' found among the elderly (Barnett et al. 2012).

Multimorbidity is characterized by complex interactions of co-existing diseases where a medical approach focused on a single disease does not suffice. New models of care for these patients are needed (Roland and Paddison 2013).

Usually, the geriatric patient presents with several age-related chronic diseases and geriatric syndromes simultaneously. Geriatric syndromes are common clinical presentations that do not fit into specific disease categories but have substantial implications for functionality and life satisfaction in older adults. Examples of geriatric syndromes are immobility, instability, falls, impaired cognition, incontinence, as well as sensorial impairments and dependency in activities of daily living (Inouye et al. 2007).

Heart failure, cerebrovascular disease, chronic obstructive pulmonary disease, osteoarthritis, dementia, diabetes and cancer are among the most prevalent chronic and disabling diseases in older people. Although there is considerable evidence-based knowledge about management of single chronic diseases, little to no evidence exists about the management of the same chronic conditions in multimorbid geriatric patients. Not rarely, recommendations for a single disease are contraindicated in the management of other conditions (Boyd et al. 2005).

Chronic diseases and age-related conditions are highly associated with functional decline, like gait impairment or inability to perform basic or instrumental activities of daily living.

Functional impairment not only reduces patient autonomy, quality of life and sense of wellbeing, but also can prevent access to healthcare facilities and compliance to medical recommendations. In this scenario, formal and informal caregivers are crucial to achieve treatment goals and preserve the quality of life of the older patient. They should be involved and empowered in the planning of care according to the best interest of the patient.

40.2.2 Fragmentation of Care

Typically, several healthcare professionals of different levels of medical care participate in the management of the multimorbid geriatric patient. For instance, a single patient can be assisted by the general practitioner, the medical or surgical specialists and the nursing home physician at the same time. When communication between them is not effective, there is fragmentation of care, and the risk of complications due to interactions between treatments and diseases is potentially increased. In current healthcare provision, fragmentation, rather than integration, is the norm. Fragmentation can be defined as focusing and acting on the parts, without appreciating their relation to the whole. Statistics on fragmentation of care are not available. Fragmentation of care leads to inefficiency, ineffectiveness and inequality (Stange 2009).

40.2.3 Place of Living: From Community to Institutions

The place of living of the geriatric patient depends not only on the health status, functional and cognitive status, and medical needs, but also on the patient preferences and community and social resources available in a specific place or society. Older people tend to prefer to continue living at home as long as they can, even if they have some limitation that impairs their ability to live alone, rather than transit to residential care or nursing homes. This requires comprehensive social and community services, training in geriatrics for health and social care professionals working in the community, and promoting an increased awareness of ageing in the local community.

Maintenance of quality of life of older people that remain living at home requires a global assessment of several aspects that interfere with daily living, and not only a purely medical assessment.

The concept of *Ageing in place* is defined as ‘the ability to live in one’s own home and community safely, independently, and comfortably, regardless of age, income, or ability level’ (Centers_for_Disease_Control_and_Prevention 2013). Older people usually see *Ageing in place* as an advantage in terms of a sense of attachment or connection and feelings of security and familiarity in relation to their homes as well as their communities. ‘Ageing in place’ is seen to promote maintenance of independence, autonomy, social relationships and therefore higher satisfaction and quality of life (Wiles et al. 2012).

To sum up, the geriatric patient is very complex and heterogeneous. The ability to plan individually tailored interventions must be developed as each older person is a single one, with specific needs, disabilities and functional limitations.

40.3 Models of Integrated Care for Older People and Outcomes

40.3.1 Models Mentioned in the WHO Europe Report 2016

The WHO Europe Report 2016 devotes a special paragraph to *integrated care models for elderly and frail people*, stating that this group of integrated care models is distinguished due to the high specificity of service individual needs that guide the design of care models and the extent to which care requires integration between health and social services (WHO Regional Office for Europe 2016 *A*).

Examples given are the *PRISMA model* and the *Torbay model*.

PRISMA (Program of Research to Integrate Services for the Maintenance of Autonomy) is a Canadian model designed to integrate service delivery for community-dwelling people with moderate-to-severe impairment, who need coordination between two or more services. The aim of the model is to preserve the functional autonomy of individuals.

The model is designed to serve as a single entry-point to the system and to coordinate care across a network of different providers. Case-management and the use of computerized charts are essential components for coordination.

According to the model, integration is achieved through an established joint governing board of health and social care. The board defines the strategy, allocates resources to the network and manages provider groups.

An assessment of the impact has shown that the PRISMA model sustained the functional stability of individuals, decreased the extent of unmet needs.

and reduced the burden placed on carers. Individuals enrolled to the PRISMA programme also decreased their risk of hospital readmissions (Hébert et al 2010; WHO Regional Office for Europe 2016 *A*).

The Torbay model:

To overcome fragmentation of care for older people, the borough of Torbay *in England* established five integrated health and social care teams. The teams were organized according to territorial principles and were aligned with general practices in the same localities. The model targeted elderly patients with multimorbidities, who required intensive support from community matrons. The model employs health and social care coordinators, who act as the single point of contact within each team. Similar to PRISMA, Torbay Care Trust was established as a joint health and social care board with pooled budgets. Budgets were allocated according to the needs of population and are not restricted to certain types of care.

Proactive discharge planning and transitional care have allowed Torbay's model to achieve performance improvements, such as reductions in average length of hospital stay and hospital readmissions (Curry and Ham 2010; WHO Regional Office for Europe 2016 *A*).

40.3.2 Literature Update on Integrated Care Geriatrics

For the update of our chapter on Geriatrics, we performed a literature search with the following search strategy:

Search, in Pubmed, of ["integrated care" AND geriatrics] OR ["integrated care" AND "older adults"], english, since 2017 to date.

In addition, we added some so-called gray literature.

We describe the relevant studies targeted at older populations and sum up the current European Projects about Integrated Care and their key elements.

40.3.2.1 Review

In a broad overview on what works in implementation of integrated care programmes for older adults with complex needs, Kirst et al. (2017) discuss a total of 65 articles, representing 28 Integrated Care programs published between January 1980 and July 2015.

Two context-mechanism-outcome configurations (CMOcs) were identified: (i) trusting multidisciplinary team relationships and (ii) provider commitment to and understanding of the model. Contextual factors such as strong leadership that sets clear goals and establishes an organizational culture in support of the program, along with joint governance structures, supported team collaboration and subsequent successful implementation. Furthermore, time to build an infrastructure to implement and flexibility in implementation, emerged as key processes instrumental to success of these programs (Kirst et al. 2017).

40.3.2.2 Factors Associated with Negative Outcomes

A multicenter study in the Netherlands, EMBRACE, supports older adults to age in place. A multidisciplinary team provides care and support, with intensity depending on the older adults' risk profile. A RCT was conducted in 15 general practices in the Netherlands. Older adults (≥ 75 years) were included and stratified into three risk profiles: Robust, Frail and Complex care needs, and randomized to Embrace or care as usual (CAU). Outcomes were recorded in three domains. The EuroQol-5D-3L and visual analogue scale, INTERMED for the Elderly Self-Assessment, Groningen

Frailty Indicator and Katz-15 were used for the domain ‘Health.’ The Groningen Well-being Indicator and two quality of life questions measured ‘Wellbeing.’ The Self-Management Ability Scale and Partners in Health scale for older adults (PIH-OA) were used for ‘Self-management.’ 1456 eligible older adults participated and were randomized to EMBRACE or CAU. EMBRACE participants showed a greater-but clinically irrelevant-improvement in self-management, and a greater-but clinically relevant-deterioration in health compared to CAU. This study found no clear benefits to receiving person-centered and integrated care for twelve months for the domains of health, wellbeing and self-management in community-living older adults.

The authors argue that their finding of no clear benefits for Embrace on the outcomes measured could be due to the duration of the intervention (12 months), the nature of the intervention, the selection of outcomes, or methodological limitations. (Spoorenberg et al. 2018). This study was also shown not cost-effective. (Uittenbroek et al. 2018).

40.3.2.3 Integrated Care to Improve Care Transitions

Brown and Menec (2018) reviewed 48 documents, 26 journal articles and 22 grey literature documents.

Results suggest that **clinical and service delivery integration** is being targeted rather than integration of funding, administration and/or organization. The authors argue that in order to promote international comparison of integrated care initiatives aiming to improve care transitions, detailed descriptions of organizational context are also needed.

40.3.2.4 Home Care

Home-Based Primary Care

A study in the USA compared home-based primary care (HBPC) integrated with long-term services and supports (LTSS) for frail older adults [cases (n = 721)] with concurrent comparison groups (HBPC not integrated with LTSS: n = 82; no HBPC: n = 573). HBPC integrated with long-term support services delayed Long-Term Institutionalization (LTI) in frail, medically complex Medicare beneficiaries without increasing costs of home- and community-based services (HCBS) (Valluru et al. 2019).

Hospital-At-Home

In a quasi-experimental longitudinal study, with 30-day follow-up, Mas et al. (2018) compared clinical outcomes in older patients with acute medical crises attended by a geriatrician-led home hospitalization unit (HHU) versus an inpatient intermediate-care geriatric unit (ICGU) in the Barcelona area. Most patients in both groups recovered from their health crises. No differences were found between the 2 groups in 30-day mortality. There was a trend toward lower 30-day readmission to an acute care unit in the Hospital at Home (HaH) group. HaH patients had higher relative functional gain, and a slightly longer stay in the unit. The results suggest that the geriatrician-led HHU seems effective in resolving acute medical crises in older patients with chronic disease.

Positive results were also achieved with HaH for geriatric rehabilitation in the Barcelona area, i.e., the same functional outcomes as in the bed-based geriatric rehabilitation unit, but shorter stays (Mas et al. 2017).

40.3.2.5 Preventative Care for Frail Older Adults in an Integrated Way

The + AGIL program (Pérez et al 2019) integrates geriatrics with primary care and with the existing community resources (civic centers etc.), to provide a CGA-based individualized multi-component intervention to stop or revert frailty and delay disability; 112 (83.6%) participants (mean age = 80.8 years, 67.9% women) were included in this research. Despite being independent in daily life, participants' physical performance was impaired. After three months, 90.2% of participants completed ≥ 7.5 physical activity sessions. Improvements occurred for SPPB, gait speed and chair stand test, and 53% improved their balance.

The principles for the design of this sort of preventative interventions for frail older adults include: design a *multi-factorial* strategy; design a *person-centered* approach; design an evidence-based but *sustainable* and *contextualized* intervention; promote *users' participation* (older adults, caregivers, professionals); use an *opportunistic* case-finding/recruitment strategy; move the intervention *close to the person* (primary and community care); build *integrated care* models, involving *community agents*; *empower* the person and its caregivers; raise *awareness* and sensibility in decision-makers and the general population; make an adequate and sound *plan for investments* and *assessment* (Inzitari et al 2018).

40.3.2.6 Impact on PROMs

In a systematic review, Liljas et al (2019) investigated the impact of integrated care on Patient Related Outcomes (PROMS).

They included 12 studies (2 RCTs, 7 quasi-experimental design, 2 comparison studies, 1 survey evaluation). Five studies investigated patient satisfaction, 9 hospital admission, 7 length of stay, 3 readmission and 5 mortality. Findings show that integrated care tends to have a positive impact on hospital admission rates, some positive impact on length of stay and possibly also on readmission and patient satisfaction, but not on mortality.

40.3.2.7 Qualitative Studies

In a scoping review, Lawless et al. (2020) highlight the salience of the relational, informational and organizational aspects of care from an older person's perspective. Participants across the 30 included studies desired accessible, efficient and coordinated care that catered to their needs and preferences, while keeping in mind their rights and safety.

In an analysis of the implementation of an integrated care model for older adults in Quebec, Breton et al. (2019) explored the views of key stakeholders: policymakers ($n = 11$), providers ($n = 29$), managers ($n = 34$), older adult patients

($n = 14$) and caregivers ($n = 9$), along the lines of the six dimensions of the Rainbow Model of Integrated Care. While patients/caregivers were mostly concerned by their unmet individual needs, policymakers, managers and providers were concerned by structural barriers to integrating care. Stakeholders' diverse perspectives indicated implementation gaps in a top-down implementation context.

In summary, mandated system-wide integration appears to have structural, organizational, functional, and normative transformations, but its clinical changes are more uncertain in view of the observed divergent perspectives of actors.

A qualitative descriptive study entailed one-to-one interviews with 80 caregivers from Canada and New Zealand where roles, experiences and needs were explored (Kuluski et al. 2018). Integrated care approaches that aim to coordinate primary care with community care known as community-based primary health care (CBPHC) pay most attention to the needs of patients and not caregivers. The objective of this paper was to explore the unmet needs of caregivers of older adults with complex care needs receiving CBPHC. The authors conclude that to support caregivers, models of care such as CBPHC need to look beyond the patient to meaningfully engage caregivers, address their needs and recognize the insight they hold, and that this knowledge needs to be valued as a key source of evidence to inform developments in health and social care.

40.3.2.8 Social Components of Care

Social Prescribing (SP) is considered a means to improve wellbeing and self-care and reduce demand on the NHS and social services. The SP experience in the Torbay and South Devon NHS Foundation Trust was directed to older adults (≥ 50 years) with complex health needs (≥ 2 long-term conditions). SP is a way of connecting patients to practical, community-based support, including access to advice on employment, housing and debt (NHS England). A before-and-after study measuring health and social wellbeing, activation and frailty at 12 weeks and primary, community and secondary care service use and cost at 12 months prior and after intervention. Most of the 86 participants achieved their goals (85%). On average health and wellbeing, patient activation and frailty showed a statistically significant improvement in mean score. Mean activity increased for all services. Forty-four per cent of participants saw a decrease in service use or no change (Elston et al. 2019).

40.3.2.9 European Projects About Integrated Care

We conclude with a summary of *current European Projects on Integrated Care for Older Adults*, and *their key elements,* (*see* Table 40.1).

Table 40.1 Summary of current European Projects and their key elements

Project SCIROCCO	**Key indicators/elements**
Scaling integrated care in context (SCIROCCO) https://www.scirocco-project.eu/maturitymodel/ Accessed March 18, 2020	*Maturity model for integrated care* *Includes 12 dimensions* 1. Capacity building 2. Readiness to change 3. Structure and governance 4. Information and eHealth services 5. Finance and funding 6. Standardization and simplification 7. Removal of inhibitors 8. Population approach 9. Citizen empowerment 10. Evaluation methods 11. Breadth of ambition 12. Innovation management
Project SUSTAIN	**Key indicators/elements**
Sustainable tailored integrated care for older people in Europe (SUSTAIN) https://www.sustain-eu.org/project/detailed-project-information/ Accessed March 18, 2020	*5 Core elements of integrated care* 1. Proactive assessment of health and social care needs 2. Person-centeredness by involving older people and their informal carers in decision-making and planning their care process 3. Involvement of professionals from multiple disciplines (prevention, health care, social care) that collaborate with older people and their informal carers 4. Coordination of care to ensure continuity of delivery of care and support 5. Delivery of multiple interventions: care-related interventions as well as facilitating (e.g., shared ICT systems) interventions
Project CHRODIS PLUS	**Key indicators/elements**
Implementing good practice for chronic diseases https://chrodis.eu/about-us/ Accessed March 18, 2020	*MULTIMORBIDITY care model* 1. Delivery System design 2. Decision support 3. Self-management 4. Clinical information system 5. Community resources
Project integrate	**Key indicators/elements**
Integrate https://www.projectintegrate.eu.com/cross-cutting-themes Accessed March 18, 2020	*5 cross-cutting themes* 1. Care process design 2. IT management 3. Patient involvement 4. Financial flows 5. Human resource management and workforce changes

(continued)

Table 40.1 (continued)

Project Act@Scale	**Key indicators/elements**
Act@Scale https://www.act-at-scale.eu/about-the-project/ Accessed March 18, 2020	*4 areas are important to improve IC* 1. Stakeholder and change management 2. Service selection 3. Sustainability and business models 4. Citizen empowerment
Project SELFIE	**Key indicators/elements**
Sustainable integrated care models for multi-morbidity delivery, financing and performance (**SELFIE**) https://www.selfie2020.eu/ Accessed March 18, 2020	*6 key areas for integrated chronic care models* 1. Information and research 2. Service delivery 3. Workforce 4. Leadership and governance 5. Technology and products 6. Financing

40.4 Matters of Integration in Technology Design for Ageing People

The demographic trend of an ageing society has triggered a range of new products and services. Since the 1st edition of the Handbook of Integrated Care (Handbook of Integrated Care 2017), the number of reports and protocols on technologies and services to facilitate integrated care for seniors has increased considerably.

In a systematic review, Khosravi and Ghapanchi (2016) found eight key issues in aged care that had been targeted by researchers from different disciplines (e.g., ICT, health and social science), namely dependent living, fall risk, chronic disease, dementia, social isolation, depression, poor well-being, and poor medication management. They identified various assistive technologies proposed by ICT researchers to assist the elderly and categorized these assistive technologies into six clusters, namely, general ICT, robotics, telemedicine, sensor technology, medication management applications and video games. They concluded that assistive technologies are effective and can be applied to improve quality of life, especially among older age groups.

A search, in Pubmed, of [“integrated care” AND geriatrics AND technology] OR [“integrated care” AND “older adults” AND technology], English, since 2016 to March 1, 2020, yielded 19 references (Bartels et al. 2018; Borda et al. 2018; Dolovich et al. 2016; Fürstenau et al. 2019; Hein Willius et al. 2019; Kim et al. 2017; Kiselev et al. 2018; Khosravi and Ghapanchi 2016; Loh et al. 2018; Melchiorre et al. 2018; Norell Pejner et al. 2019; Pilotto et al. 2018; Schneider et al. 2019; Sendall et al. 2017; Skelton et al. 2019; Steele-Gray et al. 2018; Tarraf et al., 2019; Taylor et al. 2018; Van der Cammen et al. 2017).

Articles ranged from protocol descriptions (Dolovich et al. 2016; Kim et al. 2017, Norell Pejner et al. 2019), feasibility studies (Tarraf et al. 2018), pilot programs (Taylor et al. 2018) and case studies (Steele-Gray et al. 2018) to completed trials (Melchiorre et al. 2018) and overviews of technology and design applications for seniors (Pilotto et al. 2018; Van der Cammen et al 2017). Areas covered ranged from wearables (Borda et al. 2018; Hein Willius et al. 2019) to information technology applications for continuity of care (Bartels et al. 2018; Fürstenau et al. 2019; Loh et al. 2018; Melchiorre et al. 2018; Norell Pejner et al. 2019; Sendall et al. 2017; Skelton et al. 2019; Steele-Gray et al. 2018; Taylor et al. 2018), quality of care (Dolovich et al. 2016; Melchiorre et al. 2018; Tarraf et al. 2019), medication self-management (Norell Pejner et al. 2019), integrated medication management (Taylor et al. 2018), integrated community-based primary health care (Steele-Gray et al. 2018), and health self-management (Borda et al. 2018).

Conditions covered include multimorbidity (Bartels et al. 2018; Melchiorre et al. 2018), mental illness (Bartels et al. 2018; Skelton et al. 2019), oncology (Loh et al. 2018), frailty (Fürstenau et al. 2019; Kim et al. 2017), as well as quality of care (Dolovich et al. 2016; Melchiorre et al. 2018; Tarraf et al. 2019).

The new technologies to assist seniors have been shown to be acceptable, useful, usable and safe (Hein Willius et al. 2019), as well as effective (Khosravi and Ghapanchi 2016), and economically attractive (Schneider et al. 2019).

Hein Willius et al. (2019) showed that a portable device in the form of a bracelet that allows storing electronic health records of older adults experiencing chronic illnesses had a high level of acceptability by the end user and a high potential to be integrated with other complementary technologies (e.g., GPS, medication reminders) and could significantly contribute to improving health management in disaster situations.

Among independent living seniors, the use of consumer wearables to collect and manage information about their personal health status was explored (Borda et al. 2018). People aged 55 or over, independent living, and currently using or having used a wearable device or devices for health self-management in the past year participated in an online survey questionnaire.

Responses to the survey did not indicate widespread use of information from consumer wearables for health self-management among older adults. However, among the respondents, more than half were willing to participate in a follow-up interview by a researcher on their wearable health information use. Further research will explore what they have to say about this information use in relation to frailty and age related changes, and about the way that such information may be integrated into health and aged care support systems (Borda et al. 2018).

Patient involvement is a core component of an integrated care approach. In the INTEGRATE Project (Kiselev et al. 2018), a mixed-methods design was used to gain a better to gain a better understanding about patient involvement in geriatric care. A questionnaire on shared decision-making was administered within a group of older adults in Germany. Additionally, seven focus groups with health professionals and geriatric patients in Germany and Estonia were held to deepen the insight of the questionnaire and to discuss experiences and barriers of patient involvement. Older people without an actual medical problem expressed a significantly higher desire to participate in shared decisions than those requiring actual medical care. In the focus groups, patients demanded a comprehensive and understandable information and education process while the health professionals' view was very task-specific. This conflict led to a loss of trust by the patients. The authors conclude that there is a gap between patients' and health professionals' views on patient involvement in older people. The involvement process should therefore be comprehensive and should take into account different levels of health literacy.

Limitations and barriers of Information Communication Technology (ICT) were extensively studied in the iCOACH case studies, and Steele Gray et al.(2018) explored how ICT is used to support activities of integrated care and the organizational and environmental barriers and enablers to its adoption.

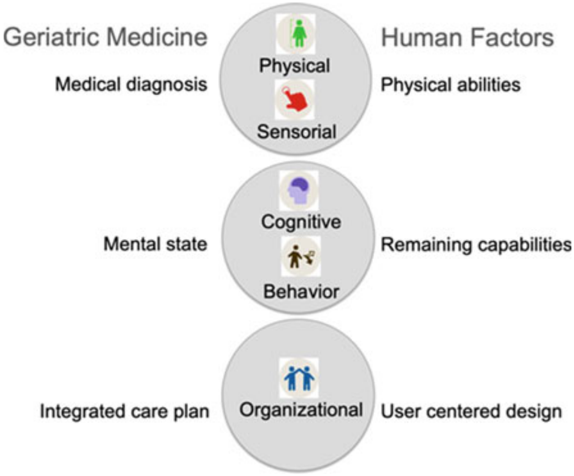
They used an embedded comparative multiple-case study approach using data from a study of implementation of nine models of integrated community-based primary health care, the Implementing Integrated Care for Older Adults with Complex Health Needs (iCOACH) study. Six cases from Canada, and three in New Zealand, were studied. As part of the case studies, interviews were conducted with managers and front-line health care providers from February 2015 to March 2017. A qualitative descriptive approach was used to code data from 137 interviews and generate word tables to guide analysis.

Despite different models and contexts, the authors found strikingly similar accounts of the types of activities supported through ICT systems in each of the cases. ICT systems were used most frequently to support activities like care coordination by inter-professional teams through information sharing. However, providers were limited in their ability to efficiently share patient data due to data access issues across organizational and professional boundaries and due to system functionality limitations, such as a lack of interoperability. The authors conclude that even in innovative models of care, managers and providers mainly use technology to enable traditional ways of working. The barriers to more innovative use of technology were considered to be linked to three factors: (1) information access barriers, (2) limited functionality of available technology and (3) organizational and provider inertia (Steele-Gray et al. 2018).

In addition, many factors impair a broad use of technology in older age, including psychosocial and ethical issues, costs and fear of losing human interaction. A substantial lack of appropriate clinical trials to establish the clinical role of technologies to improve physical or cognitive performances and/or quality of life of subjects and their caregivers suggests that the classical biomedical research model may not be the optimal choice to evaluate technologies in older people (Pilotto et al. 2018).

Despite reported limitations and shortcomings, the recent literature yields many positive reports on how technology can be applied to improve integrated care for seniors. Economic evaluations point toward effectiveness (Khosravi and Ghapanchi 2016) and possible cost savings (Schneider et al. 2019). Applications of design and technology can contribute to 'autonomous ageing, for example, independent living and lifestyle support (Van der Cammen et al. 2017).

Fig. 40.1 Similarities between the principles of geriatric medicine and human factors (adapted after Van der Cammen et al. 2019)



It is important to consider the principles of Human Factors (HF) when applying technology to improve integrated care for seniors. HF (also known as ergonomics) which studies interactions among humans and other elements of a system can facilitate that the developments in technology fit the needs, wishes and expectations of older people by considering age-related changes in physical, cognitive, visual and other capabilities, and different aspirations. Applying HF is not only about addressing the reduced capabilities of seniors, but also about focusing on more developed capabilities of seniors, such as mental growth (strategic thinking, language skills, motivation, commitment, work expertise) and some aspects of social capabilities (ability to adjust their behaviour) (Dul et al. 2012). Considering the principles of geriatric medicine and ageing ergonomics, remarkable similarities can be found between the two disciplines, as is shown in Fig. 40.1 (Van der Cammen et al. 2019).

Both disciplines apply the same multidisciplinary approach to ageing and ageing individuals, which opens a broad perspective for successful interventions.

These interventions can only be successful by following a user-centered design approach as a bridge between the two disciplines. In the White Paper Human Factors for Health and Social Care, the authors describe how human factors and ergonomics can bring depth and clarity of understanding to health and social care issues (Hignett and Lang 2018). In this regard, HF has a critical and fundamental part to play in patient safety by providing methods and approaches which address known issues of integration, impact and sustainability of change.

For successful integration of technology in the care of older adults, a further effort in interdisciplinary collaboration will be required in order to integrate technologies into the existing health and social service systems with the aim to fit into the older adults' everyday life (Pilotto et al. 2018; Van der Cammen et al. 2017). Since the home is the context of everyday life, bringing care home will be one of the challenges in the near future.

The European Institute of Innovation & Technology (EIT) Health has recently published their 2020 Business Plan Calls and one of the focus areas is 'Bringing Care Home' (EIT Health 2020). The aim is to deliver optimal home-based healthcare to older citizens, and consequent financial benefits to society, by designing and demonstrating innovation in home care services and systems. These kinds of challenges can only be addressed by integrating geriatric medicine, technology and aging ergonomics (HF), following a human-centered design approach.

40.5 Final Remarks

In order to succeed, integrated care models should rely on a set of components and delivery strategies. The components associated with successful integrated care models include enabling patient engagement and self-management support, developing multiprofessional working culture, adopting evidence-based clinical pathways and protocols, aligning incentives, effectively managing resources, continuously monitoring and improving performance, and investing in supporting information technologies (WHO Regional Office for Europe 2016 *B*). In general, multicomponent approaches can be characterized as the optimization and innovation of service delivery processes.

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Integrated Care for Frail Older People Suffering from Dementia and Multi-morbidity

41

Henk Nies, Mirella Minkman, and Corine van Maar

41.1 The Challenge

Due to improved living conditions and better health care, life expectancy is expanding in many countries (OECD 2019). Overall, we consider this as a blessing. But this blessing is to some extent ambiguous. Many people also extend their life with years in which they suffer from multiple chronic diseases, disabilities or frailty. One could wonder, whether quality of care has improved quality of life and whether the solution—better treatment and decreased mortality—has become a problem. It is a challenge to add life to years, instead of adding years to life.

This requires reconsideration of what we see as 'good health'. The concept of health as defined by the World Health Organization dating from 1948—a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity'—appears to be outdated (WHO 2006). According to this conceptual-

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ization, everyone who is not completely successful in life could be seen as unhealthy (Nordenfelt 2009). Also, the WHO definition is a rather static conceptualization of health, not recognizing that being healthy is an ambiguous and dynamic process.

It can be argued that this conceptualization of health contributes to an over-medicalization of society. Huber et al. (2011, 2016) proposed a new concept of health: the ‘ability to adapt and self-manage in the face of social, physical, and emotional challenges’ (Huber et al. 2011: 235). Resilience and self-management are keys to achieving as good as possible quality of life and well-being. The challenge for care professionals, organizations and to society is to support older people in living a meaningful life in dignity, in spite of the ‘social, physical, and emotional challenges’ they are faced with.

In this chapter, we will explore avenues to meeting the multiple health challenges for frail older people, in particular people suffering from dementia and multi-morbidity. We will take their needs as the point of departure for our analysis. Secondly, we will address how integrated care for these people can be organized. We will use the Dutch so-called Dementia Care Standard as an example of a framework for service integration at regional level. Then, we will address our view on future developments in integrated care by applying principles of person-centred care and personalized care. Generic standards need to be translated to individuals, as frail older people require tailored care and support. Finally, we will discuss how the organization of integrated care for frail older people suffering from dementia and/or multiple problems may be built up of similar elements. Adequate diagnostics and multiple interventions by care professionals and organizations will not suffice. A community approach combined with a holistic point of view is also required to improve healthy life styles, as well as adapting the environment.

41.2 Service Users’ Needs for Integrating Services

Before thinking about (multiple ways towards) solutions, the needs of the service users are to be explored. Frailty, dementia and multimorbidity are frequent among the older population.

Frailty is often used to describe the high vulnerability of older people. Gobbens et al. (2010, p. 175) define frailty as ‘a dynamic state affecting an individual who experiences losses in one or more domains of human functioning (physical, psychological, social), which is caused by the influence of a range of variables and which increases the risk of adverse outcomes’. According to these authors, the main components of frailty of older people are nutrition, mobility, physical activity, strength, endurance, balance, cognition, sensory functions, mood, coping, social relations and social support. Frailty manifests itself in adverse health outcomes such as falls leading to immobility, disability and dependency and other negative health outcomes, which may on their turn lead to increased institutionalization and mortality. It represents an imbalance of the person’s homeostatic reserve, with a weakened resistance to harmful agents (Fried et al. 2004; Puts et al. 2005; Gobbens et al. 2011; Castell et al. 2013). It is a condition of increased risk caused by functional decline and manifested multiple 'frailty' elements. Traditionally elements like weakness, poor endurance, weight loss, low physical activity and slow gait speed are seen as manifestations of frailty (Fried et al. 2004). However, in addition to these physically elements, also psychological and social factors need to be considered. In other words, frailty is a multi-dimensional condition with physical, social and psychological components. It is estimated that a large proportion of the older population are frail, ranging from around 5% among people aged 65–70, to more than 15% in persons aged 80 and over, with significant differences among various subpopulations (Fried et al. 2004; Castell et al. 2013).

Dementia occurs relatively often in old age. The term 'dementia' refers to a syndrome and describes a wide range of symptoms associated with a decline in memory. According to the World Health Organization (2015), 'It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not affected. The impairment in cognitive function is commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation.' Alzheimer's disease is the most prevalent and best known form of dementia. It accounts for 60–70% of all cases of people with dementia (WHO 2015). The second most common type of dementia is vascular dementia, accounting for about 10%. Other types are dementia with Lewy bodies, mixed dementias, dementia as a manifestation of Parkinson's disease, frontotemporal dementia and Creutzfeldt-Jacob disease. There are also reversible conditions that can cause symptoms of dementia, such as thyroid problems and vitamin deficiencies (Alzheimer's Association 2015).

Dementia primarily occurs in the 'oldest old'. After the age of 80, the prevalence increases rapidly from around 15% in the age group 80–84 to almost 50% among the 95+ population (OECD 2015). It is expected that worldwide the number of people suffering from dementia will rise from 47.5 million at present to 75.6 million in 2030 and 135.5 million in 2050 (WHO 2015). In the Netherlands, dementia is in the top five of diseases with the highest mortality among women, and it accounts for 10.3% of total health spending in the Netherlands, being the most expensive disease (RIVM 2020a).

Comorbidity can be conceived as the presence of additional diseases in relation to an index disease in one individual, when the nature of conditions, the time span and sequence of conditions are considered (Valderas et al. 2009). This assumes one disease taking a central place (for instance Alzheimer's disease), in terms of being dominant in terms of the care and well-being of the individual. *Multimorbidity* is defined as the 'co-existence of two or more chronic conditions, where one is not necessarily more central than the others' (Boyd and Fortin 2010: 453). This implies that differentiating the nature of conditions is critical to the conceptualization of comorbidity (Valderas et al. 2009).

Data on incidence and prevalence of multimorbidity are complex to aggregate. Studies vary in the populations being studied, sources of data, data collection methods, age groups and diagnoses that are included (Boyd and Fortin 2010). Data from The Netherlands suggests that around two thirds of the Dutch seniors (65+)

have more than one chronic condition. In the 85+ population, this is around 85% (Van Oostrom et al. 2011). However, multimorbidity is not only a phenomenon in the older population. An Australian cohort study found more than 40% of the people with multimorbidity are younger than 60 years of age (Boyd and Fortin 2010). The bad news is that prevalence of multimorbidity is rapidly increasing; the good news is that most older people with multimorbidity remain independent and self-supporting, and most people do not feel limited in daily functioning. However, this is different in the oldest age group. In 2018, 31% of the general population on the Netherlands suffered from multimorbidity, and of the 70 + population, more than 70% had three or more chronic conditions (RIVM 2020b).

Studies into the comorbidities of dementia are scarce. From the few studies that exist, it is known that people with dementia have on average two to eight additional chronic diseases or comorbidities. One of the larger studies among nearly 73,000 people aged 65 and over in Spanish primary care centres showed that 12% of the people suffering from dementia had dementia as the only diagnosis, almost 70% had at least two comorbidities, nearly 50% had three or more. These figures are around 50% higher than in the total older population. Like in the general population, hypertension and diabetes were most often observed among people with dementia. However, the conditions that were most strongly associated with dementia are Parkinson’s disease, congestive heart failure, cerebrovascular disease, anaemia, cardiac arrhythmia, chronic skin ulcers, osteoporosis, thyroid disease, retinal disorders, prostatic hypertrophy, insomnia and anxiety and neurosis. Some of these can be considered as risk factors, others as complications and others just as comorbidities (Poblador-Plou et al. 2014). What these studies show is that dementia often does not come ‘alone’ and that, also related to ageing, more health challenges have to be faced. Further, there is some evidence of a ‘lack of continuity in healthcare systems and structures for people with dementia and comorbidity, with little integration or communication between different teams and specialties’ (Bunn et al. 2014, p. 11).

Frailty, dementia, co- and multimorbidity are multi-faceted conditions, which require multi-faceted interventions. These multiple, mental and physical problems are often associated with (psycho-) social problems, such as limited participation in society, loneliness or weak social relations, restricted mobility, feelings of meaninglessness or uselessness, anxiety, depression and loss of dignity. From a traditional point of view of health care—being compartmentalized and organized according to medical, paramedical, psychosocial and social disciplines and organizational entities—these needs cannot be met by simply adding up single interventions. On the contrary, coherent multiple interventions are required from professionals, but also from non-professional carers, such as next of kin and neighbours, as well as by the community at large (Nies 2014). In our view, the perspective should be oriented to the new—above depicted—concept of health, in strengthening self-management and resilience. Thus, an integrated approach for these groups of people is needed which goes beyond connecting medical and social care. The new paradigm of health needs focuses on domains such as bodily functions, mental functions, perception, spiritual/existential issues, quality of life, social and societal participation and daily functioning (Huber et al. 2016). To put it in simple wordings: it is about ‘living your day-to-day life in a satisfactory way’.

In practice of care delivery, this means that while drafting an individual care/support plan with a person suffering from dementia, one needs first to discuss what matters for this person. Before thinking in solutions for care and support, a deeper insight into what is important for a satisfactory, meaningful way of living is necessary to guide interventions that do not only address the physical and mental condition. It is about how the household can be run, how social contacts can be maintained, what the person can do or mean for his or her relatives, what role intimacy and sexuality plays, whether membership of activities such as a choir or a lunch club, whether spiritual needs are being met and so on. It requires professionals to have attention beyond traditional professional domains. It requires care providing organizations to operate in collaboration in networks of relevant professional and non-professional organizations (volunteers, citizens’ initiatives). It requires dementia friendly communities, in which public (police, clubs, public transport, etc.) and private services (shops, restaurants, museums, etc.) and infrastructure (signage, ramps, housing, etc.) are attuned to people with dementia (Davis et al. 2009; Nies 2016).

41.3 Inter-organizational Collaboration by Care Standards

In order to organize care and support for older people with complex needs, new coherent inter-professional and inter-organizational arrangements are required. As in many countries, in the Netherlands, care and support for people with dementia could and can be improved. Although GP services, diagnostic clinics and home care are available for all persons in the Netherlands, the quality of dementia care is still subject to shortcomings and inter-regional differences. Areas for improvement include early detection of the disease, support after medical diagnosis and under-diagnosis of patient and caregiver depression. Lack of care coordination, timely referrals and information flows between health professionals and informal carers are other improvement areas (Minkman et al. 2009).

To improve dementia care, a number of incentives were initiated over the last fifteen years. At this moment, there are about 85 dementia care networks in the Netherlands. In these networks, professionals and managers of different organizations (e.g. mental health care, home care, long-term care, municipalities) and local Alzheimer users’ organizations work together for more coherent dementia care. The needs as defined by users and their informal carers, formulated in their language, were taken as the point of departure for the regional plans (Nies et al. 2009; Minkman et al. 2009).

To prevent that every region had to figure out their own way of setting up inter-organizational arrangements, for this purpose, a so-called care standard can be helpful. A care standard is a document developed multidisciplinarily, which describes what the important ingredients are for dementia care and support, based on the most state-of-the-art (evidence based) knowledge and guidelines. Based on this national standard, solutions can be contextualized to adapt to the specific needs of the local communities (Nies 2016).

The emergence of the dementia care networks and the needed collaboration between a wide range of professionals showed that for providing the best care and support guidelines from one perspective or profession were not sufficient. Therefore, in 2013, the first national care standard for dementia was developed, led by Alzheimer Nederland, supported by Vilans (Alzheimer Nederland, Vilans 2013). The instrument resembles to a certain extent the NICE guideline on *dementia, disability and frailty in old age* (NICE 2015) but is more specific in term of what in these services should be organized. In 2020, an updated version of this standard was published.

The process of developing a care standard, as it is presently carried out in the Netherlands, is time consuming, as all relevant professionals and stakeholders need to be involved. Professionals, providers, service users and healthcare insurers need to agree on the standard and authorize it. This is a requirement for being acknowledged by the National Health Care Institute, which gives a legal status to the standard.

The most recent standard focusses on general conditions for adequate dementia care as well as good care and support in the four phases of dementia:

General conditions for quality dementia care 1. Advance care planning 2. One care/life plan 3. Case management 4. Coordinated network of services	
Phase of uncertainty 5. Regional information structure 6. Signalizing 7. Signalizing (specific target groups)	Diagnostic phase 8. Diagnostics: physical, mental, functional and social
Living with dementia 9. Palliative support: from life extension to maintaining functions to comforting 10. Discussing with person and informal carers how to deal with consequences 11. Daily support in personal and domestic tasks 12. Supporting meaningful activities 13. Balancing between safety, autonomy and privacy 14. Medical and non-medical treatment 15. Use of medicines 16. Emergency services/crisis intervention 17. Polyclinical hospital care 18. Intermediate admission in (mental) hospital) 19. Respite care 20–24 Nursing home care (information, ownership and homeliness, environmental aspects, diversity, informal carers)	Dying and aftercare 25. Care for loss and mourning of informal carers

The recommendations describe what ‘good’ care should be, based on—for as far as possible—established guidelines and consensus, and how it should be organized. The standard does not define *which* professional (group) is eligible for providing care, this is held to the professional organizations and the local context.

A large number of dementia networks will implement this renewed care standard. There is a gap between the national (total) standard and the actual delivery of individual person-centred dementia care. To bridge this gap, region-specific or local standards or pathways need to be elaborated, to translate the ‘national standard’ into a regional version. This is a necessary step, because the standard gives a functional description of what should be considered or arranged, not whose task this is or how it looks like in practice. Translating the national standard into a regional version facilitates implementation and guides the steps that can be taken.

41.4 Implementation

In order to further and optimize regional dementia care according to the care standard, a number of quality indicators are proposed. The regional dementia care networks can choose which indicators they prefer to use, in accordance with their regional priorities for improvement.

However, organizing regional networks is not an easy task. Issues that are frequently encountered are (Van Maar et al. 2014):

1. Significant differences between regional networks, also with respect to the collaboration with municipalities (which have a role in social support and prevention);
2. Commitments on quality, diagnostics and follow-up activities exist, but are not always followed in day-to-day practice;
3. No structural funding for case management;
4. Inter-organizational collaboration not fully implemented;
5. Structural funding of the networks;
6. Client perspective is not always in focus.

The regional networks are expected to work according to the principles of the care standard, but this is not a stand-alone endeavour. The coordinators are often connected to other networks in the region, in particular generic networks for care for frail older people and networks for palliative care. Some of the networks are focusing on one of the domains of dementia care, such as case management, others are focusing on the full range of services.

The care standard provides an external framework for inter-organizational collaboration. It is also used as a basis for commissioning services by healthcare insurers, although not very strictly.

The example demonstrates that a care standard provides a national framework based on (inter)nationally agreed evidence and consensus which is to be translated at regional level as a basis for—in the terminology of Valentijn et al. (2013)—normative and functional integration of services. It needs regional or local contextualization to make collaboration work.

41.5 Personalization

The term 'Care Standard' suggests that care is standardized and that personalized care is not feasible. However, the instrument of a care standard does recognize individual needs and requires tailoring services to needs. There are two ways of tailoring service provision to needs: one is to apply methodical principles of person-centred care in interacting with the service user and his or her informal carers and that are applicable across various groups of service users. The other is to develop more evidence on which interventions work for particular groups of users and—more specifically—for which persons and under which conditions.

For person-centred care, a number of main ingredients can be defined. The key is putting the person and the family at the heart of every decision and empowering them to be genuine partners in their care. The focus shifts to new models of care that change the conversation from 'What's the matter?' to 'What matters to you?' A starting point of person-centred care is that people's care preferences are understood and honoured, including at the end of life. In providing care, collaborating with partners on programs designed to improve engagement, shared decision-making and compassionate, empathic care is important (Barry and Edgman-Levitan 2012). In this scope, it is not only about care, but a much broader perspective on daily living is captured, in line with the aforementioned new paradigm of health (Huber et al. 2011, 2016). Working with partners to ensure that communities are supported to stay healthy and to provide care for their loved ones closer to home is the leading societal perspective.

On a more detailed level, personalized care requires evidence on 'what works for whom?' Most studies on interventions in frail older people and people with dementia are generic. They do not make distinctions between the characteristics of the subgroups, the circumstances in which they are effective and the specific outcomes. However, effects of interventions, also in multi-problem target groups, can be enhanced by tailoring services to the idiosyncrasies of the person and his or her social network (see: Van Mierlo et al. 2010; 2012).

Most people with dementia show one or more behavioural and psychological symptoms such as psychological pain: depressive, anxious, apathetic, psychotic and aggressive behaviour (Bakker 2010). Both people with dementia and their informal caregivers experience these symptoms as burdensome, whether they reside at home or in a residential setting. The Dutch Healthcare Inspectorate (2015, 2020) concluded that healthcare professionals often respond tardily or inadequately to these behavioural and psychological symptoms of dementia. Exemplary for this is that so-called ‘calming’ medication is prescribed, on a non-targeted manner. It would be more appropriate to apply a stepwise approach, involving person-centred and more effective solutions. To be able to do this, it is essential to know the causes of the behavioural and psychological symptoms. In other words: first get to know and understand the person with dementia well. Only then will one be able to offer good personalized care to the person and the informal carers. For this, it is essential that both are in a central position and actively participate in finding the best solutions. It is also vital that all involved healthcare professionals discuss and coordinate everything with each other in an integrated way. A personalized, integral approach can prevent unnecessary stress and escalation in people with dementia, their informal caregivers and the healthcare professionals.

An integrated approach has been developed in the Netherlands based on the Dutch Guideline on behavioural and psychological symptoms of dementia (BPSD) (Verenso/NIP 2018). This led to the *personalized integrated stepped care approach to BPSD* (**STIP** method). This approach is built on two elements: (1) Five phases of integrated methodical clinical reasoning and (2) Four ‘Stepped Care’ interventions.

The **STIP** method follows these principles:

Phase A Detection: Early detection of BPSD with the Neuropsychiatric Inventory (NPI; Cummings et al. 1994) provides insight into the type and severity of the problems, including the degree of burden experienced by the informal caregiver. Next to that, the biography provides substantive information about the person's life course and the person’s most important positive and negative experiences.

Phase B Diagnosis and Broad Analysis: Identifying basic needs, pain, physical, psychological and social needs.

- **Step 1 Basic Approach**: Based on the NPI, biography and the broad analysis, describing the approach to the client. It is important that the nurse is able to be really present, can show empathy for the person as now known from the broad analysis and can show respect for the client.
- **Step 2 Personalized Day Program:** Applying a personalized balance between rest, cleanliness and regularity, again based on the NPI, biography and broad analysis.

Phase C Integrated Treatment Plan: Including achievable goals based on Phase A and B.

- **Step 3 Emotion-Oriented Care:** Applying, e.g. reality orientation, validation, snoezelen, reminiscence to necessary extent
- **Step 4 Pain Medication/Psychotherapy/Psychopharmacology**: Applying, e.g. life review, cognitive behavioural therapy, system therapy and targeted medication to necessary extent.

Phase D Multidisciplinary evaluation of interventions: Assessing progress based on shared decision-making and interdisciplinary consultation.

Phase E Reanalysis: Applying new NPI and broad analysis, checking implementation of stepped care interventions based on new information, adjusting interventions to necessary extent.

The **STIP** method is supported by a Web application that is specifically designed to support this integrated methodical clinical reasoning approach. In this Web application—which is also used in Sweden and Japan, among other countries—care professionals can keep track of the BPSD of clients. Such a tool supports the implementation of an integrated, methodical manner of working, thereby facilitating a stepwise approach with person-centred and effective interventions.

41.6 Future Perspectives

The current state of play is that dementia is a syndrome that with some exceptions cannot be cured, is multi-faceted and asks for person-centred integrated care. The same holds for frailty and to a large extent for the accompanying complex multimorbidities. The symptoms can be alleviated, and people can be supported in their self-management and resilience. At macro-level, the best strategy is prevention of diseases and disability. Recent research shows that the prevalence of dementia is substantially decreasing in some countries if corrected for age, sex, area and deprivation status. Although there are various factors that could have increased dementia prevalence at specific ages, associated with diabetes, survival after stroke and vascular incidents, it appears that other factors such as improved prevention of vascular disease and higher levels of education appear to have a greater effect (Matthews et al. 2013; Larson et al. 2013). This implies that preventive measures, improvements in treatment and care and disease modifying interventions combined will be the most effective strategy for the future (Prince et al. 2013).

The OECD (2015) describes the key elements of such a strategy. Generic lifestyles recommendations such as non-smoking, physical activity, healthy diets, cognitive training and formal education are linked to reduced risk of dementia. Treatment of medical conditions such as brain injury, diabetes, mid-life obesity, mid-life hypertension and depression is a second line of reducing the risk of dementia. What at present cannot be influenced are hereditary factors and age.

Following this analysis of risk factors, the OECD defines ten elements of dementia policy:

1. Risk reduction by healthy ageing strategies targeting generic risk factors;
2. Selective early diagnostics (standardized needs assessment) for people who are concerned about symptoms and post-diagnostic support to people;
3. Safer communities for and more acceptance of people with dementia by awareness raising, dementia education at schools, training of people who get in contact with people with dementia in the community;
4. Support of relatives and friends who care for people with dementia respite services, peer to peer support networks, training to informal carers, etc.;
5. Safe and appropriate environments including alternatives to institutional care for living with dementia in dignity, making houses suitable for living with dementia and communities safer and more accessible for people with dementia (dementia friendly communities);
6. Access to safe and high quality long-term care services by recruiting and training a dementia care workforce, systematic attention to behavioural symptoms, including the use of antipsychotics and physical restraints and promoting independence and self-determination through user-directed support;
7. Health services recognizing and dealing with people with dementia effectively, supported by registries or electronic health records, trained, dedicated and specialized staff in hospitals;

8. Increasing opportunities for dying in dignity in the place of people's choosing, trained home care staff in palliative care;
9. Coordinated, proactive and closer to home delivered primary care, multidisciplinary management of comorbidities;
10. Applying the potential of technology to support dementia care.

The OECD translates user-directed support also in financial terms for users and informal carers. It signals that financial systems should support independence and give control to service users and their families. This can be strengthened by appropriate benefits in the form of cash benefits, vouchers or personal care budgets, instead of services in kind. This allows people with dementia to choose the type of services they prefer, which may go well beyond traditional care and across financial, legislative and professional barriers.

Changes in funding and legislation, in roles between stakeholders and in collaboration also have consequences for governance. Governance of (traditional) organizations needs reframing, because inter-organizational collaboration becomes more important and asks for new dynamics and governance which is linked to the community (Nies and Minkman 2015).

Lastly, it can be argued that most of the above-mentioned elements for dementia policy are also relevant for frail older people and people with multi-morbidities. Hence, one of the key elements is safe and supportive living at home, be it in the community or in a care facility supported by—when useful—technology and by informal caregivers and people in the community. These elements relate to the earlier described new concept of health of Huber (Huber et al. 2016) in which 'whole person thinking' is key.

41.7 Conclusions

The challenges of care for frail older people with dementia and multimorbidity are increasing, partly due to our improved healthcare services and increased life expectancy. This challenge is not an easy one. It requires innovative approaches in order to face these challenges and to reduce current and future burden of service users, their families and society. It is a challenge that requires new care paradigms and new organizational paradigms. Working towards the principles of a new concept of health, working towards personalized and person-centred care in networks, based on shared normative and functional frameworks, needs full attention of policy makers and care providing organizations. But the challenge of an ageing population is not merely a professional task in the field of health, long-term and social care. The solution also lies in the community. It has to get tuned to a changing demography, supporting people with limited functioning and supporting healthy behaviour at all ages. Communities need to get acquainted with a changing population, where people sometimes behave 'differently'. Therefore, health and long-term care professionals and services should not limit their focus of integrated care to their peers or care partners; it is a challenge to society and to local communities.

New questions need to be addressed such as how to create adoptive and resilient communities and organizations? What are effective approaches and which preconditions are necessary? How do we improve collaboration between the public sector in a broad sense such as schools, clubs, welfare services, public transport, police on the one hand and the private sector and private life of citizens, such as housing, shops, banks, neighbours' support, volunteers and the dementia care sector? Examples such as dementia friends (see: https://www.dementiafriends.org.uk/) and dementia friendly communities (see: https://www.alzheimers.net/2013-12-12/building-dementia-friendly-communities/) (Scharlach and Lehning 2013) are promising, but ambitious. Turning population ageing into a blessing requires high ambition on a wide variety of societal actors, integrating their strengths to meet the challenging social and individual needs of frail older people suffering from dementia and accompanying problems.

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Integrated Palliative and End-of-Life Care

42

Health and Social Care and Compassionate Communities to Provide Integrated Palliative Care

Emilio Herrera Molina, Arturo Álvarez Rosete, Silvia Librada Flores, and Tania Pastrana Uruena

42.1 Introduction

The work of Dr. Cicely Saunders, founder of the modern hospice movement in the 1960s, is considered the key milestone in the development of palliative care services (Saunders 2005). In contrast to the focus on curing in the contemporary medicalized paradigm, palliative care aims at alleviating the suffering of people with advanced diseases and who are at the end of their lives, supporting them, their families and caregivers with dignified, sensitive and patient-centered care (Hall et al. 2011).

Over 29 million (29,063,194) people worldwide died from diseases requiring palliative care in 2011. The estimated annual number of people in need of palliative care at the end-of-life is 20.4 million. The biggest proportion, 94%, corresponds to adults of which 69% are over 60 years old and 25% are 15–59 years old. Only 6% of all people in need of palliative care are children (WHO 2014a, b). Europe may count as many as 7000 patients per year per million inhabitants requiring palliative care at the end-of-life. Of these, 60% would require palliative care provided by a specialized palliative care team (Centeno et al. 2013).

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Data on palliative care need to be set within the context of the growing chronic care challenge to contemporary health systems, as the chronic patient of today will very possibly become candidate to palliative care as the disease progresses. Furthermore, due to the fact that 40% of the total health care expenditure of a chronic patient concentrates at the end-of-life, palliative care becomes an obvious key element in any chronic care strategy.

There are, however, better quality and more cost-efficient ways of treating people at the later stages of their chronic diseases and end-of-life than treating them in acute hospitals. As this chapter will show new innovative models of people-centered integrated palliative care, involving health and social care staff working together with sensitized community networks, which are flourishing around the world.

42.2 Defining Palliative Care and End-Of-Life Care

The World Health Organization (WHO) has defined palliative care as "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification, impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (WHO 2010).

Through the consideration of pain as well as other problems, the 2004 WHO definition of palliative care is itself a call for integrated person-centered care. Recent conceptual developments have added further explanation to the WHO definition to highlight the comprehensive nature of palliative care and in particular, care not limited to the moment of dying. The Worldwide Palliative Care Alliance (WPCA) policy statement on defining palliative care supports palliative care earlier in illness, so that it is provided "alongside disease-modifying treatment such as anticancer therapy or anti-retroviral therapy, for people with significant symptoms or who require other support" (WPCA 2009). The WPCA policy statement includes the following key points:

- palliative care is needed in chronic as well as life threatening/limiting-conditions.
- there is no time or prognostic limit on the delivery of palliative care: it should be delivered on the basis of need, not diagnosis or prognosis.
- palliative care is not limited to specialist palliative care services but includes primary and secondary level care.
- palliative care is not limited to one care setting: it is provided wherever a person's care takes place, whether this is the patient's own home, a care facility, hospice inpatient unit, hospital, or outpatient or day care service.

In the English context, the term “end-of-life care” has been used to refer to the care that takes place at a specific period of time preceding death. However, more contemporary uses avoid such meaning and instead refer to “the care and support needs of patients and carers regardless of diagnosis and regardless of the estimated period of time before death” (Addicott 2010).

The traditional service model conceptualized palliative care as replacing curative care once the latter were no longer effective. Instead, as Fig. 42.1 shows, the modern model (Ferris et al. 2009; Hui and Bruera 2015) sees palliative care as being provided at early stages of the disease to control symptoms to alleviate pain while the disease(s) progresses. This is concurrent with other curative healthcare treatments—hence the term “time based model” (Hui and Bruera 2015). Such approach requires the inclusion of supportive care, palliative care, hospice care and bereavement as part of a continuum of care.

42.3 Challenges for Providing Care to Palliative and End-Of-Life Patients

As the end-of-life approaches, symptoms prevalent become gradually intense, physical deterioration advances rapidly and the level of dependency grows to be complete. The risk of catastrophic impact on the household economy increases, and

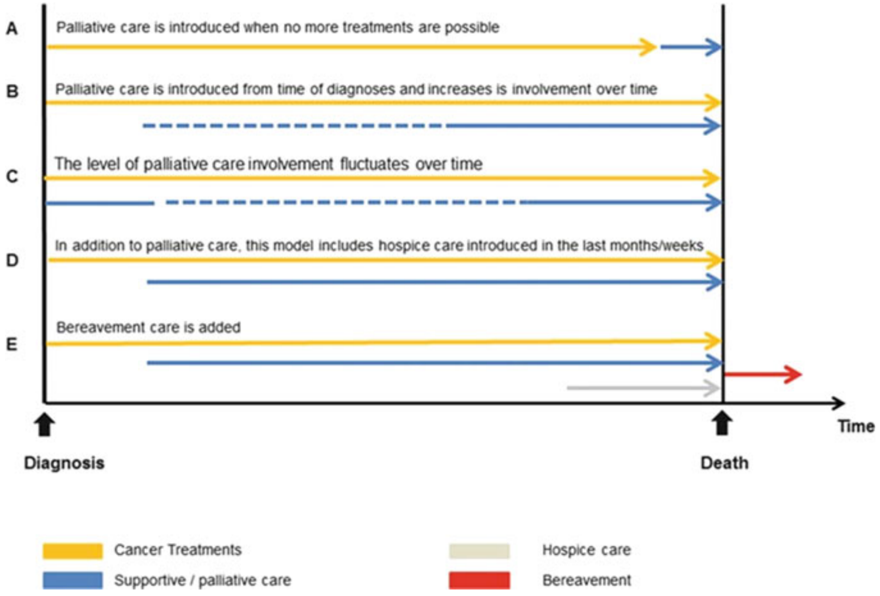

Fig. 42.1 Time-based model. *Source* Adapted from Hui and Bruera (2015)

thus the consequences of the illness are experienced, alongside emotional suffering and spiritual crises, not only by the patient but by his/her family and carers experience as well (Librada et al. 2015).

At a system level, the aging of the population and the chronic disease epidemic are changing how people suffer and what they die from. "Increasingly, more people die as a result of serious chronic disease, and older people in particular are more likely to suffer from multi-organ failure towards the end-of-life" (Davies and Higginson 2004). While traditionally, palliative care programs have been narrowly offered mostly to cancer patients, it is now being increasingly recognized as useful to people with advanced chronic conditions who are at risk of deteriorating and dying (Nuño 2014).

Healthcare systems, however, are not ready to cope with these changing dynamics. Where they exist, services for end-of-life multimorbid patients tend to remain fragmented and uncoordinated. True, many contemporary health systems have set up high-quality palliative care services, either at hospital, hospices or at home. As "most people prefer to remain in their home at the end of their life, various models of home-based end-of-life care exist, ranging from those that primarily offer nursing and personal care, to others that involve multidisciplinary teams" (Gomes and Higginson 2008; Nuño 2014). This, however, poses additional challenges to care systems, among other reasons, due to the progressive decrease in availability of family support networks at home. A retrospective study conducted in the region of Extremadura (Spain) in 2003 with 944 patients who had died showed that the risk of hospital admission (odds ratio) was 50% higher for patients who did not have a social support network at home. The reason for admission to a hospital was related to the lack of social support rather than to difficulties of symptom control. Patients with a Karnofsky index <50% (highly dependent) and lack of social support network, had a chance of 65% versus 45% of those who possessed social support network (Herrera et al. 2006a, b).

If it is not addressed as a cornerstone in the reorganization of the health and social care systems, it will result in their failure in the coming years. The lack of a supportive network increases the demand for more formal or informal social care, but the solution is not to compensate it by super specialized physicians and increased hospital-based services.

42.4 Goal of Integrated Care

42.4.1 What Needs Do End-of-Life Patients Have?

The complexity of each situation at end-of-life and the variety of psychosocial factors lead to a wide range of needs with different grade of severity, all of which need to be addressed. For example:

- Care needs regarding the patients' dependency: Assistance to perform daily activities, reduction of loss of sensory capabilities and compensating deterioration, training habits for improving personal autonomy, safety and protection measures as well as environmental adaptation.
- Caregivers' needs and social support network: Information about available support services, training of professionals and/or informal care givers, development of communication skills, psychosocial support of family members, balance of care activities/tasks and working life, prevention of family collapse, sharing experiences with other caregivers.
- Protection of the social role of the patient: Autonomy in decision making and communication of last wills, spiritual expression, leisure and entertainment, privacy versus intimacy, interpersonal and social relationships.

From the healthcare perspective, the palliative care range of support should not only be limited to provide specially trained medical and nursing services, but also seek to provide emotional support (psychotherapy, counseling, support services and caregiver relief). It should also support dependency care (support in home work/task/activities, support by personal care and occupational therapy) (Librada et al. 2015).

42.4.2 Health and Social Integrated Care Based on Empathy and Compassion

As the discipline of palliative care has been evolving, practitioners have gradually realized that palliative care cannot be considered solely from the health perspective (Juvero 2000; Georghiou et al. 2012). Health and social needs of the patient at the end-of-life and his/her family are closely related and have mutual influence. If any of these aspects is not well addressed, it can result in misuse of resources and overcharge. The lack of adequate social support causes increased consumption of healthcare resources. Although it is still necessary to improve specialized palliative care health teams, it is also relevant to meet the needs of social support for patients and their families (Herrera et al. 2013).

The call for coordination and integration of health and social care services patients at the end-of-life has featured strongly in recent declarations of international organizations. For example, the 2014 European Declaration on Palliative Care has called for

> a paradigm shift in health and social care towards basic palliative care skills for all health care professionals, to empower them to deliver patient-centred family-focused care for all people with a life-limiting illness, based on personalized or tailored care plans, with attention to all needs of the patient and his or her family (European Declaration on Palliative Care 2014; WHO 2014a, b).

Health and social care staff need to work in interdisciplinary teams, using empathy as the basis for analyzing the needs of patients and their families.

The 2014 European Declaration on Palliative Care understands empathy as the cognitive ability to perceive in a common context, what another individual may feel. Also it is described as a feeling of emotional involvement of a person in the reality that affects another with the aim to identify individual patients' and family caregivers' unique combination of needs (European Declaration on Palliative Care 2014). While empathy is a cognitive ability, compassion is the attitude toward others in trying to alleviate other's suffering, "an evolutionary construct that compels us to be concerned about the welfare and suffering of others" (Busek 2014). In sum, quality in palliative care requires people to have both empathy and compassion, forming interdisciplinary teams who are able to work together in a coordinated manner.

42.5 The Integrated Care Path

The specialist literature on integrated care has referred to a number of key elements that make possible integrated care at the service-delivery level, including the existence a single point of entry to holistic care assessments and joint care planning, delivered by multidisciplinary teams where one professional in particular act as care coordinator for patients (Goodwin et al. 2014). The home or the homely setting within the community are "the hub of care" (Ham et al. 2012), the preferred locations, alternative to hospitals, to provide palliative care services. Home is also the "preferred place of death" (Addicott 2010). Thus, the integrated palliative care path is built around these elements and has the home as the primary location of care.

These elements are embodied in the number of international innovative experiences that are providing high-quality integrated palliative care to end-of-life patients (Hall et al. 2011). For example, the Midhurst Macmillan Community Specialist Palliative Care Service in England is a community-based, consultant-led, specialist palliative care program (UK) "which covers approximately 150,000 people in a largely rural area" (Thiel et al. 2013: 7). A multidisciplinary team of nurses (who act as care coordinators), palliative care consultants, occupational therapists and physiotherapists work along side Macmillan Cancer Support volunteers to enable patients to be cared for at home. The team liaise with other healthcare providers, including general practitioners (GPs), district nurses and continuing care teams (Thiel et al. 2013).

The Marie Curie Nursing Service (MCNS) provides home-based care to around 28,000 people at the end-of-life annually in the UK. Although it initially focused on caring for people with cancer, it has increasingly provided care to people with other conditions. Staffed by registered nurses and senior healthcare assistants, the MCNS offers a number of different models of care, ranging from overnight nursing care booked in advance to urgent support in response to crises.

Similarly, in Andalusia, Spain, the Home and Ambulatory Care program of the Cudeca Foundation embodies these same key elements (OMIS 2015). Care to oncology patients is delivered at home by multidisciplinary teams of nurses, physicians, psychologists and social carers. Coordinated by the nurses, the team meets weekly to discuss, evaluate and monitor patients and adjust treatments if needed. Volunteers also have a role in the program by providing support and helping to transport patients from and to their home. Public patients are referred from the regional health service. While at the Cudeca program, there is intense liaising with the primary and hospital care levels, with whom they are aligned through agreed protocols.

The Milford Care Centre (Milford Care Centre 2015) is a voluntary not-for-profit organization which provides specialist palliative care and older person's services in the Mid-West of Ireland. Services include: 47-bed voluntary nursing home; a Day Care Centre for Older Persons; 30-bed Specialist Palliative Care Inpatient Unit; Palliative Care Day Care Centre (Specialist Palliative Care Day Unit); Community based, multi-disciplinary Specialist Palliative Care Team; and an Education, Research and Quality Unit.

Referral to specialist palliative care is made through the GP or hospital consultant. Patients living at home remain under the care of their GP, but they get the support from the Specialist Palliative Care team, which comprises a nurses (Clinical Nurse Specialists; Registered Nurses, Care Assistants), physiotherapists, occupational therapists, social workers. Then, the Palliative Day Care Centre bridges the interface between homecare services and Specialist Palliative Care Inpatient unit, so that patients can be referred smoothly from one to the other as required. In addition to the professionals above mentioned, the Day Unit multi-disciplinary team comprises dieticians, speech and language therapists, music and art therapists, etc. Referral to the inpatient unit can be also be made through the Specialist Palliative Care Day Unit or Hospice at Home services. Patients are accepted based on an overall assessment of their needs (e.g., medical needs, social circumstances, support required, etc.).

Weekly multidisciplinary care planning meetings are held in each area of care (Inpatient Unit, Hospice at Home service and SPC Day Unit). New patients are reviewed and care plans discussed and agreed; care plans for existing patients are also reviewed and updated as appropriate. Decisions about discharge of patients are discussed and agreed. Also, all deaths that had taken place since the previous meeting are reviewed and decisions made as to what level of immediate bereavement support may be required by particular family members.

In eastern Canada, the Nova Scotia Integrated Palliative Care strategy (Nova Scotia 2015) embodies the philosophy that care is delivered in a seamless manner by the various health care providers and services that function in the community. It is person- and family-centered rather than system-centered. There is integration between primary, secondary and tertiary care with a shared responsibility among all care providers along the continuum. Support to patients and families is available early in the disease process, and adapts as one's condition advances and changes. Support to families also continues on during the bereavement stage.

To meet the goal of keeping patients at home as much as possible, continuous and 24/7 support is very much needed, especially at night time and weekends. This can be delivered though telephone service or similar. In the UK, the Partnership for

Excellence in Palliative Support (PEPS) (Sue Ryder 2015) service provides 24-h support to patients in the last year of life and coordination of palliative care between 15 organizations across the county of Bedfordshire in England. A telephone number held at the PEPS center offers a single point of contact to provide a seamless service for patients, their carers and care professionals from qualified nurses when advice and support are needed. In Spain, the regional government of the Basque Country launched a specialized palliative home care program in 2014 termed SAIATU ("to try" in Basque language) (Herrera et al. 2013; Millas et al. 2015; Nuño 2014). The program provided in-home social support services rendered by specially trained caregivers, to complement the palliative clinical services offered by the public system as well as 24/7 telephone support. Initiated as a pilot in the Basque province of Guipuzcoa, lack of funding has prevented the experience to be sustained and scaled-up, however.

Integrated palliative care is not, however, exclusive of Western developed countries. The Hong Kong Special Administrative Region of China, for example, has introduced integrated palliative care pathways (Lo et al. 2009).

Colombia is taking promising steps toward the setting up of high-quality integrated palliative care programs and teams, applying the NEWPALEX® method developed by NewHealth Foundation (NewHealth Foundation 2015). This method sets up integrated care pathways and establishes specific programs and resources at the service-delivery level and offers basic and intermediate training for palliative care specialists. At present (Feb 2016), one-third of Colombia's population (around 16 million people) are registered with health insurance companies that, having applied the NEWPALEX® method, have included integrated palliative care in the basket of services to their insured members. For example, the model of palliative care included in basket of services of the health insurance company SURA is delivered by a multidisciplinary team who care for the physical, social, emotional, spiritual and psychological needs of patients (EPS SURA 2016).

At the core of the Colombian experience is the reorganization of the funding models by which health insurers pay health care providers for the existence and quality of palliative care services. These insurers are contracting with more than ten healthcare providers who have set up high-quality palliative care resources and programs.

42.6 Results of Integrated Palliative Care

There is growing research evidence that confirms that in-home palliative care achieves better quality of care, higher satisfaction rates and with lower costs than traditional models of hospital-based care (Brumley et al. 2007; Gomes et al. 2013). Results from the innovative experiences described above come to strengthen the case for integrated palliative care for patients and their families.

According to research, home-based palliative care provided under the Marie Curie Cancer Care MCNS model reduces the demand for costly and often undesirable hospital care, and allowing more people to die at home (Chitnis et al. 2012). 76.7% of those who received care under the MCNS model died at home, while only 7.7% died in hospital. In contrast, 35.0% of the controls died at home, while 41.6% died in hospital.

The SAIATU program has shown how resources developed from a social care perspective and with an emphasis on care integration can be cost-effective and efficient for a healthcare system and increase the satisfaction of families. Thus, comparison of SAIATU with traditional care (primary and specialized health care) and advanced care (primary and specialized health care and home care) resulted in a reduction in the intensity of external specialized care services utilization, emergency room visits, hospital admissions and length of hospital stays. Moreover, SAIATU favored the community intervention of primary healthcare professionals by increasing calls and interaction with caregivers trained by the family physician and community nurse. In consequence, it avoided diversions to unnecessary emergency services or inadequate early intervention of unnecessary specialized means (Herrera et al. 2013).

These results support other studies confirming that the activity of palliative care teams at home improves the performance of primary care professionals (Herrera 2006). This suggests that a more specialized palliative support, both medically and socially, does not antagonize with a strong primary care, rather on the contrary, it promotes synergies between levels of care and offers alternatives to unnecessary hospital admission. SAIATU's caregivers helped to detect problems in the patient early, liaising with primary care staff to visit patients when necessary. Finally, the results of the SAIATU also favored the possibility of dying at home when that was the preference of the patient. These data show that the integration of social status and health at the end-of-life enhances the overall efficiency of two subsystems: the health and social sectors.

In Colombia, first preliminary results of the country-wide transformative program explained above is showing reductions of approximately 10–15% in the costs of care at the end-of-life compared to standard treatments (mainly provided at hospital) (Montoya et al. 2014).

42.7 A New Paradigm: Compassionate Communities

In the context of the new paradigm of people-centered integrated care models, true integrated palliative care does not stop at the integration of health and social care services, regardless of how crucially important this is. Community-centered models for end-of-life care have been proposed, such as the "circles of care" model by Abel et al. (2013) "which appreciates the persons with illness in their everyday context of living within their communities, not separate individuals with needs that have to be met" (Abel et al. 2013: 3). The "circles of care" around the person cannot be fulfilled just by interdisciplinary healthcare teams, even if supplemented by trained social services. The care system will not be able to provide the care needed. It also requires the involvement of society through awareness and the raising of community networks. The real social change must come from the sensitized community, caring for their loved ones. Thus, the keystone of the new paradigm of people-centered integrated palliative care lies in the existence of networks of care (Herrera 2015).

At the international level, the "compassionate communities for end-of-life care" movement seeks to promote and integrate palliative care socially into everyday life (Kellehear 2005). People are trained to care for people at the end-of-life. But this does not stop at creating and managing volunteers' teams. The concept goes much further: The aim is to enable society to accept and be involved in the accompaniment and care at the end-of-life as a natural act of compassion.

The movement is quickly spreading worldwide. In Kerala (India), the Institute of Palliative Medicine has been working for over 20 years in training community members and in promoting awareness of palliative care, and is now a World Health Organization (WHO) Collaborating Center for community participation in Palliative Care and Long Term Care. One of the key projects of the Institute, the "Neighborhood Network in Palliative Care" project has more than 60 units covering a population of more than 12 million people of Kerala and is probably the largest community-owned palliative care network in the world (Kumar and Numpeli 2005; Kumar 2013).

In Ireland, the Milford Care Centre is also urging forward the movement of Compassionate Communities through awareness and leadership experiences (Milford Care Centre 2015). In Spain, the non-for-profit organization, the NewHealth Foundation promotes the development of care networks between organizations and associations under the slogan "A Global Community United by the Vocation to Care" (NewHealth Foundation 2015). Through the leadership of the NewHealth Foundation, similar initiatives are beginning to evolve in Argentina and Colombia as well.

42.8 Conclusion

Over the past 40 years, palliative care programs around the world have aimed at alleviating the suffering of people with advanced diseases who are at the end-of-life, supporting them, their families and caregivers with dignified, sensitive and patient-centered care. As the discipline of palliative care has been evolving, practitioners have gradually realized that palliative care cannot be considered solely from the health perspective, but needs to incorporate social care and the involvement of the community as well.

The integrated palliative care model proposed in this chapter involves a set of professional health and social care services, which envelop the support and assistance of family and volunteers from an empowered community capable of caring for their families and neighbours.

In the context of the growing chronic care challenge to contemporary health systems, palliative care provides better quality, more cost-efficient ways of treating people at the later stages of their chronic diseases and end-of-life than treating them in acute hospitals. Thus, as a key element in any chronic care strategy, palliative care shows the way forward in the design of a service delivery model truly embedded in the emerging integrated care paradigm.

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Physical and Mental Health

43

Chris Naylor

Physical and mental health is closely dependent on each other. Evidence reviewed in this chapter demonstrates that having a physical health condition significantly increases the risk of developing a mental health problem and vice versa. More broadly, mental health is a vital component of health and well-being and is influenced by the activities of all parts of the healthcare system. It is for this reason that the World Health Organization has long argued that there is 'no health without mental health' (Herrman et al. 2005).

Despite this interdependency, it often remains the case that the institutional architecture of health systems, the design of reimbursement systems, and the training and education of professionals, all tend to reinforce structural and cultural barriers between mental and physical health care. As described below, these barriers mean that mental and physical health is often treated as if existing in isolation of each other.

When thinking about this dimension of integrated care, there are three separate but closely related issues that require consideration:

1. Comorbidity between long-term physical health conditions and mental health problems is highly common and has a significant effect on outcomes.
2. Psychological distress is frequently expressed in the form of physical symptoms —so-called medically unexplained symptoms that lack an organic cause and are often challenging to manage.
3. All physical illness can have an important psychological or emotional component, regardless of whether or not a diagnosable mental health problem is present.

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The first two of these issues relate to defined client groups, whereas the third is a cross-cutting issue applicable to any form of health care. All three have profound implications for integrated care. In this section, we will focus largely on the specific needs of people with comorbid conditions and/or medically unexplained symptoms. However, many of the principles discussed are also relevant to the wider issue of the psychological and emotional aspects of health.

The prevalence of comorbid mental and physical health problems is high. A review of the literature suggested that overall, around 45% of people with mental health problems also have a long-term physical health problem. Similarly, people with cardiovascular diseases, chronic respiratory diseases, diabetes or chronic musculoskeletal disorders are around two to three times more likely to experience a mental health problem than the general population (Naylor et al. 2012). The strength of this interaction is exacerbated significantly by social deprivation—among those with multiple physical disorders living in the lowest socio-economic groups, the prevalence of mental ill health is almost 50% (Barnett et al. 2012). Medically unexplained symptoms are also highly common, accounting for an estimated 15–30% of all primary care consultations (Kirmayer et al. 2004) and, in one study, over 20% of all outpatient consultations among the most frequent attenders (Reid et al. 2001).

Physical health outcomes are poor among people with comorbid mental health problems. Mortality rates among people with cardiovascular diseases or diabetes are significantly higher for those who also have depression (Blumenthal et al. 2003; Junger et al. 2005; Lesperance et al. 2002; Park et al. 2013). Outcomes are particularly poor for people with schizophrenia or other psychoses, for whom excess mortality largely attributable to poorer physical health leads to a life expectancy 15–20 years below the general population (Laursen et al. 2014). The presence of mental health problems can lead to reduced access to care for physical health problems—for example, in a Canadian study revascularisation rates among people with ischaemic heart disease were found to be significantly lower for those who also had dementia or psychosis, after adjusting for clinical need (Kisely et al. 2007).

The interaction between physical and mental health has significant consequences in terms of resource utilisation and costs. In an analysis conducted in the UK, emergency department attendance rates were three times higher and unplanned hospital admissions were five times higher among people with mental health problems, compared to a matched control group drawn from the general population, with most of these attendances and admissions being for physical health care (Dorning et al. 2015). A large number of other studies have confirmed that conditions such as depression significantly increase the risk of unplanned hospitalisation for ambulatory care sensitive conditions (Davydow et al. 2013). Overall, by interacting with and exacerbating physical health problems comorbid mental health problems are estimated to increase the costs of long-term conditions by at least 45% per affected person. This suggests that at least 12% of all expenditure on chronic diseases in high-income countries is linked to poor mental health and well-being (Naylor et al. 2012). In addition to this, a conservative estimate of the cost of medically unexplained symptoms is around 3% of the entire health budget in the UK (Bermingham et al. 2010).

These and other findings suggest there is a strong case for integrating physical and mental health care more closely. Figure 43.1 lists 10 areas where the opportunities to achieve better integration are particularly striking (Naylor et al. 2016). People with comorbid mental and physical health problems, as well as those with medically unexplained symptoms, should be seen as priority target group for integrated care. The rest of this section outlines some of the challenges involved in providing integrated care to these client groups and describes the evidence-based interventions available for doing so.

43.1 Challenges Involved in Integrating Physical and Mental Health Care

43.1.1 Disease Factors

Integrating mental and physical health care is not one challenge, but rather a whole set of related challenges. This follows from the fact that underneath the umbrella term ‘mental health problems’ sits a wide array of very different conditions. This includes various kinds of depressive and anxiety disorders, psychoses such as schizophrenia, eating disorders, personality disorders, neurocognitive disorders such as dementias or delirium, and substance abuse disorders. Forms of integration

Prevention / public health	1. Incorporating mental health into public health programmes
	2. Health promotion and prevention of physical ill health among people with severe mental illnesses
General practice	3. Improving management of ‘medically unexplained symptoms’ in primary care
	4. Strengthening primary care for people with severe mental illnesses
Chronic disease management	5. Supporting the mental health of people with long term conditions
	6. Supporting the mental health of carers
Hospital care	7. Mental health liaison in acute general hospitals
	8. Physical health liaison in mental health inpatient facilities
Community / social care	9. Integrated support for perinatal mental health
	10. Supporting the mental health needs of people in residential homes

Fig. 43.1 Key areas where integration of physical and mental health is needed. *Source* Naylor et al. (2016)

that may be successful for one of these will not necessarily translate to another. However, there is enough commonality for a discussion of generic approaches and issues to be meaningful.

A distinctive feature of mental health is the degree to which needs are not currently met. For many mental health problems, this far exceeds levels of unmet needs observed in physical health—for example, even in high-income countries it is typical for less than half of those with depressive or anxiety disorders to be receiving any form of formal treatment, and in the case of alcohol and other substance abuse disorders the proportion is smaller still (Kohn et al. 2004). In this context, it is important to recognise that integration of mental health care into general health systems may lead to identification of previously unmet needs. This improvement in access to care is one of the potential benefits that a more integrated approach offers. However, it does also highlight the need to ensure that sufficient capacity exists to deal with new demand.

A significant issue in mental health is the paucity of high-quality data. In many countries, prevalence data is limited, and the nature of many mental health diagnoses and interventions makes outcome measurement intrinsically difficult. This lack of reliable data adds to the challenges involved in planning new, integrated approaches to care. It is no coincidence that some of the most successful examples of integrated mental and physical health care have made significant investments in building robust, shared data systems.

43.1.2 Patient Factors

One of the most important clinical consequences of comorbid mental health problems is the impact on self-care and self-management. A cornerstone of integrated care is the principle that chronic diseases are managed most effectively when patients take an active role in this themselves. Comorbid mental health problems can significantly reduce a person's ability and motivation to manage their physical health. For example, diabetic self-care, medication adherence and health behaviours (e.g. diet, exercise, smoking) are significantly poorer among people who also have depression (Lin et al. 2004; Egede et al. 2009). Clinicians may need to adopt different consultation techniques to help motivate and support people with mental health problems to look after their physical health. However, there is evidence that self-management programmes and lifestyle interventions can be effective for this group, particularly when adapted to the specific needs of people with mental health problems (Cimo et al. 2012).

A challenge for clinicians working in this area is the multiple and diverse understandings that patients may have of the relationship between their mental and physical health. The sensitivities around this require particular skill in the case of medically unexplained symptoms. People experiencing physical symptoms which may be highly painful and debilitating should not be given the impression that a clinician believes their symptoms are 'all in the head'. Introducing the notion that physical symptoms and mental health are closely intertwined takes a high level of clinical skill and sensitivity, and professionals may require training in specific techniques that can be used to discuss the psychological aspects of health without undermining the physical reality of symptoms.

43.1.3 Professional Factors

The trend for increasing sub-specialisation in medical education reinforces the notion that some clinicians are responsible for the body, while others are responsible for the mind. In most countries, there is little or no mandatory mental health training in the core educational curricula for general practitioners, acute physicians or nurses. Where mental health rotations are available, these are often in acute psychiatric facilities and fail to provide trainees with exposure to mental health in a form that will be relevant to general healthcare settings. Similarly, many mental health professionals report feeling under-confident in relation to even basic aspects of physical health care, such as measuring blood pressure.

While the issue of skills is important, a more fundamental challenge is the existence of deeply engrained attitudinal barriers and a restrictive understanding of the boundaries of professional responsibility. Integrating physical and mental health care requires that professionals on either side of the ‘divide’ see themselves as being responsible for health, in the fullest sense of the word. This does not mean that all professionals need to become mental health experts, but it does mean that the culture of seeing mental health as something distinct and separate from the rest of health care needs to change. Part of the challenge here will involve acknowledging and confronting the stigma that still exists around mental health, and related issues regarding the relative status of mental health professionals.

43.1.4 Institutional and System Factors

Physical and mental health care is often, although not always, provided by separate organisations. While integration at the organisational level is neither necessary nor sufficient for integration at the clinical or service level (Curry and Ham 2010), this institutional separation does create some specific barriers. For example, the impact of some attempts to deliver more integrated services has been reduced as a result of separate and incompatible IT systems being used in physical and mental healthcare providers. A specific example of this is that liaison psychiatrists working in acute hospital settings (but employed by a separate mental health provider) are not always able to access the medical records used by other staff in the hospital.

Separate reimbursement systems can also create a barrier to integration. For example, in the UK most physical health care is reimbursed through activity-based payment, whereas mental health providers are paid largely through a single block contract covering the full set of services they provide. Financial incentives to integrate physical and mental health care more closely are often weak, with the costs and benefits of integration accruing to different budget-holders.

New provider models such as accountable care organisations potentially offer a way of overcoming this institutional separation and creating financial incentives to manage physical and mental health together. However, it appears that in the USA this opportunity has not yet been widely embraced, with few accountable care organisations pursuing innovative service models that integrate mental health care with general health systems (Lewis et al. 2014).

43.2 Goals of Integrated Physical and Mental Health Care

As discussed in the introduction, the rationale for integrating physical and mental health care is founded on evidence demonstrating that treating physical and mental health separately leads to poor outcomes for patients and unnecessary expense for health systems. The overall goal of integrated physical and mental health care should be to overcome this separation in such a way that there is improvement in terms of both outcomes and costs. Figure 43.2 provides a more detailed analysis of what some of the specific goals might be, in terms of clinical practice, health outcomes, professional skills and attitudes, and healthcare utilisation.

43.3 Key Components of Integrated Physical and Mental Health Care

43.3.1 Collaborative Care

Improving support for the mental health and psychological aspects of physical illness cannot mean treating a large number of additional people within specialist mental health services; an expansion along these lines would be both unaffordable and undesirable. Instead, a primary care-based approach is needed. The best-developed model available for this is collaborative care.

Collaborative care is a model for managing patients with chronic conditions in primary care that has been extensively tested in a number of countries. A major focus has been on using collaborative care to improve support for people with comorbid physical and mental health problems. The core components of collaborative care are:

- Proactive management of physical and mental health conditions by a non-medical case manager, working closely with a GP and/or other primary care staff
- Regular supervision meetings involving the case manager, primary care staff and a mental health specialist, in which new cases and progress made by existing patients are reviewed
- Use of standardised treatment protocols by the case manager

Clinical practice

- Routine exploration of the psychological and mental health aspects of physical health, including through routine screening for mental health problems among people with long-term physical health conditions
- Routine physical health checks for people with mental illnesses
- More effective management of medically unexplained symptoms in primary care
- Closer working between mental health specialists and other professionals, with collaborative care protocols and clear referral pathways

Health outcomes

- Improved clinical outcomes for people with comorbid physical and mental health conditions
- Reduction in all-cause mortality rates among people with mental health problems
- Improved self-management and self-efficacy among people with comorbid physical and mental health conditions
- Lower rates of smoking among people with mental health problems and improvements in other health behaviours e.g. diet, exercise

Professional skills and attitudes

- All health and social care professionals see physical and mental health as part of their job
- Physical and mental health included in core educational curricula and ongoing training for all professionals
- Greater confidence among physical health professionals to discuss mental health and well-being with patients – and vice versa
- Eradication of stigmatising beliefs in the health and social care workforce about mental illness

Health service utilisation

- Reduction in unplanned hospital admission for ambulatory care sensitive conditions among people with mental health problems
- Reduction in emergency transfers from mental health inpatient facilities to acute general hospitals
- Reduction in unnecessary tests and investigations among people with medically unexplained symptoms

Fig. 43.2 Goals of integrated physical and mental health care

- Active exploration of the interaction between mental well-being and physical conditions by the case manager
- In some cases, case managers may also be trained to deliver brief psychological interventions
- A focus on education and skills transfer among the different professionals involved in the collaborative care process.

Collaborative care is often delivered within a stepped-care framework, with escalation to more specialist support where required. For example, NICE recommends the use of collaborative care for people with moderate to severe depression alongside a chronic physical health condition, particularly in cases where the depression has not responded to initial psychological or pharmacological treatment, but is not considered sufficiently severe to warrant a referral to specialist mental health services (NICE 2009).

The collaborative care model has been used both in multi-provider systems and within the context of integrated delivery systems. In the USA, the principles of collaborative care have been used by organisations such as Intermountain Health Care (see Box 43.1), the Veterans Health Administration and Kaiser Permanente as part of major integrated care programmes seeking to integrate mental health services into primary care. Collaborative care approaches have also been used in Europe, for example, in the UK (Coventry et al. 2015), Italy (Rucci et al. 2012) and the Netherlands (Goorden et al. 2015), and in some lower- and middle-income countries, for example, through the 'PRIME' and 'Emerald' research programmes (see https://www.prime.uct.ac.za/ and https://www.emerald-project.eu/).

The principles of collaborative care have been adapted for use in other settings outside of primary care. For example, there is some evidence indicating that collaborative care can be successfully used in obstetrics and gynaecology clinics for managing depression during the perinatal period (Katon et al. 2015).

Box 43.1 Case Study: Mental Health Integration in Intermountain Health Care

In the early 2000s, primary care practitioners in Intermountain Health Care, a non-profit health system operating in Utah and Idaho, USA, identified a need for a more effective way of supporting the large number of people presenting with mental health needs, often alongside a mixture of physical illness, substance abuse problems and complex social circumstances. In response to this, Intermountain developed a mental health integration (MHI) programme, which has now been rolled out in the majority of primary care clinics.

The MHI programme involves primary care practitioners accepting an increased responsibility for providing mental health, with the support of an enhanced multidisciplinary team embedded in primary care. Key elements of the model include:

- Team-based care with mental health professionals embedded in the primary care team, including input from psychiatry, psychology, psychiatric nursing and social work
- A nurse care manager to coordinate medical, psychological and social support
- Significant investments in training practice staff (including physicians, nurses, receptionists and others) in mental health awareness, empathic communication skills and shared-decision making
- Shared electronic medical records accessible by all team members
- Proactive screening for mental health problems among high-risk groups in the population
- Supported self-management of physical and mental health
- Making use of extended community resources and peer support

- Using disease registries and evidence-based guidelines
- Exploiting new technologies, e.g. telehealth and telecare

Under MHI, mental health care is delivered through a stepped-care approach, with the balance of responsibilities between primary and specialist care depending on the level of complexity. Overall, around 80% of mental health care is delivered by non-specialists. Evaluations of the model have found significant improvements in both physical and mental health outcomes, better self-management and lower per patient medical costs (Reiss-Brennan et al. 2010).

43.3.2 Multidisciplinary Case Management

Community-based multidisciplinary teams are a key mechanism for coordinating the care provided to people with multiple or complex chronic diseases. Successful integration of physical and mental health care requires that mental health is fully embedded within these teams. A number of different approaches towards this have been tried, some of which are disease-specific whereas others cut across multiple diseases.

Disease-specific approaches include multidisciplinary teams established to respond to the physical and mental health needs of people with diabetes. For example, as part of an integrated care programme in North West London, liaison psychiatrists attend a regular multidisciplinary case conference at which the needs of people who are struggling to manage their diabetes are discussed. An evaluation found that mental health issues were discussed in over 80% of all cases brought to these meetings, with the impact of mental well-being on self-management being a particularly common theme (Sachar 2012). Another successful example of multidisciplinary care for the physical and mental aspects of long-term conditions is the ‘three dimensions for diabetes’ service (see case study in Box 43.2 below).

An alternative to the disease-specific approach is to use multidisciplinary team meetings to discuss patients identified as being at greatest risk of unplanned hospital admission (generally through the use of a risk prediction algorithm). Again, it is important that input from mental health specialists is an integral part of this approach. An example is the ‘extensive care’ model. In this, a dedicated primary care clinic exists (often virtually) to provide intensive, multidisciplinary case management to the highest need patients in a defined locality. This model has so far been used largely for frail older people, but its applicability to other multi-morbid patients, including those with co-occurring physical and mental health problems, is now being tested. For example, as part of the ‘vanguard’ integrated care programme in England, an extensive care service has recently been established in Blackpool focusing on people with complex mental health problems, substance abuse issues and other problems including co-morbid physical health conditions. The effectiveness of these approaches still requires evaluation.

Box 43.2 Case Study: Three Dimension of Care for Diabetes

'Three dimension of care for diabetes' (3DFD) was an award-winning service in an inner-city area of London, UK, which provided integrated care for the physical, mental and social aspects of diabetes. The service was specifically targeted at people with poor glycaemic control, and served a highly mixed population, including many people with multiple complex co-morbid conditions and high levels of social deprivation. More recently, the 3DFD service has evolved into a broader service aimed at people with other conditions beyond diabetes, and is now known as 'three dimensions for long-term conditions'.

While inclusion of a mental health professional in multidisciplinary team meetings is increasingly common in diabetes care, the 3DFD model went further than most by having a wider range of mental health professionals fully integrated in the team and including the social dimension of support. Alongside diabetologists and diabetes nurses, the team included a psychiatrist, psychologists and social support workers. This allowed the team to provide support to people with a wider range of mental health problems—not only mild-to-moderate depression or anxiety, but also severe depression, psychosis, eating disorders or dementia.

The team provided brief psychological therapies as well as interventions targeting social problems, such as issues with housing, debt management, carer support or domestic violence. In addition to seeing patients directly, an important part of the role of mental health staff in the 3DFD team was to provide formal and informal training to diabetes physicians and nurses, for example in motivational interviewing techniques, basic principles of cognitive behavioural therapy, and general training in mental health.

An evaluation of 3DFD found significant improvements in glycaemic control, reduced psychological distress and a reduction in emergency attendances and unscheduled admissions.

43.3.3 Liaison Mental Health

Liaison psychiatrists, and related professionals such as liaison nurses and clinical health psychologists, are experts in the interface between mental and physical health. These professionals are most commonly employed in acute hospital settings, often as part of liaison psychiatry or psychological medicine teams. These teams perform a vital function in identifying mental health needs among people attending emergency departments, outpatient clinics or using inpatient services, and ensuring that appropriate support is then available to meet these needs.

Mental health problems are highly prevalent in hospital settings, and the need for high-quality liaison mental health services is clear. It is therefore regrettable that the provision of these services is often highly variable. Guidance for commissioners of liaison mental health services suggests that the following standards should be met (JCPMH 2013):

- Liaison services should be comprehensive, with clear and explicit responsibility for all patients in acute hospital settings.
- Liaison services should cover all ages, including children, adults and older people.
- Part of the role of liaison clinicians should be to build capacity within the wider hospital workforce, for example, by improving the mental health skills of nurses.
- There should be a single integrated set of healthcare notes.
- Integrated governance arrangements should exist to allow the liaison team to work closely with the acute hospital.
- There should be capability for providing a range of interventions including brief psychological therapy.
- Liaison teams should have strong links with specialist mental health services in the community and good knowledge of local resources
- Liaison clinicians should be able to assess physical health as well as mental health.

In some cases, liaison mental health services have extended their focus beyond acute hospitals, becoming involved in supervisory and direct clinical activities in primary care and other community settings (including through collaborative care models and multidisciplinary locality teams, as described above). This is a promising development and particularly relevant to the care of people with ongoing needs likely to continue beyond their hospital stay, such as those with long-term conditions or medically unexplained symptoms.

43.3.4 Managing Medically Unexplained Symptoms in Primary Care

A critical aspect of effective care for people with medically unexplained symptoms is the quality and style of communication between professionals and patients. Clinicians need to strike a delicate balance, introducing people to new ways of understanding their symptoms without challenging the reality of their experience. Techniques such as motivational interviewing can provide a useful framework for consultations.

Some psychological therapies, in particular cognitive behavioural therapy, have been shown to be effective and cost-effective interventions for people with medically unexplained symptoms (van Dessel et al. 2014; Konnopka et al. 2012). One benefit is that these can have the effect of improving the patient's 'psychological literacy' such that their readiness to engage in discussions with their GP about the psychological aspects of their symptoms is subsequently improved. Psychological therapies and other interventions for medically unexplained symptoms can be delivered in primary care through stepped-care approaches (Guthrie 2008).

The challenges of working with people experiencing medically unexplained symptoms mean that educational interventions aimed at GPs and other primary care staff are often particularly valuable. A 'primary care psychotherapy consultation service' provided to GPs in the City and Hackney area of London is one example of an innovative service that combines an educational function with direct clinical work. An evaluation suggested the service has both delivered results for patients and been positively received by the local GP community (Parsonage et al. 2014)—see Naylor et al. (2016) for a detailed case study.

43.4 Results of Integrated Care Approaches

Integration of physical and mental health is a new frontier for integrated care and is an area where further evaluative studies are needed. However, in some areas a significant body of research already exists, and the evidence that is available suggests that there are significant opportunities both for quality improvement and potentially for improving the cost-effectiveness of care.

Collaborative care is one area where the evidence base is relatively well established. Studies such as the TEAMcare trial in the USA (Rosenberg et al. 2014) and the COINCIDE trial in the UK (Coventry et al. 2015) have found that collaborative care interventions can improve recovery from depression among people with diabetes and/or coronary heart disease, at the same time as improving self-management of physical health. This was also the conclusion of a systematic review conducted by Huang et al. (2013). Collaborative care also appears to be highly cost-effective and potentially cost-reducing (Katon et al. 2008, 2012; Simon et al. 2007).

Liaison psychiatry has received significant recent interest in the UK, partly in response to the impressive findings of an economic evaluation of a 'rapid assessment interface discharge' (RAID) service in Birmingham. Parsonage and Fossey (2011) found that by facilitating early discharge from hospital and reducing rates of readmission (particularly among older people), the value of reduced bed use within the acute hospital exceeded the costs of the RAID service by a factor of more than 4 to 1.

Similarly, there is evidence of significant potential benefits to both patients and the system stemming from embedding mental health specialists within chronic disease management programmes. There is particularly good evidence of the benefits of including a psychological component within pulmonary and cardiac rehabilitation programmes. For example, a systematic review found that psychological interventions for people with coronary heart disease led to improvements in depression and anxiety, and also a small reduction in cardiac mortality. However, it also concluded that more research is needed to establish which patient groups benefit most and what the core components of effective interventions should be (Whalley et al. 2014). There is some evidence that integrated psychological support can reduce costs related to conditions such as COPD (Howard et al. 2010) and angina (Moore et al. 2007).

43.5 Lessons Learned

It is clear that in the absence of integrated care, the interaction between physical and mental ill health can lead to significantly poorer health outcomes, reduced quality of life and increased costs to the healthcare system. The prevailing approach to dealing with chronic disease is at risk of failing unless it is recognised that many of the people most in need of integrated care have comorbid psychological or mental health problems that can impair their ability and motivation to self-manage. Care for large numbers of people could be improved by better integrating mental health support within primary care, acute hospital care and chronic disease management programmes.

Fundamentally, integrating physical and mental health care involves redrawing professional boundaries, such that all practitioners working in health and social care accept their role as de facto mental health professionals. Similarly, mental health specialists should see physical health and well-being as part of their responsibility. For many, this poses a significant cultural change as well as a technical one. It will therefore require skilled and committed leadership, and new forms of integrated training and education.

Naylor et al. (2016) discuss the practical lessons learned from the process of implementing integrated service models for physical and mental health in the UK. A key finding is that innovation has often been driven by individual clinical champions working, at least initially, in relative isolation from the rest of the system. To be sustainable, the work of these clinical innovators needs to receive support from senior leaders within local organisations and must be reinforced by consistent messages from this leadership. Without this, there is little hope of widespread cultural change taking place. A powerful catalyst for cultural change is direct contact between professionals working in different parts of the system—specifically, those traditionally responsible for physical health and those specialising in mental health. Given this, the service models which have the greatest potential may be those which combine direct clinical work with joint supervision and educational functions, creating opportunities (formal and informal) for skills transfer between mental and physical healthcare professionals.

Integration of physical and mental health care should be seen as a core component of any integrated care programme. This important aspect of integrated care has often received insufficient attention in the past and should be a priority for research and service improvement in future.

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Rare Diseases

44

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44.1 Challenges Faced When Providing Care to People Living with a Rare Disease

The following chapter focuses on presenting rare diseases and the needs of people living with a rare disease, as well as providing context on the provision of integrated care to this client group in Europe.

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44.1.1 Background on Rare Diseases

"When you have a rare disease it feels like you are so alone and no one cares", Janet, mid-50s, living with Alkaptonuria (EUCERD Joint Action 2012).

Rare diseases (RDs) affect a small number of people relative to the general population. A disease is defined as rare when it affects less than 1 in 2000 people in Europe (Nguengang Wakap 2020) and less than one in 1250 people in the USA (Schieppati et al. 2008). Definitions vary in different countries/world regions according to population sizes. The World Health Organisation suggests a frequency of less than 6.5–10 in 10,000 (Aronson 2006).

There are over 6000 RDs (Orphanet 2012). Although each RD is characterised by a low prevalence, they affect 30 million people in Europe and 400 million people worldwide (World Health Organisation 2013). Most patients suffer from less frequent diseases affecting 1 in 100,000 people or less and are consequently particularly isolated and vulnerable (Council of the European Union 2009).

The cause remains unknown for many RDs. Most of them are genetic, but there are also very rare forms of infectious diseases, autoimmune diseases and cancers (Orphanet 2012). RDs may affect patients in different ways and are often multisystem disorders, affecting various organs and tissues.

RDs are heterogeneous in terms of prevalence, age of onset, clinical severity and outcome. However, they share various common features: they are serious, often chronic, progressive, degenerative and associated with comorbidities (Orphanet 2012). As a result, they substantially affect life expectancy and altogether account for a considerable rate of the early-life deaths and lifelong disabilities in the European population (Rare Diseases Task Force 2008).

RDs are the cause of various severe impairments, and a high percentage of people with a RD is affected by motor or intellectual impairments, which can occur simultaneously (Guillem et al. 2008; Tozzi et al. 2013).

There are currently no treatments available for 4000–5000 RDs (Orphanet 2015). Scientific knowledge is growing rapidly but not translating into therapies quickly enough. Patients are facing major hurdles to access approved new therapies. About one-third of patients do not have access to the orphan medicine they need. Another third have access only after waiting several years, as medicines are introduced first in the main markets and then progressively over 6 years in the other markets (Le Cam 2015).

Additionally, existing and accessible treatments are not always able to minimise all the complex impairments generated by the disease, highlighting the need for integrated care provision to alleviate the impact of RDs in patients' and families' daily life.

44.1.2 Unmet Needs of People Living with a Rare Disease

> We were looking for a diagnosis (which took roughly 6 years). By asking a year "non-paid break"—to pursue my diagnosis journey and to take care of my children, one of them also having similar symptoms—I received a refusal from the employer. So I decided to give up my job and stayed unemployed for 4 years. Feeling stronger after the diagnosis and the information about the disease (which my husband I and I sought by ourselves), I decided to pick up work again. One year: part-time and thus earning half as much as before. Female, Luxembourg (EURORDIS 2017)

> I don't look ill but I am very ill, with a condition which no one understands or has heard of. Female, United Kingdom (EURORDIS 2017).

> MP has so many medical appointments, and therapy sessions that I had to stop working. I have only 4 hours free to come back home, do the cleaning, cook, go to supermarket, deal with the infinite bureaucratic processes. Then, I pick him up, come back home and accompany him in all the exercises his therapist has given him. I go to bed exhausted and I don't get a lot of help at home. At this moment, it is impossible for me to find a job. Female, Spain (EUCERD Joint Action 2012).

The failure to meet the serious unmet needs of people with a RD and their families affects their dignity, autonomy and other fundamental human rights expressed in the Universal Declaration of Human Rights and in the United Nations Convention on the Rights of Persons with Disabilities (Commission Expert Group on Rare Diseases 2016).

People living with RDs are psychologically, socially, economically and culturally vulnerable. The cumulative effects of illness and disability generated by RDs amplify the social exclusion experienced by patients and their relatives.

85% of the respondents to the first European survey on the everyday impact of RDs declared that the RD impacts upon several aspects of their health and everyday life (EURORDIS 2017[1]). The evidence from this survey demonstrates that the consequences of living with a RD reach far and wide beyond the health niche, extending to the socio-economic, family, education, employment and other social inclusion spheres:

- RDs have a significant impact on functioning and activities of daily living: seven in ten respondents have difficulties with motor/sensorial functioning while seven in ten also have difficulties with basic daily activities and tasks;
- RD patients and carers spend significant time managing the disease and the care pathway—42% of the respondents spend more than 2 h a day on illness-related tasks (e.g. hygiene, administration of treatments) and one-third of the carers spend over 6 h a day on these tasks;

1European survey—"Juggling care and daily life: The balancing act of the rare disease community", to 3071 respondents from 42 countries. The survey was conducted in 23 languages, by EURORDIS−Rare Diseases Europe, through its Rare Barometer Programme, and within the EU-funded project INNOVCare. More information available at: https://download2.eurordis.org.s3.amazonaws.com/rbv/2017_05_09_Social%20survey%20leaflet%20final.pdf.

- RDs generate a strong impact on employment and work-life balance, as well as significant economic burden: seven in ten respondents had to reduce or stop their professional activity, while 58% were absent from work over 15 days in the year prior to the survey. Additionally, 73% of the respondents stated that the costs related with their disease are high while 69% also faced an income decrease;
- Care pathways are complex and hard to manage: 65% of the respondents have to visit different health, social and local services in a short period of time; 67% feel that these services communicate badly with each other;
- There is a lack of information and preparation from social services: seven in ten respondents do not feel well informed about their rights; 71% feel that professionals from social and support services are badly prepared to support them in managing the consequences of their RD;
- There is a serious impact on the mental health of people living with a rare disease and their carers: feelings of depression and unhappiness are three times more common amongst people living with a rare disease and their family carers, compared with the general population.

As a consequence of all these challenges, both patients and family members—often the main carers—frequently find themselves in burnout situations, unable to cope physically and psychologically with the situation.

RDs indeed generate a considerable moral suffering (French Social and Economic Council 2001), and it has been recognised that they result in reduced quality of life and affect individuals' potential for education and learning abilities (Schieppati et al. 2008).

Compared to more prevalent chronic disorders, people living with a RD have a worse quality of life and experience higher losses in terms of medical care and social and economic activities (Van Nispen et al. 2003).

44.1.3 Challenges in Care Provision

> Inter-professional communication works only through the good intentions and efforts of particular professional individuals. This is one of the main difficulties. Today, departments communicate with each other primarily through patients themselves or their parents. However, this only works for very dedicated people. Not everyone is able or willing to carry this out. Male, Czech Republic (EURORDIS 2017).

> It is not possible to get a 'check list' of all the people you need to talk with. Also, service providers differ in the amount of interest they show. Male, Ireland (EUCERD Joint Action 2012).

A person with a RD is seldom a standard patient or service beneficiary. The combination of the rarity, complexity and lack of treatment creates particular hurdles in the provision of holistic care:

- Expertise and information on RDs and their consequences are scarce and difficult to access. Therefore, professionals often lack knowledge on RDs, and the scarcity of expertise forces many RD patients to seek care abroad;
- People living with RDs need continuous and, often, lifelong, follow-up care and support from different categories of professionals. These often include several different medical specialties, as well as social workers and other social and local service providers (Commission Expert Group on Rare Diseases 2016):
  - Indeed 65% of the respondents to the European survey had to visit different health, social and local services in a short period of time (EURORDIS 2017);
  - In a survey conducted in Denmark, people living with RDs reported having been referred to between 10 and 30 social and healthcare professionals as contact points (Byskov Holm and Jensen 2014);

Adding to these challenges, people with RDs experience barriers when accessing health and welfare services (Grut and Kvam 2013). The challenges faced include as follows:

- Care systems are usually designed around common diseases, and mainstream services are not flexible enough to take into consideration unprecedented health needs (EURORDIS 2009);
- Care pathways are fragmented and extremely difficult to navigate for patients and families:
  - Obtaining the correct diagnosis, the needed social care and support to manage the transitions between hospital and home and between childhood and adulthood remain a challenge (Brains for Brain Foundation 2014);
  - Seven in ten respondents to the European survey find that organising care is time consuming and six in ten find it hard to manage (EURORDIS 2017);
  - In the Danish survey, people living with a RD and carers reported having to spend an average of 25 h per month in contact with health and social professionals (Byskov Holm and Jensen 2014);
  - There is a lack of communication and coordination within and between the health and social care sectors, as well as between national and local services (Byskov Holm and Jensen 2014); 67% of the respondents to the European survey feel that health, social and local services communicate badly with each other while seven in ten respondents do not feel well informed about their rights (EURORDIS 2017);
  - In most cases, the management and coordination of care have to be done by patients and families, which places a heavy burden on family life (Dammann 2015);

- Medical and social care professionals are insufficiently informed and trained to care for people living with a RD and tend to be reluctant to treat patients due to the complexity of their disease (EURORDIS 2009);
- Cross-border health care remains a challenge due to the fragmentation of legal systems, different access to and reimbursement of services, lack of information on how and when to access it, as well as burdensome administrative requirements.

These issues are of particular importance given that patients and families perceive that their quality of life of is more closely linked to the quality of care provided than to the gravity of their illness or the degree of the associated disabilities (EURORDIS 2009).

44.2 Goal of Integrated Care for Rare Diseases

The low prevalence and complexity of RDs, as well as the significant unmet needs of RD patients, highlight the need for the implementation of holistic, integrated and patient-centred care pathways, which respond to the complexity of RD challenges through an interdisciplinary approach.

Integrated care, within the health system and between health, social and community services, is essential to enable people living with RDs to overcome their care challenges and to secure the services and support that they need (EURORDIS 2019). This will thus allow them to achieve a quality of life on equal footing with other citizens and to increase their participation in society and in the job market (INNOVCare 2018b).

The Commission Expert Group on Rare Diseases recommends that European Member States promote measures that facilitate multidisciplinary, holistic, continuous, person-centred and participative care provision to people living with a rare disease, supporting them in the full realisation of their fundamental human rights (Commission Expert Group on Rare Diseases 2016). And indeed, recent studies show that integrated care is especially beneficial for people with complex needs (Klinga et al. 2015). Integrated care for RDs ensures:

- The transfer of scarce information and expertise on RDs;
- Coordination and communication between health, social and local care providers;
- Optimisation of care pathways and resources, increasing patients'/families' quality of life and reducing healthcare expenditure and economic burden for society (Reich et al. 2012);
- Integration of RD specificities into mainstream services;
- An answer to some of the main challenges of RDs, such as diagnostic delays, transitions from child to adult services and from hospital to home, access to social and community services;

- Reduction of the burden on patients and families who will no longer be responsible for coordinating care and will be supported in navigating the care system.

44.3 The Integrated Care Pathway for Rare Diseases

44.3.1 Proposals for the Provision of Integrated Care to People with Rare Diseases[2]

Care for people living with a RD needs to be holistic, multidisciplinary and specifically tailored to patients' unique needs (McGarvey and Har 2008).

This implies the provision of a set of health, social and support services, including rehabilitation, day care, home care, personal assistants, respite services, adapted schools and work place, psychological support and social prescribing, amongst others.

There is agreement in Europe upon the necessity of coordinating RD patients' care nationally and internationally. The recommendations of the European Union Committee of Experts on Rare Diseases (EUCERD) and of the Commission Expert Group on Rare Diseases (CEGRD)[3] to the European Commission (EC) and Member States (MS) promote a set of important measures and quality criteria,[4] supporting the development of healthcare pathways at national level and European networks at international level.

A set of specific recommendations from the CEGRD also focused on the incorporation of rare diseases into social services and policies, highlighting the need for multidisciplinary, holistic and continuous care for people with RDs (Commission Expert Group on Rare Diseases 2016).

At national level, the development of National Plans[5] for RDs is encouraged, alongside the organisation of national care pathways embedded into the health system, including Centres of Expertise[6] and national networks for a RD/cluster of

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[2] More information is available at: https://www.eurordis.org/carepaper.

[3] The EUCERD was a multi-stakeholder group including RD experts, MS and patient representatives, charged with aiding the EC with the preparation and implementation of community activities in the field of RDs, in cooperation and consultation with the specialised bodies in MS, the relevant European authorities and other relevant stakeholders. In 2014, the EUCERD was replaced by the European Commission Expert Group on Rare Diseases (CEGRD). More information is available at: https://www.eucerd.eu/.

[4] EUCERD recommendations are available at: https://www.eucerd.eu/?page_id¼13.

[5] More information is available at: https://www.europlanproject.eu/Content?folder¼1.

[6] Centres of Expertise (CEs) are physical expert structures for the management and care of RD patients. Each CE is specialised in a single RD or group of RDs and shares the mission of providing patients with the highest standards of care to deliver timely diagnosis, appropriate treatments and follow-up. More information is available at https://www.eurordis.org/sites/default/files/publications/factsheet_Centres_Expertise.pdf.

RDs. On the other hand, the development of European Reference Networks[7] for RDs is regarded as essential to facilitate the provision of cross-border health care[8] and to reduce the burdens associated with seeking care abroad.

EURORDIS-Rare Diseases Europe, based on extensive surveys and consultations with people living with RD, as well as on the work of the multi-stakeholder EU-project INNOVCare, released the following recommendations for the implementation of integrated care for RDs (EURORDIS 2019):

- Creating a supportive political environment at national level:
  - All national plans and strategies for RDs must include provisions on integrated health–social care;
  - Specific mechanisms are needed to guarantee coordination between national policy sectors within a multidisciplinary approach, engaging health, social, work, education and research ministries. Inter-ministerial working groups and shared budgets between ministries should be implemented;
  - Sustainability mechanisms for integrated care for RDs must be put in place and accessible to public bodies, civil society and service providers.
- Implementing specific mechanisms to ensure integrated care for RDs:
  - Coordination and interoperability between all parties involved in the care provision must be promoted, including health, social and community services and patient/carer organisations. Coordination protocols, procedures, IT and e-health tools can be used for this;
  - RDs must be considered by the risk stratification tools used by healthcare systems to make decisions on integrated care, via the use of implemented codification systems;
  - All people living with RDs must be entitled to an individual, person-centred care plan, to be delivered within a multidisciplinary, holistic approach in coordination between all care providers;
  - National care pathways for RDs should be developed, indicating the process and care steps, identifying the existing coordinating mechanisms and the different care providers' responsibilities;
  - Case management, as an effective care coordination mechanism, should be implemented. Training on case management for RDs should be developed.
- Gathering and disseminating knowledge/good practices on integrated care for RDs:
  - Countries must recognise and support existing RD Centres of Expertise, national reference networks, resource centres, RD organisations and

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[7] European Reference Networks (ERNs) for RDs should serve as research and knowledge centres, updating and contributing to the latest scientific findings, treating patients from other MS and ensuring the availability of subsequent treatment facilities wherever necessary. More information available at: https://ec.europa.eu/health/rare_diseases/european_reference_networks/erf/index_en.htm.

[8] More information is available at: https://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uriJ:L:2011:088:0045:0065:EN:PDF.

Orphanet[9] teams, capitalising on their robust expertise and knowledge to improve integrated care for RD;
- European Reference Networks and their constituent health care providers must continue to function as a platform to collect and disseminate data, good practices and guidance on health care and integrated care for RD, in cooperation with RD patient organisations;
- Training for health and social service providers must be delivered, building on the expertise of RD specialised services and RD patient organisations;
- Pilot projects must be supported, as generators of good practice and innovative services.

In regard to access to treatment, society, patients, experts, healthcare systems and the pharmaceutical industry need to think outside the box to address new challenges facing the rare disease community. There is an urgent need for a seamless approach to European cooperation on medicines development to bridge the gap between EU regulatory decisions and fragmented national/local pricing and reimbursement decisions. And patients need to be engaged in these processes (Le Cam 2015).

In line with the recommendations of the CEGRD and of EURORDIS, we explore below several concrete measures to support the implementation of integrated care for rare diseases.

44.3.1.1 Centres of Expertise[10]

Centres of Expertise, as health structures specialised in RDs, have a key role in sharing information and knowledge and building networks to facilitate integrated patient-centred care provision to people living with a RD and their families (EURORDIS 2013).

According to the EUCERD[11] (2011) Recommendations on Quality Criteria for Centres of Expertise on Rare Diseases, these centres should bring together or coordinate multidisciplinary competences/skills, including paramedical skills and social services; contribute to building healthcare pathways and to the elaboration and dissemination of good practice guidelines; provide education and training to non-healthcare professionals and produce information adapted to the specific needs of patients/families and of health and social professionals.

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[9] Orphanet is a unique resource, gathering and improving knowledge on RDs so as to improve the diagnosis, care and treatment of patients with RDs. Orphanet aims to provide high-quality information on RDs and ensure equal access to knowledge for all stakeholders. Orphanet also maintains the Orphanet rare disease nomenclature (ORPHAcode), essential in improving the visibility of rare diseases in health and research information systems. More information is available at: https://www.orpha.net/consor/cgi-bin/index.php.

[10] Centres of Expertise (CEs) are physical expert structures for the management and care of RD patients. Each CE is specialised in a single RD or group of RDs. More information is available at https://www.eurordis.org/sites/default/files/publications/factsheet_Centres_Expertise.pdf.

[11] The CEGRD replaced the EUCERD in 2014 in supporting the EC with the preparation and implementation of community activities in the field of RDs. More information is available at: https://ec.europa.eu/health/rare_diseases/expert_group/index_en.htm.

44.3.1.2 Individual Care Plans

Simple, holistic and flexible individual care plans which can be implemented by central, regional and local services would be of great use in the context of RDs. Based on the assessment of individual needs, including health and social dimensions of care, these plans should be developed and implemented in collaboration between care providers, patients and families. Ideally, a coordinator should be assigned to manage and follow up the individual care plan.

44.3.1.3 Care Pathways and Standards of Care

Care pathways and standards of care are multidisciplinary care management tools which define the different tasks to be undertaken by professionals involved inpatient care and are essential to create equality in the level of care and services provided to people with a RD.

In Sweden, for example, the care pathway for RDs is organised through the Act on Support and Service for Persons with certain functional impairments,[12] an entitlement law that guarantees good living conditions for people with extensive and permanent functional impairment, ensuring that they receive the help they need in daily life and that they can influence the support and services they receive. The Swedish care pathway ensures a permanent contact in health, responsible for interactions within health care and for coordination of stakeholders, treatments and services, in line with an individual coordinating plan. The Centres of Expertise ensure interactions between medical and non-medical issues, and there is ongoing work on national treatment and care programs, within a holistic and lifelong approach.[13]

Other EU MS are currently developing care pathways for RDs using standards of care. For example, France and the Netherlands are establishing standards of care, in which the organisation of care within the national health network is described for a certain RD.

In France, by 2020, 128 national good practice guidelines for diagnosis, treatment and follow-up of people with RDs were published by expert health centres, while nearly 200 more were under development. The third French RD plan 2018–2022 aims thus to boost the production of these guidelines to 100 per year during 5 years and the updating of each one every 5 years.

In 2012, the French National Authority for Health (HAS) published a new simplified method to develop these guidelines, aiming to boost the production of the protocols in the following years (EUCERD 2014a; b)[14] The HAS then published and disseminated these protocols as they were developed.[15]

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[12] More information is available at: https://www.socialstyrelsen.se/Lists/Artikelkatalog/attachments/8407/2009-126-188_2009126188.pdf.

[13] More information is available at: https://bit.ly/1M2noBZ.

[14] The full French National Plan for Rare Diseases (2018–2022) is available in English here: https://solidarites-sante.gouv.fr/IMG/pdf/pnmr3_-_en.pdf.

[15] More information on the French protocols is available here: https://www.has-sante.fr/jcms/c_1340879/fr/protocoles-nationaux-de-diagnostic-et-de-soins-pnds [French].

In the Netherlands, there has been important progress concerning RDs and integrated care, with the development of standards of care for 16 diseases, some of which are already implemented (Vajda et al. 2012).[16] The Dutch Genetic Alliance has been an important stakeholder in this process and keeps developing standards of care and other quality standards, according to a new national guideline.[17]

44.3.1.4 Case Managers

Case managers are essential for integrated care in RDs. They can ensure coordination between centralised and local care and alleviate the care coordination burden faced by patients and families.

Case managers have an instrumental role in adapting the existing care system to patients' individual needs and in supporting holistic and continuous care by: establishing networks of care providers; providing information and support to local professionals, patients and families; coordinating individual care plans; and providing information on cross-border care when needed.

Ideally, case managers should be trained and employed by, or work in connection with, Centres of Expertise. Case managers should be located at regional/local level in order to facilitate local care provision and should remain the same for as long as possible in order to ensure stability during transition periods.

The pilot of case management for RDs implemented within the EU-funded INNOVCare project (2017–2018) resulted in various positive outcomes within important daily life and care areas. People living with RDs and carers who benefited from the service increased their level of information about their disease, their rights and available services. Their capacity to manage their care also increased, while the service also reduced the burden faced by the caregivers. Furthermore, the case management brought improvements for care providers and public bodies, enhancing the coordination amongst these stakeholders involved in the care provision (INNOVCare 2018a).[18]

Another pilot implemented in France, PRIOR-RH, shows how case management can be organised by a regional centre of expertise for RDs. PRIOR-RH employs a multidisciplinary mobile team—health manager, genetic counsellor, social worker, psychologist, occupational therapist—which undertakes the role of case management for people with RDs in the region, thus improving their care pathways. PRIOR-RH has built a regional network of competence both in health and social care involving 23 partners. Additionally, PRIOR-RH provides information on RDs, draws up an inventory of regional expertise, directs patients towards social and medical care services, provides social follow-up to support patients in their life course and organises stakeholders meetings.[19]

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[16] A national network of expertise is being set up for some RDs to provide integrated care. Moreover, the Dutch Genetic Alliance hosts a website to disseminate RD quality standards. More information is available at: www.zorgstandaarden.net.

[17] More information is available at: https://bit.ly/1WPmhgt [Dutch].

[18] More information is on Sect. 25.4 Results of Integrated Care Approaches to Care Delivery and at https://innovcare.eu/wp-content/uploads/2018/11/INNOVCare-Results_October-2018.pdf.

[19] More information is available at: https://download.eurordis.org.s3.amazonaws.com/emm2015/ws4/5.DOMINIQUE_FRANCE_Prior%20Eurordis%20Madrid.pdf.

Following the successful pilot of PRIOR-RH, several other platforms were created in France, mainly on the initiative of hospitals. Thereafter, the creation of other regional platforms was stimulated by the action of the French national plan RDs: ten regional RDs expertise platforms were endorsed and financially supported in 2019. Thirty others are to be implemented during the following 3 next years, enabling the full coverage of the French territory. Four RD coordination platforms were also created in 2019 in the French overseas territories.[20]

44.3.1.5 Resource Centres for Rare Diseases

Resource centres for RDs[21] are a one-stop shop service, complementary to health and social care services, specifically designed for people living with RDs and their carers. Resource centres provide holistic services and support, while also creating a bridge between patients and families and various stakeholders, services and professionals providing health care, social care and social support—including rehabilitation, education and employment.

Resource centres thus empower patients, families, carers and professionals at various levels and undertake an essential role in integrated care provision to people living with a RD. Resource centres' services include information and guidance, training courses, respite care, therapeutic education, information on social benefits and research. Sometimes daily therapies, medical/psychological consultations and therapeutic recreation are also provided.

The EUCERD Joint Action (2012–2015)[22] mapped existing resource centres for RDs, identifying 21 services in 12 European countries.[23] Amongst these are NoRo (Romania), Frambu (Norway) and Ågrenska (Sweden).

The NoRo Pilot Reference Centre for Rare Diseases is a resource centre, accredited both as a social service and a medical service, which provides holistic care based on a multidisciplinary and complementary approach and on the individual assessment of patients' needs. The centre ensures continuity of care through collaboration with other services in the community and by establishing networks with medical universities.[24] NoRo runs a helpline for RDs and organises training for patients, volunteers and professionals,[25] as well as support groups, therapeutic weekends for families and therapeutic camps for children.

Frambu's multidisciplinary team provides services to people living with over 120 different RDs as well as to carers and service providers. The centre complements the services provided by the Norwegian health system and works in

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[20] More information is available at: https://solidarites-sante.gouv.fr/IMG/pdf/pnmr3_-_en.pdf.

[21] More information is available at: https://innovcare.eu/social-services/resource-centres-for-rare-diseases/.

[22] 17 The EUCERD Joint Action: Working for Rare Diseases, co-funded by the EC, supported the activities and mandate of the EUCERD until the end of 2013 and the activities of the CEGRD, from 2014. More information is available at: https://www.eucerd.eu/?page_id¼54.

[23] 18 Map and list of services are available at: https://www.eurordis.org/specialised-social-services.

[24] 19 NoRo has organised a network of videoconference facilities with seven Romanian medical universities which aims at facilitating direct access to information/good practices and meetings between patients and professionals.

[25] 20 More information is available at: www.edubolirare.ro.

connection with university hospitals. Frambu is a meeting place for families and professionals providing competence, knowledge, documentation and guidance and organising residential courses, summer camps, research projects and outreach activities in local communities.

Ågrenska's main objective is to gather, develop and spread knowledge on RDs and their consequences. The centre provides family programmes, adult programmes, respite care services, summer camps, a family support unit, courses for professionals and social research. The centre aims at supporting and empowering people to cope with everyday life and to be as independent as possible.[26]

These resource centres have now joined together with other resource centres from across Europe to create RareResourceNet[27]—the European Network of Resource Centres for Rare Diseases. The network aims at accelerating the development and the implementation of holistic high-quality care pathways for people living with RDs across Europe, to contribute to raise standards of care and support.

44.3.1.6 Networking and Training Programmes for Service Providers

Coordination and networking between all parties involved in care provision is essential to support the transfer of the scarce expertise on RDs from central structures to regional and local services.

National authorities should allocate funding to support the creation of multidisciplinary teams composed by health (including Centres of Expertise), social and local care providers. Networking at an international level could be facilitated via the European Reference Network for RDs.

Training health and non-health professionals is essential to support the integration of RDs specificities into mainstream services. Centres of Expertise should take the lead in developing training and networking programmes/tools for social and local support service professionals involved in the different stages of the care pathway. The EUCERD Joint Action has developed guiding principles and case study documents essential to support the design of training programmes for social care providers (EUCERD Joint Action 2014a, b).

44.3.1.7 Integration of Rare Diseases into National Functionality Assessment Systems

A high percentage of people with a rare disease are affected by motor, sensorineural or intellectual impairments, which can occur simultaneously (Guillem et al. 2008).

72% of people living with RDs involved in the European survey declared having difficulties with motor or sensorial functioning. The recognition of their disability was the main challenge: 34% of the respondents who had been submitted to a disability assessment found the percentage of disability assigned to them too low;

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[26] More information is available at: https://download.eurordis.org/documents/pdf/sss/3-RCS-Agrenska-Gunilla-Jaeger.pdf.

[27] More information is available at: https://innovcare.eu/social-services/rareresourcenet/.

and 19% of respondents had not been submitted to a disability assessment despite feeling that they needed to (EURORDIS 2017).

The Commission Expert Group on Rare Diseases recommends to Member States that RD specificities should be integrated into national systems when assessing a person's level of functioning, in line with the United Nations Convention on the Rights of Persons with Disabilities (Commission Expert Group on Rare Diseases 2016). A fair assessment of patients' functionality would ensure that health care and welfare systems take into account the complexity of RDs, supporting medical and social services to develop integrated care plans.

To ensure an adequate evaluation, the assessment system should be flexible to adapt to people with a RD affected by complex combinations of several impairments, less visible impairments, degenerative conditions or acute disease periods. The Orphanet Disability Project[28] (de Chalendar et al. 2014) which develops RD disability core sets derived from and compatible with the International Classification of Functioning, Disability and Health (ICF) is an important tool that can support national authorities to improve the assessment of functionality and disability of people living with a RD.

44.3.1.8 e-Health to Facilitate Data Sharing and Interoperability

Integrated care for RDs can also be supported by the use of e-Health solutions which can improve the quality of treatment, broaden access to medical care, improve health outcomes and quality of life, get the most out of technologies and new services, and reduce pressures on public healthcare budgets.

Additionally, e-Health can help address a major issue for the RD community: data protection and interoperability. A priority for any e-Health service should be to enable the integration of (possibly disparate) sources of data, based on unambiguous electronic identification of patients, across countries and across databases.

44.3.1.9 European Reference Networks[29]

The concept of a European Reference Network (ERN) represents a major step forwards in optimising and equalising care for Europeans living with health conditions which require a particular concentration of highly specialised expertise, most notably people with RDs.

Twenty-four ERNs were officially launched in 2017, uniting Centres of Expertise all across Europe, with the ambition that under this suite of networks all RDs would have "a home".[30] The era of the ERNs holds huge promise to advance and expand the provision of integrated, holistic and person-centred care for people with RDs. The networks could add value in many practical ways:

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[28] More information is available at: https://www.rare-diseases.eu/wp-content/uploads/2014/05/0602_Myriam_de_CHALENDAR.pdf.

[29] More information available at: http://ec.europa.eu/health/rare_diseases/european_reference_networks/erf/index_en.htm. and http://www.rd-action.eu/wp-content/uploads/2018/09/Final-Overview-Report-State-of-the-Art-2018-version.pdf, Section 5 (Hedley et al. 2018).

[30] This founding principle is explained in the Addendum to the EUCERD Recommendations on ERNs: https://ec.europa.eu/health/sites/health/files/rare_diseases/docs/20150610_erns_eucerdaddendum_en.pdf.

- ERNs can build and disseminate knowledge and understanding of the true medical, social and holistic needs of people with RDs, by collecting data (including "quality of life" data) and conducting research;
- ERNs can spread understanding of the benefits of creating integrated pathways between health and social care. Although national realities differ significantly, ERN clinicians and patients can define the specialisms and stakeholders who should be involved at each stages of a patient's journey (encompassing medical specialists from multiple disciplines but also physiotherapists, psychologists, social workers, etc.);
- ERNs could stimulate the creation of personalised health and social care plans for patients attending their respective member centres (known as healthcare providers);
- In the past, European countries agreed ambitious but critically important criteria by which to define a true Centre of Expertise for RDs. ERNs could help to embed good practices in their respective healthcare providers, to encourage them to meet the criteria concerning integrated, person-centred and holistic care.[31]

Several sets of European Recommendations espouse the added value of ERNs for this essential topic[32]: the next steps will be to support the networks in implementing activities such as the above. The impact here would be tremendous. The launch of ERNs united almost a thousand leading healthcare providers across Europe,[33] and in late 2019, the networks took steps to significantly increase their membership and outreach, affording unprecedented opportunities to uncover and disseminate good practices.

44.4 Results of Integrated Care Approaches to Care Delivery

Regardless of the scarcity of data and studies on integrated care provision to people living with RDs, models of care which take into account integrated care methods have proven to be effective in optimising health outcomes and quality of life of people with RDs.

The pilot of case management for rare diseases implemented within the EU-funded INNOVCare project (Romania, 2017–2018) resulted in various positive outcomes within important daily life and care areas. People living with RDs and carers who benefited from the service increased their level of information about

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[31] This founding principle is explained in the Addendum to the EUCERD Recommendations on ERNs: https://ec.europa.eu/health/sites/health/files/rare_diseases/docs/20150610_erns_eucerdaddendum_en.pdf.

[32] This founding principle is explained in the Addendum to the EUCERD Recommendations on ERNs: https://ec.europa.eu/health/sites/health/files/rare_diseases/docs/20150610_erns_eucerdaddendum_en.pdf.

[33] More information is available at: https://ec.europa.eu/health/ern_en.

their disease, their rights and available services. Their capacity to manage their care also increased, while the service also reduced the burden faced by caregivers (assessed via the Zarit Caregiver Burden scale). Furthermore, the case management generated improvements for care providers and public bodies, enhancing the coordination amongst these stakeholders involved in the care provision (INNOV-Care 2018a).[34]

An example of integrated care provision for cystic fibrosis patients in Europe shows that the establishment of a centre providing multidisciplinary care for this RD—including consultants, nurse, microbiologist, physiotherapist, dietician, pharmacist, psychologist, social worker, geneticist and allied healthcare professionals experienced in cystic fibrosis care—results in a significant increase in life expectancy for patients (Conway et al. 2014).

A study conducted by Ågrenska's one-stop-shop service for RDs, revealed that this resource centre is perceived as an improvement relative to patients' experience within the healthcare system in terms of treatment, outlook for the future, socio-economic support, peer support and consideration by professionals and by the institution. Additionally, this type of holistic approach is cost-effective and leads to a nearly threefold decrease in costs to society (Olauson 2002).[35]

Various pilots of integrated care provision for people with RDs and families are currently ongoing throughout Europe. In the upcoming years, the results of the evaluation of these pilots are expected to provide further insight into the health, social and economic benefits of integrated care provision to people living with a RD, as well as data on the cost effectiveness of these services and on their impact on the optimisation of resources for national care systems.

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[34] INNOVCare (2015–2018), a project co-funded by the EU, addressed the issue of integrated care for people affected by RDs by developing, testing and promoting a holistic, personalised care pathway. A pilot of case management was implemented and evaluated during the project. The pilot took place in Romania, in 2017–2018, and involved 121 patients with RDs, who had access to the service for 9 months, over a course of 18 months in total. The evaluation method consisted of a two-condition repeated measures design/rotation design with randomised control trial. The patients were divided with two groups, and each group was accessing the service in alternance, allowing for comparisons between the groups and within the same group. More information is at: www.innovcare.eu.

[35] Study done by the Department of Economics of the University of Gothenburg on Ågrenska: the approach offered by the centre saves money compared to ordinary programmes for disabled children. Moreover, a family requires less support from social services when having access to the centre. There is a nearly threefold decrease in costs when the child is correctly diagnosed and accesses proper treatment, compared to a child who is improperly diagnosed and treated through ordinary programmes. The savings appear to result from the reduction of costs with seeking emergency help, visiting specialists and sick leaves.

44.5 Lessons Learned and Outlook

The rarity, complexity and lack of treatment of RDs lead to significant unmet medical and social needs while creating particular obstacles to the provision of integrated care.

The provision of integrated care is essential for people with RDs to: ensure the transfer of the scarce expertise and information available; to support the coordination and communication between care providers; to optimise resources; to integrate RD specificities into mainstream services; to improve care and care pathways; and to reduce the burden for families, consequently increasing their quality of life.

Studies and pilots conducted so far have shown that integrated holistic care provision in RDs increases quality of life of people living with RDs, while being cost-effective and decreasing costs for society. A recent pilot of case management services for RDs, implemented within the EU-funded project INNOVCare, brought important benefits to people with RDs and their family members, while also improving the coordination amongst care providers.

Despite this growing evidence of the benefits of integrated care for RDs, much remains to be done to achieve integrated care for people living with RDs in Europe.

The Commission Expert Group on Rare Diseases recommends that European Member States promote measures that facilitate multidisciplinary, holistic, continuous, person-centred and participative care provision to people living with RDs, supporting them in the full realisation of their fundamental human rights.

To support this process, the European umbrella organisation for rare diseases has released a set of recommendations to support the implementation of integrated care for RDs in Europe. These recommendations include measures to create a supporting environment at national level, specific mechanisms to ensure integrated care and concrete measures to support the gathering and dissemination of essential knowledge and good practice.

Various methods can and should be used simultaneously to promote integrated care for RDs including: Centres of Expertise and resource centres for RDs; case managers; care pathways and standards of care; individual care plans; networking and training programmes for service providers; eHealth; European Reference Networks; and the integration of RDs into national functionality assessment systems.

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Integrated Care for People with Intellectual Disability

45

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45.1 Definition and Classification of Intellectual Disability (Intellectual Developmental Disorder)

Intellectual disability (ID) is not a disease or a disability, but a syndrome grouping similar to that of dementia, characterized by a pervasive cognitive impairment occurring in the early developmental period. It includes a heterogeneous group of conditions with considerable differences in the nature, ranging from genetic to environmental factors. The prevalence rate of ID for Northern European countries is reportedly around 0.7%, but it may rise to 4% in low- and middle-income countries (LAMIC) (Durkin 2002; Maulik et al. 2011; Girimaji and Srinath 2010; Jeevanandam 2009). In these regions, the excess rate of ID appears to be associated with fully preventable aetiologies such as teratogens, diet deficiencies, pregnancy and birth-related conditions (Persha et al. 2007; Bertelli et al. 2009). However, the cause remains not identified in 60% of persons with ID.

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Besides a few genetic and congenital problems, international agencies have not given enough attention to the causes of ID (Salvador-Carulla et al. 2000). In their review, Bertelli et al. (2009) identified five major factors contributing to this lack of visibility. First, the ID field suffers from the lack of both a reliable construct of intelligence and a commonly agreed and freely available tool for IQ measuring. Second, comprehensive epidemiological data are still not available, particularly in relation to the different levels of severity of these conditions. Third, ID is an underfunded field, and this is a consequence of not being a key topic in many national health research programmes. In many countries, ID management is not included within the health department but it is considered matter of the social or educational area. As a result, the attention given to ID from the health sector is constrained. Finally, the case of ID is particularly challenging due to an ongoing debate on whether it should be classified in the International Classification of Diseases (ICD) as a health condition or in the International Classification of Functioning (ICF) as a disability. The lack of agreement on such a basic question reflects the complexity of this construct. As a matter of fact, many national agencies follow the approach of the American Association of Intellectual and Developmental Disabilities (AAIDD) that defines “intellectual disability” as “a disability characterized by significant limitations both in intellectual functioning [IQ < 70] and in adaptive behaviour, which covers many everyday social and practical skills”.

The time frame for age of onset is defined from birth to 18 years. This has oriented the recommendations made by this group for naming and conceptualizing this condition at ICD (Tassé et al. 2013; Wehmeyer et al. 2008). Other organizations such as the World Psychiatric Association (WPA) have defined it as a group of health conditions, namely developmental conditions, characterized by a significant impairment of cognitive functions associated with limitations of learning, adaptive behaviour and skills (Salvador-Carulla and Bertelli 2008).

The latter conceptualization was adopted by the ICD Working Group in 2011 which coined the term “intellectual developmental disorders” (IDD) to define this group of aetiologically diverse conditions, present from birth or occurring during the developmental period, characterized by a marked impairment of those cognitive functions that are necessary for the development of knowledge, reasoning and symbolic representation in comparison with typically developing peers. IDD has been also defined as a lifespan condition requiring attention and support during all developmental stages and life transitions (Salvador-Carulla et al. 2011; Bertelli et al. 2014).

In the attempt to develop a better definition of ID, the ICD Working Group proposed revised diagnostic criteria for ICD-11 on the basis of an articulated model of cognitive impairment. The proposed approach aimed to assess cognitive skills in the most comprehensive way, using tests, semi-structured observations and direct clinical examination. Such tests should combine measurement of IQ with measures of the complex aspects of executive functioning, e.g. perceptual reasoning, processing speed, verbal comprehension, and of more specific aspects, such as attention maintenance, attention switch, visual–spatial perception, working memory or short-term memory, along with contextualized description of the consequent adaptive and learning difficulties. Such evaluation will allow the identification of the specific cognitive dysfunctions that have the greatest negative impact on the person's lifespan, not only in the cognitive domain but also in the domains of behaviour, ability, adjustment, autonomy and others that rely on person-centred health (Salvador-Carulla et al. 2011; Bertelli et al. 2014).

45.2 General Health Issues

People with ID may present a wide range of comorbid physical problems and poor health-related habits (Bertelli et al. 2009; Perry et al. 2010). To date, epidemiological studies deal with a 2.5-fold greater prevalence of physical illnesses in this group than in the general population (Van Schrojenstein Lantman-De Valk et al. 2000; Dixon-Ibarra and Horner-Johnson 2014). The most observed medical states are obesity, metabolic disorders, osteoporosis (Center et al. 1994; Dreyfus et al. 2014), thyroid and cardiac diseases, sensory impairments (Kapell et al. 1998) and dementia (Janicki and Dalton 2000). Furthermore, people with severe or profound ID present a prevalence of eating problems and epilepsy (Robertson et al. 2015).

Specific physical alterations and diseases can appear both in developmental age and at a later time. For example, in Down syndrome some clinically relevant anatomical and functional disorders appear after birth, and others arise in infancy, in adolescence and youth (Pueschel and Pueschel 1992) or in late adulthood, such as epilepsy (McVicker et al. 1994) and dementia (Devenny et al. 1996). The vulnerability of persons with ID results also in frequent visits to the emergency room and in hospitalization. Persons with ID present a twofold greater prevalence of hospital admissions rather than the general population (14% vs. 26%) (Mencap 2004), including emergencies (50% vs. 31%) (Emerson et al. 2012).

Physical vulnerability associated with ID is also shown in the causes of death. Persons with ID present an increased risk of early death in comparison with the general population (Hollins et al. 1998; McGuigan et al. 1995; Hosking et al. 2016). In a recent study conducted in the state of New South Wales (Australia), the population with ID was found to have a standardized mortality ratio (SMR) of 2.48 for all ages and an SMR of 3.15 for those aged 5–69 years, higher for females (4.26) (Florio and Trollor 2015). The age-standardized death rate (ASDR) for the ID cohort was 4.04 (deaths per 1000), whilst the ASDR for the rest of the population was 1.58, with a comparative mortality ratio of 2.55.

In a study conducted by Hollins and colleagues at the end of last century, the risk of dying before the age of 50 was 58 times higher than in the English general population (Hollins et al. 1998).

The list of causes of death in persons with ID also differs from the general population. In the former, the main death causes are cardiovascular diseases, respiratory disorders and neoplasms whilst main causes of death in the latter are neoplasms, ischaemic heart disease and cerebrovascular diseases (Janicki et al. 1999; Tait 1983). Significantly, other relatively frequent causes of death in ID include epilepsy, asphyxia and gastrointestinal disorders (Robertson et al. 2015;

Ouellette-Kuntz et al. 2015; Puri et al. 1995; Eyman and Call 1991; Raitasuo et al. 1997; O'Brien et al. 1991). Hollins et al. (1998) found that early death was significantly associated with cerebral palsy, incontinence and institutionalization. In the last two decades, the average life expectancy for persons with ID living in high-income countries has increased, due to the improvement of life conditions and healthcare practices, although it remains lower than in the general population (Janicki et al. 1999; Bittles et al. 2002; Reppermund and Trollor 2016).

Simultaneously, a rise of ageing-related diseases has been recorded (McCallion and McCarron 2004). Nevertheless, ageing-related diseases and life conditions in persons with ID have not yet received the attention they deserve and the few available studies on these issues present several limitations, such as sampling errors, distortions of clinical characteristics (Evenhuis 1997; Bittles et al. 2002), unreliable admission practices and policies (Carter and Jancar 1983), lack of control for concurrent illnesses and related health interventions (Edgerton et al. 1994; Beange et al. 1995).

45.3 Mental Health Issues

In persons with ID, mental health problems are even more frequent than physical ones. In fact, a third of this population has comorbid psychiatric disorders, and another 10–20% has behavioural problems not related to psychiatric illness, but to psychological, environmental or physical conditions. As a consequence, nearly one half (0.75–2% of the total population) of individuals with ID need psychiatric care, exceeding those with any other major psychiatric disorder in the general population (Salvador-Carulla et al. 2000; Cooper et al. 2007; Salvador-Carulla and Bertelli 2008).

There are various causes underlying the high psychological and physical vulnerability of persons with ID. Some biological factors are linked to genetic or infectious alterations that outline a complex syndromic framework. Other bio-psychological factors are represented by alterations of the central nervous system, chronic physical disabilities, hygiene problems, inappropriate eating habits, pharmacological side effects, hypoactivity and communication difficulties (Van Schrojenstein Lantman-De Valk et al. 2000). Most frequently reported psychological factors are difficulties in coping, self-determination and environmental mastery. Social–environmental factors are also implicated, such as traumatic experiences, negative life events, repeated failures, lack of satisfying relationships, lack of interests, variable or inadequate housing conditions (Eyman and Call 1991; Raitasuo et al. 1997; Carter and Jancar 1983).

Diagnosing psychiatric symptoms in persons with ID entails several complications, including the hardness to recognize the impact of symptoms on daily functioning and personal distress. Assessment, diagnosis and treatment of mental problems in this population demand particular adjustments due to the cognitive dysfunctions, communication limitations, sensory impairments, skill deficits, difficulties in adaptation and other disabilities that are often present in ID (Bertelli et al. 2015). A frequent problem is the diagnostic overshadowing between psychiatric symptoms and behavioural alterations or expressive ways that could be typical both for ID in general or for certain phenotypes in particular.

The prevalence of problem behaviours (PBs) in ID ranges between 5 and 60% (Smiley 2005) with several limitations on the social functioning and the rehabilitative processes. It is difficult to prove whether PBs are the outcome of organic conditions, psychiatric disorders, environmental influences or a combination of these factors (Bertelli et al. 2015). Nevertheless, some studies support the existence of a relationship between PBs and psychiatric disorders (Emerson et al. 1999; Felce et al. 2009; Kishore et al. 2005), with a particular strength in people with limitations in functioning (Felce et al. 2009). Furthermore, some behavioural equivalents have been recognized for specific psychiatric symptoms (Hurley 2006).

The difficulty in the identification of symptoms relies also on communication problems. These persons may have poor verbal expression abilities, be inclined to acquiescence and show deviations from the norm in the attribution of meaning to communicative contents. In addition, some individuals present a limited introspection capacity, having difficulties in defining their own life experiences and in communicating states of uneasiness or suffering. Furthermore, sources of information other than the individuals themselves may be limited, heterogeneous and contradictory. Family members are often in difficulty in finding answers aimed at detecting the presence of further mental functioning disorders or problem behaviours (Salvador-Carulla et al. 1998). First-line support personnel do not have appropriate tools for discriminating the observed behaviours and are not able to attribute a possible pathological meaning to these behaviours. Also for therapy outcome, self-assessment can be challenging or impossible for most persons with moderate-to-severe ID and there is some agreement on that it could be integrated with proxy assessments.

Generally, ID produces a considerable burden on families and caregivers throughout the lifespan (Salvador-Carulla and Bertelli 2008), which becomes even higher in case of co-occurrence of psychiatric disorders (Martorell et al. 2011; Irazábal et al. 2012). Moreover, psychiatric problems and behavioural disorders are the main causes of isolation and stigmatization associated with ID (McIntyre et al. 2002). In spite of its global burden, which surpasses the burden of dementia, ID is regarded as a second-level condition within health care, particularly in psychiatry. This lack of attention is evident in the limited clinical and practice guidelines on identification, assessment and intervention for mental health needs. Many reasons have been identified for this misconsideration, including the above-mentioned peculiarities in the presentation of symptoms and the diagnostic overshadowing with the manifestations of the neurodevelopmental disorder itself. However, the most relevant cause is probably the assumption that the early neurodevelopmental impairment represents an untreatable neurological condition which significantly and definitely compromises the overall psychic functioning, so that there is not even the possibility to have any psychiatric suffering or at least to use any of the psychopathological knowledge acquired with the general population. In order to get attention from the medical sector, public health planners and other health organizations, these issues should be thoroughly reviewed. Results from several studies report a lack of appropriate resources available for persons with ID and their carers, in spite of the difficulties and health-related problems they experience. Thus, more support should be provided to this population, especially in the field of primary and mental health care where vertical integration across the different levels of specialization and horizontal integration with social services is needed.

45.4 Access to Care

To date, there is a significant gap between the health-related needs of persons with ID and the provision of care (Van Schrojenstein Lantman-De Valk et al. 2000; Perry et al. 2010). As regards to the health status, the European POMONA study, which included 13 countries, revealed that 65% of the sample of persons with ID used one or more forms of medication, 28% had a diagnosis of epilepsy, two-thirds were either underweight, overweight or obese, and 52% reported a sedentary life (Perry et al. 2010).

Failings in healthcare provision represent a significant problem for this vulnerable group of patients that requires well-timed, adequate and sensitive care interventions. Actually, in several European countries, health care does not succeed in providing adequate services. Gaps include access to primary care, to medical prescriptions, to the disclosure of useful information, to actual treatment for serious mental illnesses and to the communication between health and social services (O'Hara 2006). According to Tuffrey-Wijne et al. (2014), the major barriers to care provision in this population include the detection of persons with ID, the lack of clear lines of responsibility and accountability for implementing care, and in the shortage of financial supports and resources.

Other difficulties concern the communication of the consumer with professionals (Ali et al. 2013; Wilson and Haire 1990) and the lack of general practitioners (GPs) adequately trained to manage and treat these patients (Lennox et al. 1997). This is further compounded by the lack of an adequate and rigorous training of mental health professionals in the field. In Norway, a recent study examined the experience and aptitude of ten GPs providing health care for persons with ID and co-occurring mental health and/or behavioural problems. It revealed training problems and difficulties in patient management. GPs admitted to have a poor knowledge about communication manners and clinical peculiarities of this population (Fredheim et al. 2013). Their knowledge came from daily clinical practice (medical examinations and pharmacological treatment) and individual educational paths. Training in ID is not included in the psychiatric curriculum of professionals in many countries, and the majority of psychiatrists are not prepared to deal with the specific health needs and demands of persons with these conditions (Salvador-Carulla et al. 2015).

Similar trends and needs have been described in other countries (Kwok and Chui 2008; Jeevanandam 2009; Werner and Stawski 2012), suggesting that problems of manpower and service delivery may be considered as a universal phenomenon.

Usually, information coming from rigorous research trials helps the clinicians in any field of health to take appropriate decision on intervention, and this applies also to psychiatry. Nevertheless, an extensive search of databases spanning over 16 years performed by Balogh et al. (2008) indicated that there were only six randomized controlled trials in the field, and virtually none on organizational interventions, and a few more were in need of corroboration. Obviously, more clinical training opportunities are mandatory for psychiatrists to gain the knowledge, competence and attitudes that are necessary to improve specialist clinical services.

A wide disparity between high-income countries (HIC) and LAMIC with regard to the mental health care of ID has been reported. In HIC, there is no dearth of manpower and advanced mental health facilities for the general public as well as for people with special needs, including those with ID. Conversely, in LAMIC even the general population struggles for basic, accessible health facilities, and therefore the particular needs of people with ID receive less attention. However, it is not possible to affirm with certainty that ID uniformly figures at the bottom of health care across LAMIC. For example, in countries like India, there are some advanced facilities for ID, mainly located at national and regional centres, and a few in the private sector, which are usually located at urban settings. On the other hand, basic health or rehabilitation facilities are abysmally poor in the rural settings where a majority of the disabled population lives.

Hence, there is a greater need for high-quality, holistic mental health services to cater to mental health needs. Moreover, there is an urgent need for a multi-level healthcare system that should be accessible, equitable but more importantly with a monitoring system. In the absence of such facilities, benefits might be obtained by a system providing cost-effective screening methods and referral processes by community-based workers or caregivers.

Taking all these issues into account, it is hoped that once the psychiatry training is systematized, and information on intervention research is available to professionals, quality services can be provided even through general settings. As it is, there is no clear evidence in favour of general or special settings to provide mental health services (Chaplin 2004).

45.5 Specialized Services for ID Associated with Other Mental Disorders

Specific services for ID associated with other mental disorders (ID-MD), mainly non-acute hospital care, are lacking across many of the European countries, and very few areas have more than two different service types available for this particular population. With the exception of few northern countries, the Netherlands and the UK, the majority of European region lacks a full range of specialized services including hospital care, community residential care, day care and outpatient care for ID-MD. There is a generalized indifference towards the ID-MD care needs in the mental health policy plans. In those places where services have recently expanded, hospital care originally intended for acute patients has been transformed in non-acute hospital facilities and there is still a lack of residential care in the community for this specific population group. Similar problems have been identified in other world regions. The care gaps in integrated care have been recently reported in New South Wales (Australia) (Howlett et al. 2015) and Ontario, the latter through the Health Care Access Research and Developmental Disabilities (H-CARDD) programme. H-CARDD is a partnership of scientists, policymakers and clinicians which uses administrative data to provide information on the health of a cohort of adults with developmental disabilities in respect to other adults in Ontario (Lunsky et al. 2014). The key findings of H-CARDD have been published in the Atlas of the Primary Care of Developmental Disabilities in Ontario (Lunsky et al. 2013).

Taking into account all the available data, a European expert group estimated that 50% of the persons with ID-MD have not been offered a minimum clinical assessment and that 95% did not received adequate clinical support (Salvador-Carulla et al. 2013). In order to overcome this, the expert group prepared a model of minimum standards required for basic ID-MD care. According to the plan, agreed minimum care needs included an outpatient ID-MD unit and 6.5 beds per 1 million population. Specialized outpatient ID services required at least one multidisciplinary team per 1 million inhabitants. These facilities should include at least one ID psychiatrist, one clinical psychologist, a nurse and a social worker, plus administrative personnel. This minimum mobile team should provide support and be an intermediary between over 10 community mental health centres in its catchment area and around 30 primary care centres in the same area. It should also ensure on-site care to complex cases and set a continuity of care programme with hospital and non-hospital community care.

As next step, care needs for the different regions in Spain were estimated. The minimum estimate of outpatient specialized mobile services (preferably within an already existing mental health centre) was 44, and one psychiatrist and one psychologist should be present in each team. For this project, at least 277 new beds were needed in over 20 units with 10–15 beds each. These in-patient units should be designed for medium stay patients, usually over 6 weeks. They should give support to the non-hospital residential care subsystem, but also to the community care subsystem in order to support acute and sub-acute care needs for persons with ID-MD. The services aforementioned required at least 46 new trained psychiatrists and psychologists in Spain. In all, a minimum of 134 specialized psychiatrists and psychologists were necessary to fit the basic ID-MD services in Spain, apart from nurses, social workers and other support staff.

Additionally, the expert group suggested to develop complementary residential community services for this specific group, a bridging strategy that would necessitate share funding and management strategies from the health and social sectors, and recommended five centres of excellence for integrative evaluation of ID (one per every 7 million inhabitants). These supra-regional integrative diagnosis services should promote person-centred bio-psycho-social screening, assessment, intervention planning, counselling and liaison in ID, including mental health. Finally, in consideration of the mentioned problems regarding the information databases and the existence of other care needs in ID-MD, it was recommended to develop a national observatory on ID-MD. Table 45.1 summarizes why ID patients need special attention in psychiatric care.

Table 45.1 Factors explaining why ID patients need attention in psychiatric care

Factors		
General health issues	Presence of a wide range of co-occurrent physical problems and poor health habits	Bertelli et al. (2009), Perry et al. (2010), Van Schrojenstein Lantman-De Valk et al. (2000) and Dixon-Ibarra and Horner-Johnson (2014)
	Higher rate of hospitalizations	Mencap (2004) and Emerson et al. (2012)
	Increased risk of early death	Hollins et al. (1998), McGuigan et al. (1995) and Florio and Trollor 2015
	Paucity of studies on ageing-related diseases in IDD and interventions	Evenhuis (1997), Bittles et al. (2002), Carter and Jancar (1983), Edgerton et al. (1994) and Beange et al. (1995)
Mental health issues	Higher rates of comorbid psychiatric disorders	Salvador-Carulla et al. (2000), Cooper et al. (2007) and Salvador-Carulla and Bertelli (2008)
	Assessment challenged by cognitive and communication deficits and sensory impairments	Bertelli et al. (2015)
	Co-occurrence of problem behaviours (PBs)	Smiley (2005), Emerson et al. (1999), Felce et al. (2009), Kishore et al. (2005) and Hurley (2006)
	Higher burden on families and caregivers throughout the lifespan	Salvador-Carulla and Bertelli (2008), Martorell et al. (2011) and Irazábal et al. (2012)
	Higher risk for isolation and stigmatization	McIntyre et al. (2002)
	Lack of specific assessment tools, clinical guidelines and expertise for interventions	Bertelli et al. (2015) and Salvador-Carulla et al. (2011)
Access to care	Limited access to primary care and shortage of adequate services	Van Schrojenstein Lantman-De Valk et al. (2000), Center et al. (1994), Perry et al. (2010) and O'Hara (2006)
	Poor knowledge regarding IDD patients because of the lack of an adequate training for practitioners	Lennox et al. (1997), Fredheim et al. (2013) and Salvador-Carulla et al. (2015)
	Wide disparity in IDD mental health care between high-income and low-income countries	Maulik et al. (2011) and Salvador-Carulla et al. (2011)
Specialized services for ID-MD	Dearth of hospital care, community residential care, day care and outpatient care	Howlett et al. (2015)

45.6 Integrated Care and Person-Centred Approaches

Person-centred care as a model of care provision, care individualization and lifestyle support was first developed in the ID sector long before other areas of health and social care picked it up. However, and although some agencies have actually implemented person-centred care (PCC) over decades in the USA, Australia and Europe, the claims of adherence to the PCC goals are larger than its actual application (Balogh et al. 2008; Kendrick 2012). Leutz (1999) defines "integrated care" as a broad inter-sectorial system approach that aims to connect the healthcare system with other human service systems in order to improve outcomes (clinical, satisfaction and efficiency). Even though these two models, PCC and integrated care, have evolved jointly in the field of ID and are widely supported for improving accessibility and quality of health care, a comprehensive shared knowledge base about issues related to integrated care and PCC is lacking and its full implementation is slow due to barriers in the philosophy or culture of care, power and funding structures, high levels of staff turnover and lack of training, inexperience among service management, inadequate staff supervision and ambiguity among some stakeholders (Dowling et al. 2007). From a clinical point of view, integration requires the adoption of a person-focused perspective. This is an essential aspect to improve an individual's overall well-being and to take into account their needs. The main characteristic of person-focused care is defined by a bio-psycho-social approach applied to health. From this point of view, diseases are simultaneously a medical, psychological and social problem (Valentijn et al. 2013). Comprehending the personal meaning of a disease is at the base of person-focused care that attempts to comply with individual needs and preferences. Conversely, focusing on the illness reveals a clinical perspective that connects the needs of an individual to separated biological entities (Starfield 2011; Pulvirenti et al. 2014).

Generally, Western health systems adopt a disease-focused approach which often overlooks the implicit reasons of health or illness, but this perspective is inappropriate in a population where more and more patients present chronic and overlapping diseases (Nolte and McKee 2008). Therefore, adopting a person-focused view seems to be more functional, particularly in the context of integrated care. Actually, in this holistic vision most health and social issues are interrelated and its adoption allows to identify the links between the different systems. Integration is also required from an organizational point of view to ensure a continuing and comprehensive supply of services matched to the necessities of the users. The major challenge is to convert general understandings about integrated care into practical terms to make available more effective health services able to improving quality of care and quality of life for the individuals.

A significant contribution has been provided by the International College of Person-centred Medicine (ICPCM) and the Person-centred Integrative Diagnosis (PID) multidimensional matrix (Mezzich et al. 2010), which takes into account not only the health condition and the disability but also the positive aspects defined as well-being and good functioning. IDD/ID may not be an exception in health but a prototypical example of how the holistic and comprehensive approach recommended by ICPCM is useful for understanding these complex constructs in health care.

45.6.1 Integrating Care of Somatic Illnesses

Up until now, people with ID continue to experience disparities in healthcare provision. Integrated care approach should be addressed to those factors which have been identified as obstacles to their access to services and proper treatment provision. Therefore, greater efforts should be made in providing adequate training in ID for all health professionals, in order to improve knowledge regarding the identification and treatment for chronic health conditions which affect this population. This will also promote a better understanding of how to monitor health conditions among those who are ageing. Increasing evidence shows that in the general population adopting healthy lifestyles in old age can yield health benefits (Kenfield and Stampfer 2013), but indications for better health habits have not been provided and supported for persons with ID. It would be necessary to promote adequate strategies for including this population in health and wellness prevention programmes, through an early identification of such problems, and to develop and use structured assessment tools, coupled with tailored interventions.

According to some recent studies, mental and physical problems relate to each other to a greater extent and in a more direct way in ID than in the general population (Kwok and Chui 2008; Cooper et al. 2015). This suggests a collaboration between psychiatrists and other specialists, such as GPs, neurologists, dental practitioners, orthopaedists or otolaryngologists to be particularly advisable (Galli-Carminati et al. 2006; Patja et al. 2001; Gimbel 2000; Bohmer et al. 2000).

45.6.2 Integrating Care of Psychiatric Disorders

It is important to note that the ID construct presents also several positive implications for psychiatry. A review conducted by Salvador-Carulla and Bertelli (2008) highlights several dimensions for which ID deserves more attention. First, ID provides genetic models for scores of psychiatric disorders. It also provides models for the assessment, support system and diagnostic frameworks (e.g. provision for incorporating a developmental/ideographic approach) in severe mental and cognitive disorders. It is worth to note that models of care—such as residential care, respite care and multidisciplinary approach to care—as well social issues of health—such as stigma and labelling and self-advocacy—were developed first in the ID field, and now they are widely used in general psychiatry. Similarly, the need for close interaction between various agencies related to social, education, legal and health sectors for the integration of services to form a holistic management of the individual originated in the ID field. Therefore, the mainstream mental health organization can benefit from the field of ID regarding successful models of identification, assessment, care and support system. In spite of all, ID is still a disregarded topic in psychiatry, not to say in medicine.

It is clear that ID requires full attention with regard to both general health and mental health needs. This attention is of particular importance to face other issues that are intricately related to the nature of ID and the settings of evaluation. First, there will always be an overlap between the symptoms of mental health disorders and features of the developmental problems of ID and thus mental health services are not sought or extended (Szymanski and King 1999; Ailey 2003). Sometimes, diagnostic decisions tend in favour of either psychiatric disorders or maladaptive behaviours depending on the setting in which evaluations are conducted, and on the professionals involved in the examination (Nezu 1994; Einfeld and Aman 1995). Even after accurate diagnosis, people with both ID and mental health problems slip through the service delivery system as in many countries the services are dichotomized into hospital-based services predominantly utilized by the non-ID population and the rehabilitation centres and special education centres meant for persons with disabilities, including those with ID. Furthermore, many countries lack appropriate policies to bridge this gap and cater to the mental health needs of people with ID within the mainstream health delivery system. As a result, unmet mental health needs are common across the lifespan of ID, and the challenges arise accordingly with increased severity levels of ID (Allerton et al. 2011). But the real challenge is to both provide interventions to reduce these health inequalities and support a structure that systematically monitors the impact of the interventions over time. The interactions between early age-onset and older age-onset conditions may have relevant negative effects on functional impairment in PwID, physical and mental morbidity, and even mortality. For this reason, it seems to be particularly useful to adopt a dynamic lifespan approach since it may contribute to the identification of improvements or consequences of specific diseases and interventions (Hogg et al. 2000).

The Person-centred Integrative Diagnosis highlights the importance of engagement, empathy and partnership in the clinical care process, and sustains the patients' autonomy, responsibility and dignity whilst advancing the recovery and promotion of well-being. To assess the domain of person's experience and values, PID uses descriptive categories, dimensions and narratives, to cultivate patient–family–clinician partnerships for achieving shared diagnostic understanding and shared commitment to care. The application of this model to the assessment of personal well-being, experiences, satisfaction and aspirations of persons with IDD faces significant challenges in persons with IDD as the self-reported assessment of these complex concepts is limited due to the cognitive and communication impairments (Bertelli and Brown 2006).

The conceptualization of ID should shift the traditional over-reliance on the intelligence (IQ) score in favour of the daily life expression of specific cognitive functions, and the determination of the levels of severity of intellectual functioning that was previously based on the person's IQ score should be reached through a system that is predicated on the person's satisfaction attainment towards life (Bertelli et al. 2014).

45.6.3 Integrating Specialized or Secondary Mental Health Care

The usefulness of an integrated psychiatric assessment results from the consideration of several factors, most of which have been already mentioned. Considering the high vulnerability of PwID and the significant prevalence of psychiatric disorders (PDs) in this group, it is important to adopt an approach that comprehends as many points of views as possible in their assessment.

Also, PBs may be an example of usefulness of the participatory paradigm. Generally, PBs in PwID are pharmacologically treated and the search for a therapy which takes into account the individual specific conditions and the improvement of quality of life is disregarded. Actually, clinical practice suggests that an effective intervention on PBs should be characterized by a simultaneous consideration of organic, psychiatric and socio-functional aspects and their pathogenetic contribution, on the basis of a multimodal analytical approach. This indication is confirmed by recent evidence from scientific literature that supports the effectiveness of therapeutic processes developed starting from specific clinical and environmental information related to each patient. Such procedures can also be helpful in providing effective models for the assessment of PwID's adaptive skills with positive effects on their life.

An integrative assessment which consists of contributions from various disciplines might also allow the identification of problems in the classification systems, strictly linked to clinical practices. It can be useful also in providing genetic models for psychiatric disorders commonly experienced by PwID, with potential benefits for their early identification and identifying more and more sensitive diagnostic tools, instead of starting from very generic symptoms in assessing skills and performances. In fact, more than any other mental health condition, ID provides enough opportunities to explore the clinical expression of the body–mind link. In order to have a clear understanding of it, all parameters of a quality mental health management such as holistic consideration of individual, sensitive diagnostic methods including skills and tools are highly relevant (Bertelli and Brown 2006).

Multiple perspectives may lead to the development of new intervention models based on person-oriented approaches so as to address individual preferences. For that reason, the usefulness of Patient-Reported Outcomes (PROs) are more and more emphasized. The adoption of PROs is widely encouraged as a method to assess the patients and to improve the quality of health care. The term covers a set of potential types of measurement which can play a significant role in assessing patients' performances and evaluating the efficacy of the treatments. These measures include the model of quality of life (QoL), widely applied with reference to PwID. The assessment of QoL should take aim at identifying priorities and interests of each person in order to increase satisfaction in these aspects, improving the general satisfaction towards life.

Thus, a contextualized multimodal assessment and a multidisciplinary integrated intervention, involving different professionals, family and life environments seem to be a more useful solution, with several positive implications. The aim should be

Table 45.2 Reasons for integrated secondary care in persons with ID experiencing mental disorders

Higher prevalence rate of PD than in the general population
Identification of problems in the classification systems (i.e. ICD)
New understanding for intelligence
Models for the assessment of behavioural problems in severe mental disorders and cognitive deficit
Genetic models for PD
Direct clinical expression of the body–mind link
Changes and adaptation of diagnostic criteria and diagnostic process for PD
Sensitive diagnostic skills and tools (one often has to start from very generic symptoms, like behavioural changes or problems)
Models for the assessment of adaptive skills as well as supports
Lifespan approach
Holistic consideration of the patient and requires multidisciplinary intervention Model for high vulnerability to distress
Person-related outcome measures, like generic quality of life

to achieve a holistic consideration of physical, behavioural and mental health issues related to PwID, involving in their care a range of disciplines and health professionals.

Traditionally, health care for individuals with ID has been parsed out to multiple providers and/or agencies along disparate funding lines. Physical health, mental health and behavioural providers often have separate allocations and are managed by different entities. Bringing together those disciplines who have traditionally served individuals with ID, as to make them aligned with the person-centred approach, challenges the status quo and implies a drastic renewal of the current system of service provision in many countries across the world.

The main factors supporting the relevance of an integrated care in psychiatry for ID are summarized in Table 45.2.

45.7 Conclusion

Intellectual disability is a very interesting area to explore and to understand the design and implementation of person-centred integrated care due to its complexity in the classification and assessment, interventions, care delivery and policy planning. There is a significant ambiguity in the conceptualization and classification of this health condition, disparities emerge between the health sector and the social and education sectors on this condition, and these disparities have significant implications for service planning and delivery.

The early development of strategies of both person-centred care and integrated care in this field may contribute to a better knowledge of the challenges of developing integrated care both in the interaction between primary care and secondary care and in the integration of health and social care. There is an urgent need to encompass the existing developments and models in this specific areas of care with the general models developed in the integrated care sector, particularly in relation to the WHO strategy on people-centred integrated care for all (WHO 2015) and the international taxonomy of integrated care (Valentijn et al. 2015).

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SORCe—An Integrative Model of Collaborative Support for People in Need

46

Frank Cattoni, Duane Gillissie, and Heidi Fournier

46.1 Introduction

The **Safe Communities Opportunity and Resource Centre (SORCe)** is a multi-agency collaborative consisting of 13 government and not-for-profit agencies working in a brick and mortar store front in downtown Calgary. With 1.3 million people, Calgary is a major urban centre in Alberta, Canada, and consistently ranks amongst the most livable cities in the world. On 11 April 2018, the Alberta Point-in-Time Homeless Count was conducted across the province's seven major cities (Calgary Homeless Foundation 2018). The count found that Calgary had 2911 chronically homeless individuals. That accounts for 51% of the province's homeless population and makes Calgary the epicentre of homelessness in the province of Alberta.

SORCe connects people experiencing homelessness, or those at imminent risk of homelessness, to programmes and services that can help address the barriers to stable housing. SORCe focuses on housing assessments, mental health/addiction supports, justice interventions and connections to employment/training. By addressing an individual's upstream issues, two primary benefits should occur. The client receives better outcomes, and the two major systems that are impacted by this

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population should see a reduction in usage, specifically the justice and healthcare systems.

The original model for the collaborative was developed in 2009. The model grew from the recognition that the justice system has become a default mechanism for dealing with this demographic and that the system fails homeless people and their integration into the community. When police respond to calls from the public to deal with social disorder complaints, the homeless offender is typically charged with an offence ticket and/ or potential criminal charges. Failure to pay the ticket or deal with the criminal charges eventually leads to arrest and incarceration. This incarceration is usually only for short-term stays (30, 60, 90 days) and rarely does it have an impact on this demographic in the form of changed behaviour or recidivism rates. After release from the Calgary Remand Centre, the cycle starts again. This approach fails to address the underlying causes of homelessness and results in a substantial waste of resources.

A closer look at Calgary's homeless population shows a clear picture of vulnerability and instability (Campbell et al 2015; Nicholson et al. 2008). Trauma, mental health disorders and addiction are highly prevalent and are paired with physical health issues. Recent local data would suggest that 48% suffer from moderate to severe mental health issues and 54% from severe addiction. Calgary's homeless people self-medicate on street narcotics to address their mental health and rely on alcohol, non-beverage alcohol (hand sanitizing bladders, Listerine, rubbing alcohol) and crystal methamphetamine. Opioids are now appearing with a higher level of frequency within this population and in some cases are mixed with other street narcotics. In some cases, the mixing of the narcotics is intentional; in other cases, the chemical contents of the narcotics can be a complete mystery and the clients do not know what they are consuming. Many suffer from concurrent health problems ranging from frost bite to AIDS. Enforcement on this population has no impact on their behaviour and leads to cycling them through the criminal justice system. Data from the Homeless Management Information System (HMIS) shows that as much as 50% of the homeless self-report a previous encounter with the justice system (Calgary Homeless Foundation 2018). This number is likely significantly underreported as are the numbers for those suffering from mental health issues and addictions. Based on her caseload, the SORCe mental health clinician estimates that close to 85% suffer from mental health issues (as many homeless people do not have a formal diagnosis), and that about 80% of them have a severe addiction.

SORCe is based on the supposition that the Calgary Police Service (CPS) cannot enforce its way out of these broader community-based issues such as trauma, mental illness, addiction or homelessness. In fact, during its early conception, it was posited that the CPS had to work closely with other government agencies and not-for-profit organizations to support Calgary's homeless citizens.

In 2012, three community leaders came together to create SORCe: Chief Rick Hanson from the Calgary Police Service (CPS), Dr. Lucy Miller the CEO of the United Way of Calgary and Area and Mrs. Brenda Huband the Chief Operating Officer for Central and Southern Alberta for Alberta Health Services (the Regional

Health Authority). Fourteen agencies in the not-for-profit and government sector responded to their call for action, and SORCe was born. The CPS would provide the facility and the management, and the other agencies would provide "service providers" as an in-kind contribution. This was an opportunity to work in a collaborative setting and see if this innovative approach could have an impact. The vision was to benefit clients by looking upstream and addressing the root causes of their criminal behaviour: trauma, mental health, addiction and homelessness.

46.1.1 Results to Date

Fast forward to 2020, SORCe is now a key institution in Calgary's social fabric. In operation for just over 7 years (18 September 2013), the model continues to evolve. The most recent numbers speak to the success of the model:

Service volume	May 2017—March 2018 data (11 months)	April 2018—March 2019
Unique clients recorded	4001	4736
Total client visits	14,324	17,496
New clients per month	338	280

Note: Numbers are from the Homeless Management Information System

The majority of SORCe clients:

- Receive 3 services from their primary service provider;
- Seek services from at least one additional service provider at SORCe;
- Average 8 service transactions overall.

Since SORCe's inception on 18 September 2013, the Calgary Homeless Foundation through their Coordinated Access and Assessment housing triage process has placed 3217 clients into housing in concert with programming. Of those, 1528 clients (47%) were SORCe clients.

Participant Outcomes:

A program evaluation reported the following participant outcomes:

- Time savings; simplified system navigation; access to multiple resources/ programme in one location;
- Data sharing across the system of care, so clients can move between agencies and services seamlessly;
- Faster approval for, and access to, appropriate housing;
- Case management for those suffering from mental health and addiction issues;
- Outreach within the community to support reintegration;

- Access to food hampers and access services from case managers;
- Applications for municipal, provincial and federal funding programmes;
- Faster assessment, monitoring, planning, advocacy and referral to support services to manage ongoing issues and prevent relapse.

System Outcomes:

The Housing First Programmes require each participant to answer a set of questions prior to entering programming. Follow-up surveys are completed every three months up to a period of 45 months after being released from the programme. During a twelve-month period from April 2015 to March 2016, while clients were in programming, they reported the following outcomes.

Justice system:

- Contacts with police (↓ 73%);
- Days in jail (↓ 82%);
- Court appearances (↓ 44%).

Heath System:

- EMS usage (↓ 61%);
- ER visits (↓ 61%);
- Days in hospital (↓79%).

Please note that this is client-reported data. A fuller evaluation is currently underway with findings released later in the year.

46.2 The SORCe Model

SORCe is not itself an agency, but rather a multi-agency collaborative and was developed as a grass-roots initiative that is supported by a variety of community-based organizations. These organizations strive to expand the capacity, reach and coordination of existing programmes and services aimed at addressing the barriers to stable and sustainable housing.

By bringing together multiple agencies and programmes in a single location, SORCe strives to connect each client to all necessary programmes and services to support the individual and complex needs of each client that comes in the door.

Two key values drive SORCe:

> **Housing First**: By providing the stability of permanent housing first, those experiencing homelessness will be better equipped to address the underlying issues contributing to homelessness.

> **Inclusivity**: SORCe is a welcoming space where all people are treated with respect and dignity, regardless of race ancestry, place of origin, religious belief, skin colour, sexual orientation, gender, gender identity, marital status, family status, physical or mental disability, or age.

SORCe operates primarily through in-kind contributions from the agencies participating in the collaborative, along with a small annual operating grant.

The SORCe partnership has evolved over the years and currently includes thirteen partners:

- *Alberta Health Services:* urgent mental health and addiction services;
- *Alberta Justice and Solicitor General:* access to a Probation Officer for individuals who have probation conditions and no fixed address;
- *Alpha House:* offers a safe space for those whose lives are affected by alcohol and drug dependency;
- *Calgary Catholic Immigrant Society:* resettlement and immigration services;
- *Calgary Child Advocacy Centre:* through Prenatal Outreach Support Team provides resources and support to pregnant women experiencing homelessness;
- *Calgary Police Service:* justice system navigation support for individuals seeking to address justice system-related barriers to ending homelessness;
- *Calgary Public Library:* connects clients to library resources by issuing library cards and providing information and available programmes and services;
- *Distress Centre Calgary:* provides financial empowerment services (financial education, tax assistance, support in accessing financial assistance); connects individuals to social services; primary access point to housing in Calgary;
- *The Calgary Drop-in and Rehab Centre:* victim outreach services for homeless people that have been a victim of crime;
- *Inn from the Cold:* provides housing information, referrals and assessments for families;
- *The Mustard Seed:* employment programme (resumes, referrals, coaching);
- *Woods Homes:* primary youth intake for Calgary's housing system;
- *YWCA Calgary:* domestic violence outreach and intensive case management outreach for women experiencing or at risk of homelessness.

Programmes and services are offered on a walk-in and appointment basis during regular business hours and are free to anyone who is experiencing or facing homelessness. SORCe is open Monday to Friday, from 9 a.m. to 4:30 p.m. To access programmes and services, clients are required to complete an intake process which includes a client profile questionnaire. Clients must acknowledge that intake information shared with SORCe will be shared with all agencies that are participating in the collaborative, although a single client record does not exist. The service providers are all well versed on what each agency can do to support the clients and at what stage in the continuum of care a client is in. Client-centredness is critical, and client needs or wants in that moment in time determine what resources will be mobilized for that individual. Case conferences between SORCe agencies ensure that a client gets referred to the most appropriate services.

An early evaluation focused on the quality of the collaboration, i.e. how well the collaboration was working. The evaluation was completed by the United Way of Calgary and Area. The evaluators were tasked with interviewing a number of the front-line service providers. SORCe leadership stressed the importance in taking part in this process and reinforced with the staff that they were all subject matter experts in their respective fields and that they would determine the “speed, flow and direction” of SORCe based on their feedback. Not surprisingly, a number of issues emerged that reflect the challenges of traditionally autonomous agencies working in partnership (e.g. lack of trust and turf protection). From the evaluation, 21 recommendations were proposed; the most important was to be more client-centred (SORCe 2020). Initially, all the services were appointment-based (an agency-centric approach) and, anecdotally, only about 40% of clients would show up for their appointments. SORCe agencies now offer walk-in appointments primarily for highly acute clients to serve their immediate needs.

The Calgary Police Service was the backbone agency that supports SORCe. It provided the facilty and SORCe’s Executive Director. It is governed by a Community Leadership Group (CLG). The CLG is comprised of the following agencies and positions:

1. United Way of Calgary and Area—CEO (Chair);
2. City of Calgary—Strategist Child and Family Service;
3. AHS—Executive Director Addictions and Mental Health Calgary Region;
4. Calgary Drop-In Centre—CEO;
5. Calgary Alpha House—Executive Director;
6. Calgary Distress Centre—CEO;
7. City of Calgary—Director Animal and Bylaw Services;
8. Calgary Homeless Foundation—CEO;
9. Calgary Police Service—Deputy Chief;
10. Government of Alberta—Prosecution Services—Chief Crown Prosecutor;
11. YWCA—CEO;
12. Government of Alberta—Probation Services—Director Southern Alberta.

As SORCe has evolved and matured, the question has been brought forward whether a different governance model would be more appropriate. Some have argued that there should be two levels of governance: one committee to examine how SORCe integrates into the broader community and its alignment with municipal and provincial government mandates and a second committee to support SORCe more on an operational level. These issues are being examined and explored by the current CLG committee.

46.2.1 Evolution of SORCe

From the success of SORCe, two other initiatives have organically grown. The first is the **Cross Roads Centre**, and the second is the **Calgary Community Court**.

46.2.1.1 The Cross Roads Centre

The Cross Roads Centre brings together four distinct entities:

(a) iitaohkanitsini'kotsiiyio'p "Place of Conversation": Canada's first Indigenous Hub was launched by the Aboriginal Friendship Centre of Calgary, this hub is based on the 94 Recommendations of the Truth and Reconciliation Commission of Canada (2015) and the Missing and Murdered Indigenous Women and Girls report (2019). It currently provides 16 different culturally sensitive programmes such as outreach connections programme, youth mental health mentoring, an indigenous homeless initiative, access to elders and ceremonies, a spring cultural camp, and youth and family drumming.
(b) Safe Communities Opportunity and Resource Centre (SORCe).
(c) Alberta Health Services (AHS) Mental Health and Addiction Service Centre: This centre supports five different programmes, as well as two group therapy sessions (Addictions Talk Therapy and a Mental Health Talk Therapy). It also houses the Canadian Mental Health Association's Street Outreach and Stabilization programme and Alberta Addicts Who Educate and Advocate Responsibility (AAEAR), which is a peer support programme.
(d) Calgary Homeless Foundation's Learning Lab. This computer laboratory allows service providers from a variety of agencies to come and learn how to do housing assessments, Needs and Services Questionnaire (NSQ), and how to access and use Homeless Management Information System (HMIS).

The Cross Roads Centre provides social services, cultural supports, health care, justice and a centre for learning in a single location in the downtown core, where vulnerable street populations are known to congregate. Co-location is not the ultimate goal, but rather a critical first step to building a future of co-creation. The centre explores new ways of designing and delivering services in the community and across sectors, to a very vulnerable population with complex needs. Having SORCe embedded in this bigger collaborative allows extending the reach and impact for Calgary's homeless population, in particular indigenous groups. The indigenous hub offers diverse culturally appropriate services to urban indigenous clients who make up 3–5% of Calgary's population but make up 20% of the Calgary's homeless population. The question that is being explored is whether these large systems can come together and move the clients between the systems to create a "warm hand off".

46.2.1.2 The Calgary Community Court[1]

In 2015, the Calgary Police Service, through the SORCe programme, initiated collaboration with representatives from several Alberta/Calgary organizations to research and understand the revolving door of vulnerable persons engaged in public disorder (Lemieux et al. 2020) and establish an intervening mechanism, possibly a

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[1] As of 2021 this program has not launched as a result of resource shortages, within the Justice System.

community court. This cross-agency steering committee eventually became the Community Justice Collaborative Calgary (CJCC) that drove the proposal for an initiative serving the City of Calgary. CJCC established a mission of helping vulnerable Calgarians charged with non-violent social disorder offences whose criminal activity is related to issues of marginalization, addiction, mental health and/or homelessness. These individuals were to have improved access to integrated support services while still being held accountable for their behaviour.

In 2017, after visiting community courts in Canada and in the USA, CJCC engaged the Center for Court Innovation to assist in the planning efforts for a community justice initiative in Calgary. The result was a comprehensive review and a business plan for the initial launch of the Calgary Community Court (Center for Court Innovation 2018).

The Calgary Community Court is an individual-centred alternative court system that uses a therapeutic approach to justice and focuses on individuals struggling with trauma, addiction, mental health and/or homelessness as underlying causes for criminal involvement. The Community Court's individual-centred approach reduces the burden on the traditional justice system by combating recidivism. This is achieved by focusing on individual needs and the root causes of criminal involvement that are not addressed in the current criminal justice system.

Key elements of the Calgary Community Court are:

(a) Takes the traditional adversarial justice model and moves to a collaborative approach with the introduction of a probation officer with a social work background to engage with the client and build case plans.
(b) Uses the justice system to leverage supports for the clients, through mandated interventions.
(c) Is extremely effective with high system users.
(d) There are 50 jurisdictions around the world that have Community Courts. All these courts have been top down, usually driven by governments. Calgary's is the first which comes from a grass-roots community movement.

The Calgary Community Court is seen as supporting a number of current issues and strategies such as the mental health and addiction strategy, strategies to combat the crystal meth and opioid crisis, as well as counterbalance recent funding cuts to corrections and probation. Once at full capacity, the court could see over 2000 clients a year. It is anticipated that the new approach would save the justice system close to $35 million over three years. While some seed funding has been received, the initiative is still working on securing funding to move to implementation.

46.3 Summary and Conclusion

SORCe is the only one of its kind in Canada and is setting a standard, provincially, nationally and internationally. There were no templates or best practices that the instigators could refer to as they went about their business. The model took time and evolved through tenacity and a desire to bring about tangible change for Calgary's most vulnerable population. SORCe partners were able to prove that they could work together and can jointly impact on the clients, and subsequently the justice system and health system. When new agencies are brought to SORCe, the provision of care evolves, and this has a multiplier effect that cascades through the other service providers.

SORCe has fundamentally changed the approach to dealing with one of Calgary's most vulnerable populations. It is important to remember that historically, this population has not had a positive relationship with the police or other uniformed authorities (e.g. Calgary Transit Peace Officers, Calgary Bylaw Officers or mall security). In many cases, police officers now bring clients to SORCe because they have invested the time in building a relationship with those clients. Also, homeless people increasingly seek out the services of SORCe voluntarily, encouraged through word of mouth. Both attest to the acceptance SORCe has created with a level of trust that did not previously exist between these clients, Calgary Police Services and service providers.

The 2019 Social Return on Investment (SROI) evaluation was recently completed by the CPS. For every dollar invested at SORCe, there is a SROI of $4.14 (SORCe 2020). This return will continue to grow with the increase in the number of participants and continued implementation of this initiative. The SROI analysis also provides insight into key project gains, inclusive of:

- Confirmation of the appropriateness of the services being offered;
- The critical importance to focus on housing support and mental health or addiction help;
- The value of the services added to this population as expressed by the clients themselves;
- The growing need of the services as evidenced by the increasing service use year over year;
- The ability of SORCe to continue to find ways to offer new services to meet the needs of their clients, despite having received very little programme funding.

SORCe has become part of the fabric of the homeless serving system of care. In conjunction with the Cross Roads Centre, it provides an opportunity to test a unique model of system integration for vulnerable populations. Supported by the Community Court, this integration model has the potential for significant collective impact.

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Two Decades of Integrated Stroke Services in the Netherlands

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Helene R. Voogdt-Pruis, Martien Limburg, Luikje van der Dussen, and George H. M. I. Beusmans

47.1 About Stroke

Worldwide, stroke remains the second leading cause of death and the second leading cause of 'disability adjusted life years' (GBD 2019). The prevalence of stroke is expected to increase due to a growing and ageing population and due to lower stroke case fatality rates associated with better acute ischaemic stroke care and improved recurrent stroke prevention strategies addressing metabolic and behavioural factors (GBD 2019). Ischaemic stroke occurs when the blood supply to part of the brain is interrupted or reduced, preventing brain tissue from getting oxygen and nutrients. Less frequently, cerebral haemorrhages occur with similar, often devastating results. Early action and effective treatments can reduce brain damage, complications and disabilities. Recovery after stroke mainly occurs within the first six months. Stroke patients can experience long-term difficulties in terms of quality of life, social reintegration, life satisfaction and emotional functioning, including depression and anxiety (van Eeden et al. 2015). After stroke, about 70% of patients are discharged from hospital back home, 20% are referred to rehabilitation centres or nursing homes and about 10% die within 30 days (KNCN 2012).

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47.2 Integrated Patient-Centred Stroke Care

Effective treatment and management of stroke require seamless integration across the healthcare and social care interface (KNCN 2012). Cooperation and collaboration between professionals, patients and caregivers is needed to deliver patient-centred care, to align healthcare services, to decrease repeated assessments, incomplete or conflicting information about the patient's health status and to reduce duplications in supervision and multiple transaction costs (WHO 2016). However, different barriers reported in academic literature seem to hinder the formation and development of such collaboration, such as barriers related to administration and regulation, funding, (inter-) organisational domain, service delivery and clinical practices (Auschra 2018). From patients' perspectives, quality of stroke care in the Netherlands could be improved by better collaboration between involved professionals, by provision of tailor-made and timely information and by better preparation of transition from hospital to home care (Harteraad 2018).

47.3 Towards Integrated Stroke Services

Integration of primary and hospital services has been the subject of health policy in The Netherlands since the 1990s. Several initiatives focused on the implementation or the investigation of transmural care. Transmural care was defined as care attuned to the needs of the patient, provided on the basis of cooperation and coordination between general and specialised caregivers with shared overall responsibility and the specification of delegated responsibilities (van der Linden et al. 2001). For stroke, first studies on shared care—this concept overlaps the concept of transmural care—appeared early 2000. In the Netherlands, benefits of shared stroke care six months after stroke were: higher patient satisfaction, higher portion of patients back home, and less volume of home care (Rosendal et al. 2002). Improvement of quality of shared stroke care was also the aim of a national improvement project that started in 2002. Based on the Breakthrough Series (IHI 1995) teams from 23 regions aimed to make 'breakthrough' improvements (Kilo 1998) on specific topics in integrated stroke care. Significantly better results in health outcomes and interprofessional collaboration were attained (Minkman et al. 2005). The 'sense of urgency' for continuous improvement of integrated stroke care was set. Following this, more registered integrated stroke services emerged. Regional networks of service providers, such as hospitals, geriatric and medical rehabilitation centres, skilled nursing facilities, and primary care providers started to work together in an organised way (Huijsman and Rash 2005). These networks were led by a steering board with representatives—professionals and managers—of involved organisations. Needed were professionals and managers with the ability to create collaboration and cooperation across professions and organisations, that are comfortable with distributing responsibilities, and that thoroughly understand the stroke service (Miller and Stein 2020). One professional within the stroke service was appointed as coordinator. Within the stroke service, the aim was to work together to provide multidisciplinary, coordinated care through organised patient transfers and protocols. In addition, the ambition was to make continuous improvements on collaboration and cooperation of stroke care.

47.4 Dutch Knowledge Network of Stroke Services

In 2006, the Dutch Knowledge network of stroke services (KNCN) was founded to support all stroke services in the Netherlands in their mission to improve the coordination, cooperation and quality of the multidisciplinary integrated stroke care in the region. In 2006, 21 stroke services participated; this increased to 44 in 2009. In 2012 and 2019, 72 and 52 stroke services were member of KNCN. A decline in participating stroke services took place after 2014 due to the changed role of KNCN in the national Benchmark stroke care and discontinuing of financial support, and due to the merging of some stroke services. Still, in 2019, about 90% of all hospitals participated with their regional stroke service in KNCN. Coordinators of the stroke services were appointed for approximately one day a week on average (Table 47.1). Most coordinators are specialised stroke nurses, appointed at the hospital. These coordinators participate in the main learning network of KNCN. Important skills of coordinators include networking, organising meetings with professionals and organisations, supporting the exchange or exchanging of (new) knowledge, collecting data on quality of care, promoting or making agreements on collaboration, reflecting on current practice and stimulating quality improvement. Within the learning network, coordinators and the office of KNCN share and collect 'best practices', guidelines and studies on specific topics in

Table 47.1 Characteristic of stroke services, in 2012, 2015 and 2019 (KNCN 2019a)

	2012	2015	2019
Existence (median year)	9	12	15
Involved organisations (median *n*)	5	6	7
Volume of stroke patients, previous year (median *n*)	364	450	499
Professional roles of members in working groups			
• Healthcare professionals only	4%	0%	0%
• Managers only	13%	17%	30%
• Both	70%	78%	66%
• Not applicable	13%	5%	4%
Coordinator of stroke service			
• Appointed (% yes)	92%	100%	93%
• Working hours per week (median)	8	8	8
Formal agreements on cooperation (% yes)	81%	81%	82%
Regular meetings with steering group (% yes)	77%	91%	74%

(integrated) stroke care. An online toolbox with this information is available for all coordinators. This also includes an online forum where coordinators can communicate with each other. Each year, national meeting days with all coordinators are planned in spring and autumn. In addition, educational courses on specific topics, such as ‘creating good collaboration within the stroke services’ are organised. In addition, a national one-day congress for all participants in the stroke services is organised. About 400 professionals and patients attend the congress.

In the past years, KNCN supported several activities focused on quality measurement and quality improvement of integrated stroke care. These were as follows:

1. Benchmark of quality indicators on stroke care

Inspired by the ‘Helsingborg declaration’ (Kjellström et al. 2007), all stroke services started to register the multidisciplinary care of stroke patients on a regional level. In 2006, data on 5 indicators were collected; in 2014 this was extended to 12 indicators. These indicators, based on Dutch evidence-based guidelines, contained performance indicators as well as outcome measures. The office of KNCN was responsible for data collection and provision of performance reports to the coordinators of the stroke services. In 2014, KNCN joined the Dutch Institute for Clinical Auditing to initiate a new benchmark that registered stroke care on patient level (instead of a regional level). Between 2014 and 2016, a pilot with the registry of additional indicators, including patient-reported outcome measures, in the stroke care chain was performed (Oemrawsingh et al. 2019). In 2016, the Netherlands Society of Neurology took over the governance of the audit. Due to the high registration burden of the audit and the developments in acute stroke care treatment, the primary focus of the benchmark shifted towards the acute treatment of acute ischaemic stroke. Funding for the audit was ensured by ‘Zorgverzekeraars Nederland’ (i.e. the umbrella organisation of nine health insurers in the Netherlands) (Kuhrij et al. 2018). Stroke service coordinators share their experiences and best practices to improve data collection of the registry and the performance on indicators at the national meetings of the learning network. From 2005 until now, many quality indicators in Dutch stroke care revealed favourable trends. The overall 30-day mortality rates (in-hospital and post-discharge) declined for both ischaemic and haemorrhagic stroke (RIVM 2014). The intravenous thrombolysis rates (IVT rate: portion of stroke patients receiving IVT within 4.5 h after onset of ischaemic stroke) more than doubled and a large decline in mean ‘door-to-needle-time’ took place (DNT: the time between arrival at the emergency room until administering a thrombolytic agent. This should be less than 45 min) (Scherf et al. 2016; Kuhrij et al. 2018) (Fig. 47.1).

2. Healthcare standard integrated stroke care

In 2011, together with professional and patient organisations, KNCN started with the development of the healthcare standard for integrated stroke care (KNCN 2012). The aim of the healthcare standard was to optimise the quality of care for people

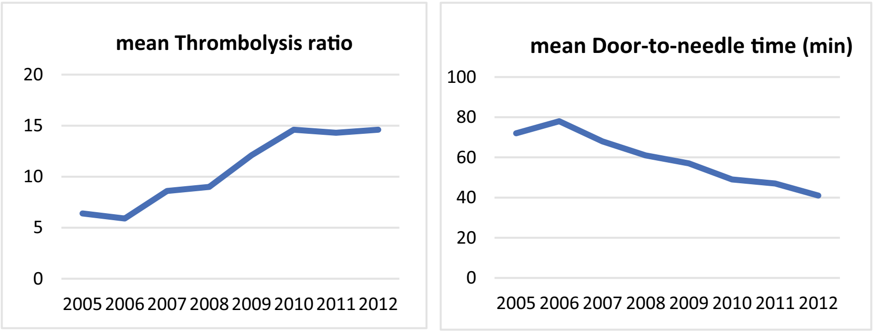

Fig. 47.1 Trend of two quality indicators in Benchmark stroke care, 2005–2012

with stroke by formulating the principal requirements of good integrated stroke care in terms of services and organisational structures necessary for long-term disease management. Two versions of the healthcare standard were made; one for professionals and one for patients and their caregivers. Following this, an implementation project with the patient version of the healthcare standard integrated stroke care was executed in three stroke services, and recommendations for implementation were formulated and spread among all stroke services (Hersenletsel.nl et al. 2014).

3. Knowledge broker network of professionals

Creation of healthcare standards, collaboration agreements or protocols are insufficient to bring about the cooperation between healthcare professionals that is needed for quality improvement. Therefore, in 2011 a knowledge broker network started, to help organisations of stroke services to make improvements on specific topics or to implement innovation. Each year, approximately 45 organisations and

Table 47.2 Cycle of yearly activities in the KNCN knowledge broker network (KNCN 2019b)

March	Training ‘Project management’
April	Formulation of the project: aim of implementation, plan of activities Regional meeting with the learning collaborative
May	Follow-up training ‘Project management’
June	Baseline measurement of goals
September	Start-up of the implementation project During the project: sharing experiences and lessons with each other (forum, toolbox)
November	Regional meeting with the learning collaborative
February, next year	Final measurement of goals and final report with lessons learnt

120 knowledge brokers participate in the network. During one year, an implementation or innovation project is conducted in order to achieve quality improvements in the organisation (Table 47.2). Support is given from other participants in the knowledge broker network. Most knowledge brokers are therapists (physiotherapist, language and speech therapist or occupational therapist) or nurses.

4. Self-evaluation tool on integrated stroke care

In 2012, 2015 and 2019, all participating stroke services received a digital web-based self-evaluation validated questionnaire to evaluate the performance and development of the stroke service. The questionnaire included questions on the execution of 97 activities of integrated stroke care, with dichotomous answering: completed yes or no. The questionnaire is based on the Development model for Integrated Care (Minkman et al. 2009) that consists of 9 clusters (Table 47.3). Participation was voluntary, and the response rate varied from 93 to 86% (KNCN 2019a). All coordinators were asked to fill out one questionnaire for their stroke service. Over the past seven years, an increase of integrated activities within the stroke services was found. Stroke services seem to have worked actively on realising integrated care for patients. Two clusters 'Interprofessional teamwork' and 'Allocation of roles and tasks' were best implemented compared to the other seven (KNCN 2019a). The coordinators received a benchmark report of the total group (anonymously reported) and an individual report. The coordinators were stimulated to discuss the results with the steering group and working groups of the stroke service, and to define an action plan for further improvements.

5. Development of an audit instrument

In 2016, a project group of KNCN developed a peer-to-peer audit instrument in order to provide a tool for the stroke service to improve quality of collaboration, education and stroke care. The audit instrument consists of the self-evaluation tool,

Table 47.3 Completed activities within the nine clusters of development model of integrated care (KNCN 2019a)

	2012 (%)	2015 (%)	2019 (%)
Interprofessional teamwork	86	93	89
Roles and tasks	72	89	86
Client-centredness	59	71	72
Commitment	59	76	70
Transparent entrepreneurship	50	65	67
Results focused learning	59	67	67
Quality care	54	66	62
Delivery system	54	68	60
Performance management	52	67	58

the indicators of the benchmark stroke care and the recommendations of recent guidelines on stroke care. An independent audit team with trained coordinators of other stroke services investigates how recommendations for good practice are applied in daily practice. First, the audit team reviews documents on structure: workforce, agreements and guidelines. In addition, the team visits the organisations of the stroke service and interviews some healthcare professionals in order to evaluate the process of care. The audited stroke service receives a final report with results and recommendations for improvement. Participation in the audit is voluntary and stroke services have to pay a fee. Each year, approximately 8 stroke services are audited.

6. Project on quality of care: Screening for impairment at home

Regular detection of problems in discharged stroke patients is necessary. In the years following a stroke, a significant proportion of patients deals with several problems, e.g. problems with participation, energy, mood, mobility and intimacy. Sometimes these complaints worsen over time. In addition, caregivers often express health problems such as fatigue and depressive symptoms. Various screening instruments are used in general practice or home care to identify problems (Barthel, EQ5D, CSI), but most of these questionnaires are aimed at a certain area of functioning in daily life. Therefore, between 2016 and 2017, a working group of KNCN developed a practical tool with limited questions for the systematic mapping of problems in the home situation. The tool could be used by different types of

Table 47.4 Screening of problems after stroke (KNCN 2016)[a]

Theme	Questions
Household	How is it going with the housekeeping, care for yourself and care for the family? What kind of support do you need?
Activities	In what way could you still do your activities, such as hobbies, work, trips?
Tiredness	Do you experience tiredness or are you fatigue?
Emotions	Does it ever happen that you are gloomy, anxious or emotional? Could you share about this?
Concentration	Have you ever been forgetful? Or are you struggling with concentration? Or with doing two things at a time?
Communication	How easy is it for you to speak with someone or to understand someone, or to read a book?
Other problems	Do you experience other physical problems (swallowing, sleeping, pain, dizziness)?
Intimacy (usually not in 1st conversation)	And how’s that with lovemaking or intimacy?
Caregiver burden (*for the caregiver)*	How's your partner doing now? (change of character and above topics) How do you experience the care for your partner? Are you overloaded?

[a] For healthcare professionals in home care. To be used 3–4 times (first year), 1–2 times later on

professionals involved in health and social care for stroke patients (Table 47.4). The tool could also be part of the regular consultation of cardiovascular prevention by general practitioners and practice nurses.

7. Project on patient-centred care: Shared decision making

Stroke patients face several decisions about treatment options and the setting in which care takes place. An optimal process of shared decision making is required in order to make integrated stroke care person-centred. However, the context-sensitive nature of the challenges in integrated stroke care calls for research to facilitate the implementation of shared decision making. In 2017, a two-year implementation programme started in five stroke services. The shared decision implementation programme consisted of training for healthcare professionals, tailored support, development of decision aids and a social map of local stroke care. Involved healthcare professionals indicated it is feasible to implement shared decision making in integrated stroke care. Several well-known implementation activities could improve shared decision making in stroke care. Special attention should be given to the following activities: (1) the appointment of knowledge brokers, (2) agreements between healthcare professionals on roles and responsibilities for specific decision points in the integrated stroke care chain and (3) the timely investigation of patient's preferences in the care process—preferably before starting treatment through discussions in a multidisciplinary meeting (Voogdt-Pruis et al. 2019).

47.5 Improvement of Dutch Integrated Stroke Care: A Never-Ending Story

Two decades of integrated stroke care have led to remarkable improvement in Dutch stroke care (Lackland et al. 2014):

- Stroke units in hospitals and integrated stroke services have been created on a large scale.
- Stroke diagnostics have been improved through the prompt use of imaging devices.
- Active treatments for intravenous or endovascular clot removal.
- Intensive attention for secondary prevention (antiplatelet treatment, cholesterol lowering, carotid surgery or stenting, lifestyle interventions)
- More attention is devoted to the prevention of complications (such as pneumonia, urinary tract infections, deep vein thrombosis, acute coronary syndrome, heart failure, digestive problems and hip fractures) and to rapid rehabilitation.

Though major steps have been set in improving care for Dutch stroke patients in the last two decades, there will always and continuously be room for improvements. Future developments for regional stroke services might encompass consolidation of the stroke service with similar regional networks in order to provide integrated care for a wider range of acquired brain or vascular diseases in the region.

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Pathways in Transplantation Medicine: Challenges in Overcoming Interfaces Between Cross-sectoral Care Structures

Lena Harries, Harald Schrem, Christian Krauth, and Volker Amelung

48.1 Introduction

Organ transplantation is a particularly sensitive area of medicine in which chronically severely ill patients are treated in an extremely complex care setting. Due to the nature of the underlying disorder, transplant surgery and postsurgical care, the transplantation process involves a variety of different healthcare institutions and sectors. Thus, outpatient and inpatient physicians of different specializations as well as various rehabilitation, nursing and mental care service providers must deal with the various treatment and ethical issues associated with transplantation in an integrated manner. The decline in the number of donors due to the transplantation

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scandal in Germany has demonstrated just how vulnerable the area of organ transplantation (Tx) and donation is: Only 864 organs were donated in 2014 compared to 1200 in 2011 (DSO 2014; Pondrom 2013; Schrem and Kaltenborn 2013).

Organ allocation is influenced by several independent variables, such as the time on the waiting list. Patients who need a liver transplant, for example, generally wait for approximately 5–13 months for a transplant, depending on their blood group and urgency (Samuel 2015; Jung et al. 2008; Schlitt et al. 2011). The situation regarding kidney transplantation is even more complicated. Once ultimate kidney failure has occurred and dialysis is necessary, the median waiting time for a donor transplant is about 43 months (Samuel 2015). As recent statistics point out, the time on the waiting list can be extremely long—up to 15 years in some cases (DSO 2015). Furthermore, because patients require continuous maintenance therapy while waiting for transplantation, all possible drug interactions must be taken into account throughout the entire waiting period (Schrem et al. 2009).

48.2 Structures of Care

48.2.1 Outpatient and Inpatient Care

During the organ donation and transplantation process, various stakeholders register patients in need of transplantation, allocate and deliver donor organs, perform transplant surgery and provide follow-up care. Additional institutions are involved in the organization, coordination, examination and quality assurance of this process (Veit et al. 2014). For the patients, this decentralized organization means many separate and individual treatment steps between the sectors as well as parallel treatments by in and outpatient physicians (Fig. 48.1). Considering the continuous deterioration of the patient's organ function and the likelihood of organ failure, this situation is precarious for the patient.

Depending on the individual patient characteristics (underlying disease, multimorbidity, etc.), outpatient care may require further medical specialists besides the General Practitioner (GP). In case of chronic liver disease, those may include gastroenterologists, hepatologists and/or oncologists. Parallel to outpatient treatment, the patients need to visit the transplant outpatient clinic regularly, as the transplant center must always be aware of the patient's health status (Niedermeyer et al. 2001; IFB-Tx 2015).

The evaluation for inclusion on the waiting list requires certain clinical assessments. For example, cardiological, pneumological, urological, gastroenterological, endocrinological, vascular and/or hematologic examinations are needed for kidney transplantation. This places enormous stress on the patient as the evaluation process is time-consuming and involves a large number of physicians (Kumar 2015).

Moreover, the patient's medical data has to be updated regularly for the waiting list, as changes can have an impact on one's position on the waiting list. Therefore,

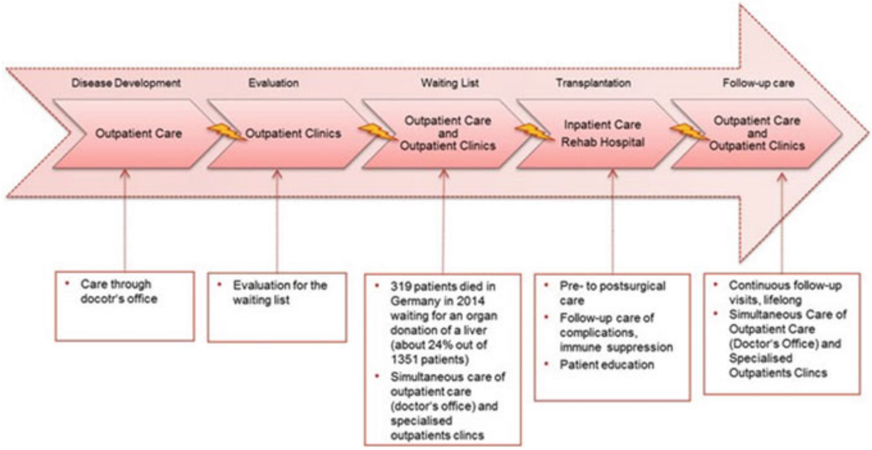

Fig. 48.1 Inpatient and outpatient treatment pathways within the process of transplantation. *Source* Own presentation

it is essential that all information about medical events involving a patient be passed on quickly and completely to the physicians in charge.

Furthermore, especially close cooperation between the several outpatient physicians, the outpatient clinics and the rehabilitation clinics are needed for optimal aftercare of organ transplant recipients. Long-term success in terms of the overall goals of complete restoration of health as well as social and professional re-integration largely depends on the quality of interdisciplinary care and aftercare. Regardless of the complexity of the original transplantation supply chain, close control is a high-priority success factor for a "good" outcome after transplantation. Close control includes continuous monitoring of the compliance of the patient and enables the early diagnosis and treatment of complications. Both aspects play a crucial role.

The fact that there is no obligatory system for the tracking of Tx patients is a critical issue in Germany. Some patients do not visit the outpatient clinic regularly, so strict monitoring is not possible (Mayr 2005; Bundesärztekammer 2015). In contrast, other countries have a transplant registry. The UK or USA, for example, has such a mandatory registry for the centralized collection of data on organ donation and transplantation. Therefore, each stakeholder (e.g., hospital staff, National Organ Retrieval Service, and recipient transplant coordinators in the UK) must report follow-up data in the registry (NHS Blood and Transplant 2014). Besides the aforementioned aspects, all possible drug interactions and relevant drug safety issues also have to be considered at all times, for instance, even when prescribing medication for a flu. Thus, the aftercare of transplant patients requires a high quality of coordination and communication between the different actors (Schrem et al. 2009).

In addition to the transplant physicians and surgeons, even more institutions are involved in the context of organ donation. In Germany, these include the German Foundation for Organ Transplantation (DSO), Eurotransplant (ET) and the hospital administration. A practical map for visualization of this comprehensive process has been developed by the Integrated Research and Treatment Center for Transplantation (IFB-Tx) and the Core Facility for Quality Management and Health.

Technology Assessment (HTA)—Transplantation at Hanover Medical School (MHH) (Fig. 48.2). It clearly depicts the variety of horizontal and vertical interfaces in the clinical workflow and identifies highly sensitive and vulnerable areas while clarifying the simultaneous responsibilities of the various institutions involved during each step (evaluation, allocation, etc.). The mapped actions in the transplantation center alone illustrate the parallel course of several steps and the complexity of the clinical processes involved in transplantation medicine. The process map also highlights the need to prepare patients for a care process carried out by a team of various physicians, in addition to the challenges concerning their inpatient stay. The fact that there are further interfaces to the social sector as well as to psychological care throughout the clinical process further increases the complexity of the treatment process.

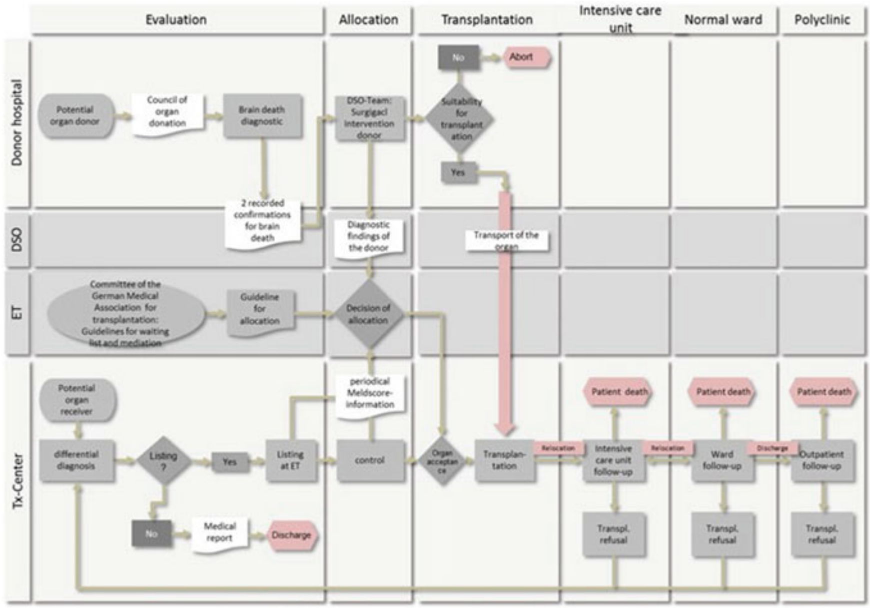

Fig. 48.2 Process map liver transplantation (post mortal). *Source* Own presentation based on the process map of the Core Facility Quality management and HTA Transplantation of the IFB-Tx (Authors: Carola Stumpp, Torsten Kirsch, Harald Schrem)

48.2.2 Living Donations

Like the complex healthcare paths for transplant recipients, the pathway for living donors is challenging in several respects as well. People who decide to make a living donation do so for altruistic reasons, to save a loved one or even a total stranger (Davis 2011). However, in some countries, it is not possible to donate an organ to someone unknown for altruistic reasons. In Germany, for example, a living donation is only permitted between individuals who are first- or second-degree relatives, married or engaged or otherwise apparently close to the donor (Bundesärztekammer 2000). Other countries such as the UK and the USA have a solidarity approach to altruistic donors (Davis 2011; NHS Choices 2014).

Other barriers to living donation include remaining risks related to insurance law. It is the responsibility of the state to provide health insurance coverage for a living donor, not just during the pre- and perioperative period, but lifelong coverage for all risks associated with a living donation. Issues like the capacity to work, safety and medical care in the event of accident or illness are important factors affecting the willingness to make a living donation (Davis 2011; Gold et al. 2001). Furthermore, the expenses associated with a donation must be taken into account. This includes not only medical costs, but also living expenses, lost salary and travel expenses. Moreover, it is also necessary to have a supportive employer who is willing to approve the employee's request for paid or unpaid leave required for the donation process. The system must offer assistance to potential donors to enhance access to donation (Davis 2011).

Further evidence is required to support new approaches to living donation. This includes collecting data on the results of newer practices, such as accepting organs from donors not traditionally accepted due, for instance, to obesity or higher risk genetic backgrounds. Furthermore, it is important to conduct more studies on donor outcomes, including potential harm to the donor, risks modifications and post-donation interventions (Davis 2011). High-quality data is necessary for quality assurance and improved performance (Living Kidney Donor Follow-Up Conference Writing Group et al. 2011).

48.3 General Key Elements for the Future

More strongly integrated cross-sectoral and cross-professional models of care are needed to build a more patient-centered and multidisciplinary approach to transplant medicine. Several key success factors are described below.

48.3.1 Communication

In transplantation medicine, it is of particular importance that interfaces concerning the continuity of a cross-sectoral treatment be supported through a process and information technology link. An integrated exchange of information between decentralized actors and institutions is essential to avoid ambiguity and prevent information loss. The necessary unifying and merging of transplant data is best achieved in terms of a national transplant register. Important aims of establishing such a register include improved documentation, harmonized data flow and increased efficiency in the documentation and integration of data from different sources. The prerequisite for this is the large-scale use of structured information and communication tools. A key element of such a system is the use of electronic health cards or electronic medical records. This expedites and simplifies the exchange of information between stakeholders, which is particularly important in case of medical emergencies (Veit et al. 2014; Amelung and Wolf 2012).

48.3.2 Forms of Compensation

Different forms of remuneration of doctors, such as a fixed monthly salary, case rates or diagnosis-related groups (DRGs), can also inhibit intersectional collaboration between the involved stakeholders. Resource allocation between the interfaces of the different care sectors is in need of improvement. Some of the existing payment practices generate incentives for the stakeholders of one sector to act to the disadvantage of those of another sector in order to ensure their own financial benefit. A form of compensation designed to overcome the organizational separation of the sectors is the so-called bundled payments system. Here, payments are based on a defined package of services generated in the context of a specific episode of care and are paid in lump sum and prospectively. This compensation strategy includes not only the separate care sectors, but also all stages of the supply chain. This form of remuneration could help to overcome the separation of the sectors as well as to promote the cooperation between service providers.

An essential prerequisite for bundled payments is adequate representation of the required resources. On the basis of evidence-based guidelines, it is recommended to determine the resource utilization for a treatment period, from which the corresponding amount of compensation can be derived. To avoid the problem that individual actors offer more lucrative services than less financially attractive services, the distribution can also be regulated by guidelines. Further disincentives, such as risk selection of patients or diminished service quality, can be counteracted by adding various modifications as needed. Risk selection of certain patients can be minimized, for example, by performing risk adjustment according to age or gender. In order to integrate a quality assurance measure, this can be carried out in combination with additional compensation. Therefore, bundled payments could be increased by a percentage, which is subject to certain conditions.

In the field of transplantation, it could be possible to demand a lump sum payment for outpatient and inpatient care as well as for medications. This remuneration could cover the time on the waiting list, for instance. After transplantation, a further lump sum payment would then be required for the aftercare, including outpatient, inpatient and rehabilitative services, as well as drug prescriptions. This system supports a better interexchange between the involved actors, as each actor has an incentive to balance their service in combination with the individual fee, as this is part of a service and compensation package (Amelung 2013). A unified system of payment would support a more frictionless care process and help to achieve a reduction of costs in transplant medicine.

It is also important to consider that the costs of transplantation vary greatly, depending on disease severity or complications. In Germany, for example, the average cost of an inpatient stay for liver transplantation is about 52,570 €, but the range is from 18,330 to 397,450 € (Lock et al. 2010). The results of a meta-analysis by van der Hilst et al. (2009) underline the great variability of costs for transplantation: the mean cost in the USA was US$163,438 compared to US $103,438 in the other OECD countries evaluated.[1]

48.3.2.1 Leadership

The complex and vulnerable care structures for transplant patients as well as the important role of the public trust require holistic management of the process besides the established management structures. It is the responsibility of management to develop and communicate effective strategies and involve all stakeholders. In health care, this appears to be a particularly difficult task because the focus is on the whole organization. The creation of such structures is more extensive than for a classical organization. Concerning the transplantation process, which has a variety of cross-sectoral and institutional interfaces, this task is even more complex. The implementation of a comprehensive management approach also requires a disruption of previous traditional role patterns and structures, which can mean intrusion into previously autonomous areas. Therefore, it is equally important to integrate the various professions, cultures and corporate structures. The leadership should be focused on isolation from the existing structures and should be implemented accordingly (Sydow et al. 2011; Reinertsen et al. 2008; den Hertog et al. 2005; Schmitz and Berchthold 2009).

Although the medical profession within the treatment process is not to be disposed of by substitution, it is important to delegate medical tasks. One strategy is to integrate a case management system. Case managers supervise the treatment process across the different care sectors. They plan, judge, implement, coordinate, assess and evaluate each step. Their tasks include obtaining medical and psychological assessments and providing guidance on financial issues or occupational difficulties. These highly ambitious functions can be performed by specially trained nurses. Such further education enables them to provide evidence-based management and to support the self-care of the patient (Amelung 2013; Harries et al. 2015).

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[1] This was a meta-analysis with a random effects model, which included nine U.S. articles and five OECD articles (van der Hilst et al. 2009).

48.4 Conclusions

The structures of care in the field of transplantation present a variety of complicated paths and hurdles for the patient. Besides challenges concerning the involvement of different sectors of care and multiple institutions, there is no so-called owner of the process for the patients. Since the treatment path includes contacts with a variety of specialists from various fields, it is important that GPs assist in organization and help patients get their bearings. Though it all, the patients need to consolidate all information and organize their own treatment process along with the different physicians. As local physicians generally do not have much experience in handling specific issues of transplantation, the patient is kind of left to deal with it alone. Considering the fact that transplant patients have to cope with a severe illness, this can be an overwhelming and additional stress for the patient. Moreover, organ transplantation is a particularly sensitive area of medicine. The failure of an organizational structure can have a strong impact on the survival of transplantation patients. For example, it has been shown that the transplant scandal in Germany resulted in a sharp decline in the willingness to donate; this, in turn, reduced the total number of organs available for transplantation (BT-Drs. 18/3566 2014).

In this context, the World Health Organization (WHO) published a report with a "Global Strategy on People-Centered and Integrated Health Service" (WHO 2015). For the field of transplantation medicine, in particular, this might influence efforts in terms of optimizing the integration of different professions and ensuring better cooperation between the different institutions and care sectors. The extremely complex supply chain of transplant medicine is a burden for patients and a challenge to providing high-quality care in terms of continuous treatment. There is an urgent need to improve the problems at the interface between the sectors, eliminate the existing breaks in the supply chain and stop the breakdown of information flows in transplantation medicine. These efforts should be focused on supporting a holistic course of treatment with a patient-oriented approach to the coordination of healthcare delivery.

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Part VI
Case Studies

Scotland

49

Elaine Mead

49.1 Introduction

Scotland is part of the UK, covers the northern third of Great Britain and shares a border with England to the south.[1] At the last census (2011), the population was 5.3 million, the highest ever recorded (Scotland's Census 2014).

Population density is low in comparison with the rest of the UK due to large remote and rural areas, particularly in the Highlands and Islands. While the population has remained stable over the past 50 years, the proportion of people aged 65 and over has grown and is projected to increase by around two-thirds over the next 20 years (Ham et al. 2013).

Health care in Scotland is mainly provided by National Health Service (NHS) Scotland, the country's public healthcare system. The NHS was founded by the National Health Service (Scotland) Act, 1947, and took effect on 5 July 1948 to coincide with the launch of the NHS in England and Wales.

Over the past two decades, there have been some significant changes in how Scotland is governed. Following political devolution that took effect in 1999, the Scottish Parliament was set up with powers to make laws across a wide range of areas including health (Taylor 2015; Mooney and Scott 2012; Keating 2010; Mcfadden and Lazareswich 1999). These new arrangements also saw a move to Scottish parliamentary elections being held every 5 years.

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[1] No passport or ID checks are required to cross the border.

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Since 2001, NHS Scotland has been organised into 14 regional-based health boards, 7 national or special boards and one public health body. Regional boards have overall responsibility for the health of their populations, and they plan and commission secondary care (which is generally provided by medical specialists in acute hospitals) and community health and primary care (which is provided in the community for people making an initial approach to a medical practitioner or clinic for advice or treatment including GPs, pharmacists, dentists and optometrists). Healthcare funding and policy are the responsibility of the Scottish Government.

This is supported by the executive functions of the Scottish Government's Health and Social Care Directorates. NHS Scotland operates with an annual budget of around 13.4 billion (Audit Scotland 2019)[2] and there is a national formula that deals with the allocation of funding for each regional board.

Adult social care and social work are the responsibility of 32 local authorities (councils). While 85% of their funding comes from central government in the form of a block grant, councils are autonomous bodies, independent of central government and accountable to their electorates for the delivery of services. The remainder of their funding is raised from local taxation ('council tax') and discretionary funds. Integrating health and social care has been on the policy agenda in Scotland for the past 20 years or so (Taylor 2015). Of particular relevance is the Community Care and Health (Scotland) Act, 2002, which enabled health boards and local authorities to delegate some of their functions and resources. The subsequent NHS Reform (Scotland) Act, 2004, required boards to establish one or more community health partnerships (CHPs) with local authorities in their area. These were seen as a focus for integrating health promotion, primary and specialist health services at a local level (Ham et al. 2013; Taylor 2015).

In 2011, the Scottish Government's 2020 Vision articulated a clear aim that 'everyone is able to live longer at home or in a homely setting'. It included a plan for achieving sustainable quality in the delivery of health and social care (Scottish Government 2011). The subsequent Public Bodies (Joint Working) (Scotland) Act, 2014, set out the most recent legislative framework for integrating health and social care.

Under the Act, statutory responsibility for social care functions remains with local authorities but with the provisions that allow for the delegation of some of these functions. This is either through the formation of an integration joint board that is responsible for planning and resourcing service provision for adult health and social care services (Option 1); or alternatively, the health board or the local authority takes the lead responsibility for planning, resourcing and delivering integrated adult health and social care services, known as the 'lead agency' model (Option 2) (Taylor 2015; Bruce and Parry 2015).

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[2] £3.9 billion was also spent on social care services (Expenditure on Adult Social Care Services, Scotland, 2013–2014).

Health boards and local authorities were required to put in place their local plans by April 2015 with the full integration of services expected by April 2016. Notably, 31 of the 32 local authorities are implementing Option 1. The Highland Council is the only local authority that is implementing the lead agency model, and in the following sections, we focus on this specific model of integrated care in Scotland.

49.2 Integrated Care in Practice

49.2.1 Problem Definition

NHS Highland Health Board[3] was established in October 2001 and since then has undergone a number of reorganisations, including the establishment of community health partnerships in 2004 (the Highland Council Area) and in 2006 the taking on the responsibility for part of the former NHS Argyll and Clyde region. In doing so, NHS Highland became responsible for the largest health board area in Scotland. It includes some of the most remote and rural parts of the country including 36 populated islands (see Map in Fig. 49.1) (Box 49.1; NHS Highland 2015a).

Box 49.1 NHS Highland at a Glance

- Co-terminus with two local authorities (The Highland Council and Argyll and Bute)
- Covering an area of 32,500 km^2 = 41% of the landmass of Scotland
- 36 populated Islands
- Population of 320,760 (National Records 2014)
- 10,088 employees (8000 whole time equivalent)
- Annual revenue budget 2015/16 c£789 m
- 100 GP practices
- 25 hospitals, made up of the following:
  - 1 district general hospital
  - 2 dedicated mental health units
  - 3 rural general hospitals
  - 19 community hospitals
- 15 care homes (The Highland Council area)
- 39,000 attendances Raigmore Hospital Emergency Department per annum

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[3] NHS Highland is managed by a board of directors and is accountable for the performance of NHS Highland. It is underpinned by committees, including: clinical governance, area clinical forum, Highland Health and Social Care Committee.

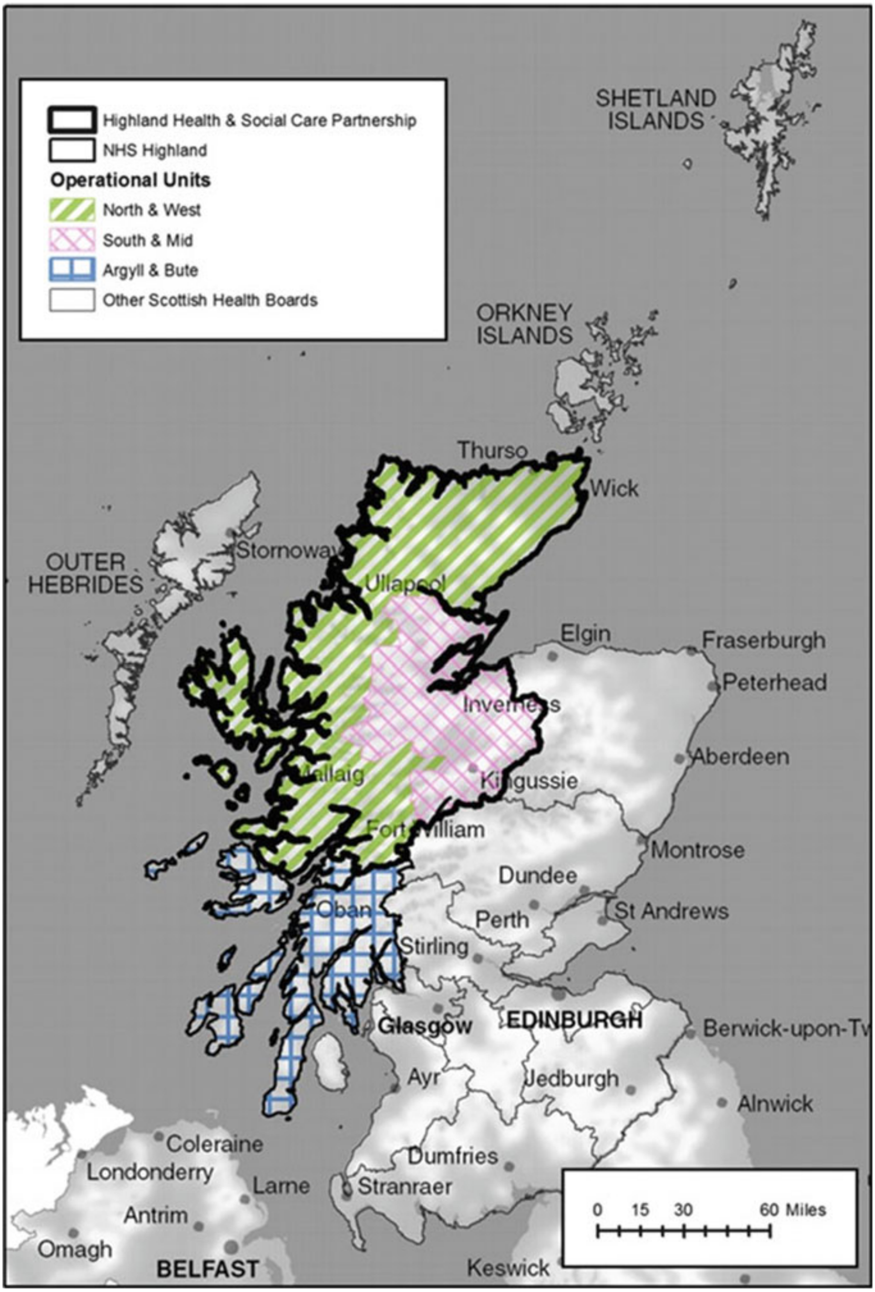

Fig. 49.1 Overview of NHS Highland

Arguably, however, the biggest reorganisation for the health board came in April 2012 with the signing of a partnership agreement between NHS Highland and the Highland Council.

With an ageing population, particularly for those aged over 75 years, and the expectation that public expenditure would fall in real terms, while pressures on health and social spending would increase, the status quo was not seen as a viable option (NHS Highland 2011, 2012a, b).

Furthermore, the Highland Council and NHS Highland recognised that the way some services were organised was not delivering the best outcomes for people. This was despite efforts by frontline staff and managers to overcome day-to-day barriers. Delayed decision-making, conflicts over budgets and accountability, and at times a blame culture, were all considered to be barriers with some significant impacts including:

- Lack of alternatives to emergency hospital admissions
- Limited care at home
- Lack of 'joined-up' responses and delivery of services
- Early (young) admissions to care homes
- Limited collaboration with third and independent sector.

Against this background, there was a perception that more radical reform was needed. A number of fact-finding visits were carried out, and various models were considered, including Torbay in England (Thistlethwaite 2011). Following on from this, a joint meeting of The Council and the Health Board was held in December 2010 and a joint statement of intent was issued:

> We will improve the quality and reduce the cost of services through the creation of new, simpler, organisational arrangements that are designed to maximise outcomes, and through the streamlining of service delivery to ensure it is faster, more efficient and more effective.

A joint board was created to deliver a 15-month programme of work to establish new arrangements to fully integrate services, particularly in relation to adult and children. Some 2 years later, on 21 March 2012, the Highland Council and NHS Highland signed a formal partnership agreement to establish the first lead agency model in Scotland.

49.2.2 Description of the Lead Agency Model

Under the lead agency model, all adult social care services were transferred to NHS Highland from the Highland Council in April 2012, and in a reciprocal arrangement, the Highland Council took on responsibility for the delivery of community children's services (Mead 2015; Mead et al. 2017; Baird et al. 2014; Brown 2013; Highland Partnership 2012).

For NHS Highland, this meant taking on new responsibilities including the management of 15 care homes, the in-house care-at-home service, day care services, telecare services and a wide range of contracts with the third and independent sectors.

It also involved 1400 adult care staff transferring under Transfer of Undertakings (Protection of Employment)[4] from Highland Council to NHS Highland while maintaining their terms and conditions. Alongside this, 200 NHS Highland staff transferred across to the Highland Council. Some of the other practical implications are summarised in Box 49.2 and set out in more detail in Mead (2015) and Highland Partnership (2012).

Box 49.2 Legal, Financial and Management Implications of Lead Agency Model

Legal Arrangements

- Changes to the Adult Support and Protection Act (Scotland), 2007, were necessary and were approved by the Scottish Parliament.
- A legal partnership agreement (detailing legal, professional leadership, governance and performance arrangements) was required.
- Some staff contracts had to be transferred across employers (NHS Highland and Highland Council).
- Change was required to pension's legislation to permit staff that were transferred to remain in their existing pension scheme.

Financial Arrangements

- New single budgets had to be prepared along with requisite resource transfer.
  - £89 million annual budget was transferred from the Council to NHS Highland.
  - £8 million annual budget was transferred from NHS Highland to the Council.
- Different VAT reporting mechanisms for each organisation had to be reconciled.

Management and Governance Structures

- Existing management and governance structures, such as community health partnerships, had to be reorganised.
- Outcomes had to be agreed along with associated performance management frameworks.

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[44] Transfer of Undertakings (Protection of Employment) Regulations (TUPE) provides rights to employees when their employment changes when a business is transferred to a new owner.

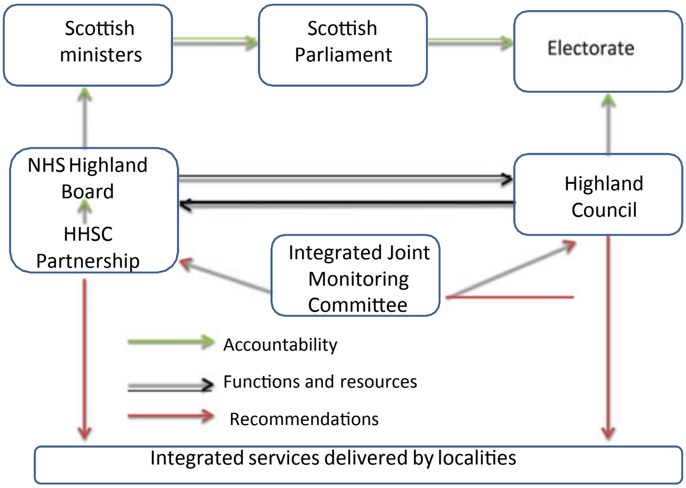

Fig. 49.2 How the lead agency model is structured

49.2.3 Governance

At the point of integration (1 April 2012), new governance and management arrangements were put in place for the lead agency model which followed legislative requirements (Fig. 49.2). These confirm that in terms of adult services the Council remains accountable but NHS Highland is responsible for the delivery of the service. Reciprocal arrangements are in place for children's services.

To make this change, three community health partnerships (north, mid and south-east) were dissolved. These were replaced by a new Highland Health and Social Care (HHSC) Partnership which was established as a committee of the board. The partnership directly oversees the governance but reports into the board via the chair who is a non-executive director of the board (Fig. 49.2). A monitoring framework is also in place.

49.2.4 New Ways of Working

There have been many examples, some small and some bigger, of the positive benefits of integration (Highland Council 2015), and some of these are summarised here.

Co-ordination and Professional Communication More effective integrated district teams have been created. Each of the nine integrated district teams within the Highland Council area has a core team of key health and social care professionals representing, for example, care homes, care at home, occupational therapy, GP practices and community nursing.

By working together in a co-ordinated way, a group of key professionals are now more able to ensure clients' and patients' health and social care needs are met. Each part of the team is linked to a care co-ordinator who ensures that each patient and client get fully co-ordinated care in a timely and efficient manner (NHS Highland 2013).

Commissioning Arrangements and Partnership Working An adult services commissioning group has been established so as to involve as many sectors and representatives as possible, in the making of strategic decisions about investment in adult social care.

In effect, The Highland Council commission services from NHS Highland, while it remains accountable for the delivery of the services. The transaction is delivered through a five-year plan which is monitored in terms of delivery of agreed outcomes and reviewed annually.

Since integration, there has been evidence of much closer working with third and independent sector, with a number of documented benefits.

One example is the introduction of the living wage for the independent care-at-home sector. Contracts are in place between NHS Highland and independent sector care-at-home providers. The Living wage was implemented in April 2014, and since this time, providers have been required to pay their staff the living wage, and provide evidence of having done so, in order to receive an increased fee.

NHS Highland has also been successful in the innovative application of the Social Care Self-Directed Support (SDS) (Scotland) Act which was implemented in April 2014. This supports the vision that care should be based around the citizen, not the service or the service provider. It provides a means through which all clients are given a choice as to how they wish to receive their services and support. This Act places a statutory duty on local authorities and integrated partnerships to offer four choices as to how people are assessed as requiring care and to how they received their care or support.

Self-Directed Support option two is known as an Individual Service Fund (ISF) and enables a service provider of the individual's choice to manage their budget. Given the shortage of care-at-home provision in many remote and rural locations in parts of the Highlands, NHS Highland worked in partnership with independent providers and local communities to put in local solutions to provide care at home. This has proved successful in delivering a care-at-home service where previously traditional models of care at home could not be sustained (NHS Highland 2015c).

Service and Quality Improvement The appointment of a NHS Highland service improvement lead for care homes has brought a more consistent and multidisciplinary approach to training and closer working across all professionals.

A new service was introduced to ensure the safer use of medicines in the care homes managed by NHS Highland. This is because medicines are frequently prescribed for residents of care homes and carry risks, such as adverse drug reactions, which are increased in frail populations. The service involves a pharmacist providing a medication review for every care home resident within 2 weeks of admission and every 6 months thereafter.

In order to ensure adequate staffing, in particular in social care, where recruitment to social worker posts has been challenging in some areas, NHS Highland has taken steps to ‘grow our own’ by introducing a trainee social work scheme which got underway in 2015 (Highland Council 2015).

Furthermore, additional community geriatricians have been recruited to provide in-reach to community hospitals and care homes, and primary care. This has supported a much more multidisciplinary and joined-up approach to ensure care provision to people outside of acute hospitals.

This has built on work over many years carried out by NHS Highland to improve anticipatory care planning[5] (Baker et al. 2012), polypharmacy reviews (NHS Scotland 2015) and virtual wards[6] all designed to take a proactive approach to reducing hospital admissions (Ham et al. 2013; Somerville 2012; NHS Highland 2011).

Major Service Redesign Under the new integrated arrangements, NHS Highland has been able to plan new service models at district level across all health and social care resources. This has included proposals for developing community and care-at-home capacity which will allow community hospital beds to be reduced (Blackhurst et al. 2015; Thompson et al. 2015).

49.2.5 People Involvement/Service User Perspective (Value)

There was significant public engagement in order to inform the development and shape of the lead agency model. During the early discussions, NHS Highland held meetings with various stakeholder groups and every community care service user or carer group was contacted by letter to invite them to feed back on their experiences. Focus groups were also undertaken by NHS Highland staff with people who used particular services, and public meetings were held across the region (Highland Partnership 2012).

The vast majority of the feedback confirmed the support for change. Those who had direct experience of accessing services expressed frustration about the often disjointed approach. Overall, the feedback provided a strong mandate to continue with integrating services. Qualitative research conducted subsequently pointed to a common theme: generally, public respondents were surprised that NHS Highland and the Highland Council did not already work in a highly co-ordinated way (Beswick 2013).

In Scotland, there is national guidance around how NHS Boards should inform, engage and consult with their local communities, service users, staff and partner agencies about proposed major service change (Scottish Health Council 2010). In the case of major service redesign as described above, this included having a steering group made up of service users, public members, elected members, staff

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[5] In 2010, NHS Highland introduced an Anticipatory Care Patient Alert (ACPA) form. This is completed for patients who have one or more pre-existing conditions which may have resulted in them being admitted to hospital as an emergency on several previous occasions.

[6] The virtual wards work just like a hospital ward, using the same staffing, systems and daily routines, except that the people being cared for stay in their own homes throughout.

and partner agencies. This culminated in a formal 3-month consultation with the public (Blackhurst et al. 2015; NHS Highland 2015b; Thompson et al. 2015).

The public consultation is a requirement, and feedback was considered by the board of NHS Highland and ultimately the Cabinet Secretary. The feedback from the public endorsed the proposed new models of care, as well as highlighting areas of concern to be addressed. A tangible example of how consultation shaped redesign proposals was the requirement to develop an integrated transport plan and for it to be in place before closing any hospitals. Another was to develop capacity in care home to provide for flexible use of beds to avoid hospital stays or support end of life care.

Two major service redesigns in Highland were the first to be approved by the Scottish Government since 2007. Arguably working in an integrated way has fostered more collaborative ways of working on moving away from a focus on buildings and beds to investing more in community services (NHS Highland 2015c).

Recently, NHS Highland made a commitment to ‘My Home Life’. This is a UK-wide initiative to promote the quality of life for individuals who live, die, visit and work in care homes for older people (Help the Aged 2007). This is achieved by engaging with the community using various approaches to discover what they are prepared to contribute to help develop services.

This approach has led to improvements in community involvement. For example, several homes now hold community events, supported by residents. Other managers of care homes have used the listening tree for residents, relatives and community as a way of facilitating feedback. As an example, one care home now hosts a monthly dementia cafe, and another hosts monthly coffee mornings. Overall, there is increased voluntary input. This builds on work since 2012 to strive to make care homes part of their communities (NHS Highland 2013).

49.2.6 Impacts

Delivering integration and necessary organisational change was a significant challenge, and there was a risk that any effort devoted to integration could have led to deterioration in service delivery. However, during the year following integration (2013), there was no documented evidence of any adverse effects on key performance indicators (Westbrook 2017).

There has been an overall steady improvement in Inspectorate Grades for Care Homes operated by NHS Highland. While there is no reporting mechanism that allows this to be compared across Scotland within Highland, a general improvement was not similarly reflected in care homes run by other providers. Furthermore, the age of people being admitted to any care home has increased by around 2 years since integration.

In addition, NHS Highland continues to perform better than most mainland boards on the performance of the 4-hour emergency target: 98% of patients wait less than 4 hours from arrival to admission, discharge or transfer for accident and emergency treatment. This has been sustained 3 years after integration (Scottish Government 2015a, b, c).

A one-year pilot on medicine management in North Highland demonstrated that the new service made medicines safer and more effective for care home residents. This service is now provided permanently to all care homes in North and West Highland, and elements of the service are also being rolled out to care-at-home service users (Claire Morrison, personal communication).

A Medicine Sick Day Rules card was also developed. The card promotes better management of long-term conditions through the safer, more effective use of medicines. Hospital admission data were collected for 9 months and showed a small fall in admissions since the cards were introduced. This was set against a trend of increasing admissions in previous years, indicating that the cards are effective. No increase in admissions for heart failure was observed, highlighting that use of the cards is also safe (Morrison and Wilson 2015).

Considerable challenges remain to further optimise integrated service delivery. Moreover, there is a need to better understand the complex relationships between services and ‘flow’ and any possible unintended consequences. For example, in 2014/15, only 63% of privately run care home places were available to admissions; five homes were subject to temporary closures, and some were permanently closed due to poor quality. However, this created a shortage of care home places and increased demand on acute and community hospitals increasing the number of people who had delayed discharges—one of the key drivers to integrate health and social care services.

The University of Highlands and Islands has been commissioned to conduct an independent review of performance against the original aims of the Partnership Agreement. Initial (unpublished) results suggest that a majority of indicators show improvements with the exception of delayed discharges.

Since integration, NHS Highland has shifted significant resources from health across to social care. An additional £9 million (recurring) was invested in 2015/16 to develop services to support people to live independently at home including to deliver the living wage. Whether this would have happened prior to integration is debateable but what is clear is that given single budgets, single management and single governance this was a decision that NHS Highland could take more readily and rapidly compared to other NHS boards in Scotland. This has allowed a clear understanding of the direct consequences of one part of the system on another and now with the direct authority and oversight to act.

New ways of integrated working have also been a catalyst for wider reform within NHS Highland. The only District General Hospital in the area (Raigmore in Inverness) has merged with community and primary care services to become one operational unit. Now with single management, single budgets and single governance, the aim is to facilitate greater integration of health services.

49.2.7 Dissemination and Replication of the Case Study

The lead agency model, as established with Highland Council in Scotland, can be seen to constitute a very specific model of integrated care, with its focus on a largely rural area of Scotland. However, the lessons on joint working that can be learned from this model appear to be entirely transferrable to other health and care partnerships. At the same time, it is important to reiterate that the Highland Council was the only council in Scotland that adopted this model, while all other councils have set up Integrated Joint Boards from April 2016 (Bruce and Parry 2015).

Many of the service interventions that have been introduced since integration have been or are being rolled out across all districts and in some cases across Scotland. For instance, the Medicine Sick Day Rules card developed, tested and evaluated in Highland (Morrison and Wilson 2015) has now been made available nationally. This was to complement the publication of the updated NHS Scotland Polypharmacy Guidance (http://www.sehd.scot.nhs.uk/publications/DC20150415polypharmacy.pdf) (March 2015).

49.2.8 Lessons Learned and Outlook

The lead agency model as established with Highland Council in Scotland has clarified governance and maximised the expertise of individual professionals. Nothing prevented these changes from taking place prior to 2012, but perceived barriers and different cultures and management structures appear to have had the effect of not enabling effective change in Highland and indeed across Scotland. Some of the key lessons learned and outlook may be summarised as follows:

- Leadership and management capacity are required to ensure that changes get embedded, sustained and rolled out across all relevant areas. In some cases, there have been practical challenges to overcome inevitable competing priorities.
- Senior leaders across both organisations demonstrated a ‘can-do’ attitude and knocked down organisational barriers to change.
- A formal project management approach was not adhered to. Given that integration is a complex, multifaceted process, leaders accepted a degree of uncertainty.
- Support for integration was garnered by avoiding a focus on cost-savings. Respondents were convinced by the argument that, in the long term, integrated services would be more cost-effective because they would involve less duplication and allow greater support for care at home (cf hospital care).
- Practitioners pointed to the importance of leaders recognising professional identities. Professional leadership was put in place outside of line management structures and was significant in allaying some professional mistrust and concerns.
- Partnership working (i.e. mutual trust and decision-making between staff and employers) was also significant in resolving terms and condition issues arising from the staff transfers.
- There are inherent difficulties in trying to measure and interpret the impact of integration both at the macro- and micro-level and in particular at points of time especially over short time scales. Nolte and Pitchforth (2014) found that

evaluative information was scant, and that its scale, complexity and lack of agreed definition made this a very difficult undertaking. They also pointed to a number of reasons why there is a lack of evidence around integration including evaluation not being prioritised.

- There is no doubt this has been a challenging area for this study, but data has been collected pre- and post-integration which will hopefully contribute to the evidence base (Westbrook 2017).
- Some things may get worse before they improve. Fully realising some of the benefits, may take many years (Goodwin et al. 2014). The significance of taking a long-term view is therefore highlighted, along with a recognition that there will inevitably be some ups and downs.
- For what was one of the biggest reforms in Highland, and indeed Scotland for over a decade, integration received remarkably little media attention and minimal interest from communities or groups. This is in stark contrast to how changes to service models or changes in practice have generally been reported in Highland.
- Overall, the one key lesson has to be to focus on the needs of the local population and to reconfigure services around this need rather than the organisational boundaries and limitations of institutions. As this case study has illustrated, however, this is anything but as simple as it sounds.

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Three Horizons of Integrating Health and Social Care in Scotland

50

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50.1 Three Horizons of Integrating Health and Social Care in Scotland

The introduction of landmark legislation to integrate health and social care in 2015 was one of the most radical reforms of public services in Scotland arguably since the inception of the NHS in 1948.

Highland was the first area in Scotland to have such a legal agreement in place as described in Chap. 49. This chapter now describes the experience of integrating health and social care across the whole of Scotland since 2015. The story is framed around the three horizons of transformational change as described by the International Futures Forum (three horizons), and considers the design principles and supporting factors at each stage (European Commission 2017).

The opening section outlines the first horizon—the political and policy landscape, financial and demographic context, stakeholder engagement and introduction of new organisational arrangements.

The second section covers important enablers for implementing integrated care. It signposts to local examples of change and considers the challenge of measuring impacts and outcomes. The journey to improve population health and reduce inequalities is the subject of the third section. The chapter concludes with some lessons learned and briefly touches on the implications of the global COVID-19 pandemic, describing one case study which is overcoming what previously seemed unsurmountable barriers to implement new ways of working. It is illustrative of other examples of rapid change throughout the UK linked to COVID-19.

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50.1.1 The First Horizon, the Political and Policy Landscape in Scotland

Scotland is part of the UK but had its own Parliament established in 1999. The Scottish Parliament has devolved legislative powers across a wide range of policy areas including health and social care (Taylor 2015). Local government is organised through 32 councils.[1] Councils are autonomous bodies, independent of central government, accountable to their electorates for a wide range of services including social care and social work. They directly provide or commission services from the NHS, independent or third sector. Around 80–85% of local authority funding comes from central government in the form of a block grant. The remainder of their funding is raised from local taxation, discretionary funds and ‘reserves’. The Convention of Scottish Local Authorities (COSLA) provides political leadership on behalf of the 32 local councils.

50.1.2 Health and Social Care Arrangements

Health care is free at the point of delivery for all in Scotland. Funding and policy are the responsibility of the Scottish Government but are resourced through a block grant from the UK Treasury. Since 2001, 14 regional-based health boards have had overall responsibility to plan, deliver and commission health care for the population in their area. Each NHS Board is accountable to Scottish Ministers through reporting to the Cabinet Secretary for Health and Sport, the Scottish Parliament and ultimately the electorate (Robson 2016).

The Community Care and Health (Scotland) Act, 2002, introduced free personal social care for older people, regardless of income or whether they live at home or in residential care. Personal social care includes support for personal hygiene, at mealtimes, help with medication and assistance with immobility or general well-being. Domestic services such as help with housework, laundry, shopping, attending day care centres or the accommodation element of care home costs may be chargeable. Nursing care that involves the knowledge or skills of a qualified nurse such as administering injections or wound care is provided at no cost to the individual. Legislation to extend free personal care to people aged 16 and over with degenerative neurological conditions came into force on 1 April 2019.

50.1.3 Making the Case for Change

Like most developed countries, the population in Scotland is increasing and ageing. At the 2011 census, the population of 5.3 million was the highest ever recorded (National Records of Scotland 2014). By 2038, one in four people are expected to be over 65 years compared with 14% in 1983 (National Records of Scotland 2019).

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[1] Throughout this chapter, the terms council and local authority are used interchangeably.

The prevalence of long-term conditions increases with age, ranging from 25% of adults aged 16–24 to 77% of those aged 75 and over (Scottish Government 2015a). In the 2013 Scottish Household Survey, 34% of households reported at least one adult or child with a long-standing illness, health problem or disability. This figure rises to 45% in households with an income of £20,000 or less as reported in (Hendry et al. 2016). This has significant workforce implications and will increase demand for health and care services.

50.1.4 Building Cross-Party Political Support and Commitment

Integrating health and social care has been on the policy agenda in Scotland for the past 20 years or so (Taylor 2015). A timeline of the related policy and legislation (1999–2016) is summarised by Audit Scotland (2018a).

The initial priority was an integrated approach to chronic disease as described in Improving the Health and Wellbeing of People with Long-Term Conditions in Scotland: A National Action Plan (Scottish Government 2009). This was followed by Reshaping Care for Older People (RCOP) (Scottish Government, 2010a) brokering closer collaboration between health, social care, housing, third and independent sector partners through a £300-million Change Fund to drive local transformation 2011–2015 (Hendry et al 2016).

The Christie Commission on the Future Delivery of Public Services argued the need for reform across all public sector (Scottish Government 2011). Four priorities were service integration at a local level, a greater shift towards prevention, addressing health inequalities and improving outcomes for people. This high-profile report had strong cross-party support such that all major political parties included a commitment to integrate health care and social care in their manifestos for the 2011 Scottish Parliament Election (Taylor 2015).

50.1.5 Engagement

Highland was the first area to press for more radical structural reform. A partnership agreement between Highland Council and NHS Highland was established in 2012 under existing legislation NHS Reform (Scotland) Act, 2004 (HM Gov 2004). Building on the experience of Highland's Lead Agency Model (Mead 2017), the Scottish Government began to engage widely on proposals to integrate health care and social care across the country (Scottish Government 2012). The vision was ambitious but simple: to ensure better health and well-being outcomes for people at home and in local communities through care and support designed around the individual. This care and support would be commissioned through effective cross-sectoral planning for the needs of the local population (Scottish Government 2013).

The positive relationships fostered by the Reshaping Care for Older People Programme (Joint Improvement Team 2015) had generated growing support for health and social care services to be jointly planned, financed and delivered across the continuum of care, drawing on the assets of voluntary and community resources to improve outcomes for individuals and communities.

Engagement on integration was both national and local (Hendry 2016). This process involved a series of national workshops for senior leaders from health care, local government, housing partners, voluntary organisations and independent care providers. These were followed by working groups for dialogue with local health and social care organisations, professional bodies, care regulators and trade union representatives over many months. Engagement also involved an accessible programme of community listening events and ‘town hall’ conversations with local citizens and workforce across the country. Building on the engagement work in Highland, qualitative research noted strong public support as separation of services did not make sense from a user’s point of view (Beswick 2013).

50.1.6 Legislation

The legislation—Public Bodies (Joint Working) (Scotland) Act, 2014—required the creation of integration authorities (Scottish Government 2014) with shadow arrangements from April 2015 and governance to fully integrate services in place by April 2016. This could be delivered through one of two models (Audit Scotland 2018a):

1. Integration Joint Board (Body Corporate) Model

The health board and local authority delegate the responsibility for planning and resourcing service provision for adult health and social care services to an Integration Joint Board (which is a separate legal entity).

2. Lead Agency Model

The health board or the local authority take the lead responsibility for planning, resourcing and delivering integrated health and social care services. In this model, staff are required to transfer to either the council or the NHS Board.

50.1.7 New Organisational Arrangements

Across Scotland, 31 integration authorities have been established.[2] Their size and scope vary markedly, but each is underpinned by an integration scheme which sets out how they will operate. All opted for the Body Corporate Model except for

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[2] While there are 32 local authorities, Clackmannanshire and Stirling Councils created a single authority with NHS Forth Valley.

Highland who continued with their Lead Agency Model established in 2012. Appointment of a chief officer and a finance officer is required under both models. Chief officers have two sets of accountabilities: (i) to the Integration Joint Board for strategic leadership and (ii) to the NHS Board and local authority for operational leadership (Audit Scotland 2018a). They are responsible for building effective relationships, trust and collaboration to deliver the same high-level objectives (Box 50.1).

Box 50.1 Objectives—Adapted from Public Bodies (Joint Working) (Scotland) Act, 2014

- Improve the quality and consistency of services for patients, carers and other users and their families.
- Provide seamless, joined-up quality health and social care services to care for people at home or a homely setting.
- Ensured resources are used effectively and efficiently to deliver services that meet the needs of the increasing number of people with longer term and often complex needs.

50.1.7.1 Financial Context

Attempts to work through the financial complexity facing both the NHS and local authorities predate integration. The Integrated Resource Framework (IRF) was developed by the Scottish Government, NHS Scotland and COSLA. It provides historical patterns of service use and enables a better understanding of costs, activity and variation for different population groups (Public Health Scotland 2019a). The dialogue around the IRF helped to build readiness for strategic planning and commissioning using integrated budgets. Each integration authority includes their financial position as part of their Annual Reports available for public scrutiny. The Scottish budget published on 6 February 2020 reported more than £9.4 billion in health and social care resources directed by integration authorities with 70% of this funding delegated by NHS and 30% by local authorities. However, budget allocation and decisions on where to make savings remain highly political issues. Most integration authorities recorded deficits or had to request additional funding from their NHS Board, local government partners or through brokerage from the Scottish Government (Audit Scotland 2019a).

50.1.7.2 Summing Up the First Horizon

Integrating health and social care has been on the policy agenda in Scotland for over two decades. The case for change was framed around improving outcomes for people by creating more effective and sustainable public services in the face of population changes, workforce challenges and increasingly financial constraints.

Widespread engagement grew the movement for change across sectors and fostered strong cross-party political support. The learning from Highland, as an early implementer in 2012, and the readiness for partnership working fostered by the Reshaping Care for Older People Programme paved the way to progressive legislation to integrate services across Scotland. The legislation was neither the start nor the end point. The process was constantly evolving, reflecting and adapting, and was supported by many other enablers of change. These are explored in the next section.

50.2 The Second Horizon: Supporting Implementation—2015–2019

While few disagree with the vision for integration, progress has often seemed slow and piecemeal. The reasons are inevitably complex. From concept to design and delivery, implementation calls upon many elements to align in order to create the right conditions for change. As different support mechanisms have variable lead times and interdependencies, there has been an inevitable ebb and flow of the pace and scale of reform. In this section, we describe some of the support for implementation across Scotland.

50.2.1 Leadership, Collaboration, Culture and Trust

The Ministerial Strategic Group for Health and Community Care was established to provide high-level and cross-sector national leadership for integration. The group predated the introduction of the legislation and brings together representatives from the Scottish Government, NHS Scotland, local government and integration authorities. The group noted that 'shared and collaborative leadership must underpin and drive forward integration' (COSLA & Scottish Government 2019). A detailed analysis of the leadership role of chief officers can be found in the independent report by Baylis and Trimble (2018). One of their recommendations was to ensure that the chief officers have space to reflect and make sense of the learning that emerges from their work.

The chief officers established Health and Social Care Scotland, a national network through which all those who lead change within health and social care can learn from each other, supported by online resources and networking events to share good practice.[3] One of the concerns of this network has been the degree of organisational churn associated with turnover in chief officers, board chairs and senior executives, a point also highlighted by Audit Scotland (2018b) and Public Audit and Post Legislative Scrutiny Committee (Scottish Parliament 2020). This has prompted a stronger focus on career development opportunities in collaboration

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[3] https://hscscotland.scot/.

with Scottish Leaders Forum and with Project Lift—a national programme for talent management and leadership development in NHS Scotland.

Where there is visible leadership and the associated positive behaviours (proactive communication, effective engagement, high levels of trust, collaboration and openness to challenge), integration works well at both grass-roots and governance levels. But achieving this is far from easy (Scottish Parliament 2020; Mead et al. 2017).

Some staff groups expressed concerns about the potential loss of professional identity, often based on misunderstanding of each other's roles. Over time this concern has faded and most staff groups now value leadership and management capability more than a professional label. This shift has been helped by integrated workforce development. For example, You as a Collaborative Leader Development Programme was designed to build operational leadership capability in primary and social care professionals and managers in statutory, third or independent social care organisations (NHS Education Scotland 2020a). This initiative is complemented by action learning opportunities for team leaders, managers and practitioners (NHS Education Scotland 2020b) and by a 'Leading People-Centred Integrated Care' Masters Programme delivered by the University of the West of Scotland for aspiring professionals from different disciplines.

50.2.2 Empowerment and Co-production

A key concern is how to give 'voice' to people who use health and care services and unpaid carers. Scotland has a long history of work on embedding personal outcomes in practice. Early efforts focused on reorienting the conversation at the point of care to achieve personal outcomes identified through shared decision-making. Focusing on what matters to people is now understood as fundamental to transforming and sustaining public services in Scotland. Enabling people to make informed choices about their care and support is promoted by the Health and Social Care Alliance Scotland—the national third sector intermediary for a range of health and social care organisations. With over 2900 members, one of their core aims is: '*to ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services'*.

More recently, this agenda has been promoted through Realistic Medicine, a series of reports on the importance of personalised care and shared decision-making first published in 2016 (Chief Medical Officer 2016). The work on personalisation is supported by a wide range of policy, education and practice development resources (Box 50.2).

Box 50.2 Resources to Support Personalisation of Care

- A suite explains the principles and practice of co-production at https://www.coproductionscotland.org.uk/
- A personal outcome collaborative provides tools for practice at https://personaloutcomescollaboration.org/
- My Condition My Life is a national campaign to promote support for self-management at https://www.alliance-scotland.org.uk/
- Supports for Health Literacy are available at https://www.healthliteracyplace.org.uk/

Empowerment and co-production are themes in other related policy and legislation. The Social Care Self-Directed Support (SDS) (Scotland) Act, 2013, promotes the vision that care should be based around the citizen and provides a means through which all people who are eligible for social care are given choices. This Act places a statutory duty to offer four choices as to how people are assessed and receive their care or support (Scottish Government 2019b).

The Community Empowerment (Scotland) Act, 2015, covers public participation in policy and planning and imposes legal duties to involve community bodies to produce 'locality plans' to improve local outcomes (Audit Scotland 2019b).

Scotland's' Caring Together Strategy (Scottish Government 2010b) was supported by education for professionals on carers as equal partners in care and by the development of a human rights-based Carers Charter and legislation (Scottish Government 2018c).

50.2.3 Digital Health and Care

Scotland's Digital Health and Care Strategy published in 2018 shows a commitment to using technology to reshape and improve services and outcomes (Scottish Government 2018d). It is one important enabler of service transformation supporting a vision for the future where all citizens can say:

> *I have access to the digital information, tools and services I need to help maintain and improve my health and wellbeing.*

The strategy is based on strong partnership working, including with the housing sector, to support people to stay at home for longer and have care closer to home, with improved access and reduced travel. Implementation is through national actions to ensure the required direction and infrastructure supported by local service transformation using Technology Enabled Care solutions such as Home and Mobile Health Monitoring, Near Me, video-enabled consultations, other digital platforms and telecare initiatives (Box 50.3).

Box 50.3 Digital Health and Care Priorities https://www.digihealthcare.scot/

National direction—a joint decision-making board from national and local government and the NHS, supported and advised by industry, academia and the third sector to make national decisions for investment, priorities and policy, and achieve greater consistency, clarity and accountability.

Information governance, assurance and cyber security ensuring appropriate safeguards are in place for the management of data and consistency in decision-making about sharing data and understanding about data protection requirements.

Workforce capability through a joint approach between NHS, Local Government Digital Office, Health and Social Care Partnerships, and the Scottish Social Services Council.

National digital platform for real-time data and information from health and care records to be available to those who need it, when they need it, wherever they are, in a secure and safe way.

Transition process improves and upgrades existing systems in a joint approach between NHS National Services Scotland and the Local Government Digital Office to ensure existing systems continue to work effectively.

Service transformation—a clear, national approach to service redesign and the scaled-up adoption of successful Technology Enabled Care models. https://tec.scot/ and https://www.nearme.scot/.

50.2.4 Integrated Information and Analysis to Inform Commissioning

Since 2017, the Care Inspectorate and Healthcare Improvement Scotland have had a joint legal responsibility to report on the effectiveness of strategic planning by integration authorities. This includes how integration authorities plan, commission and deliver services in a co-ordinated and sustainable way. Historically, many of the barriers relate to limited interoperability between different information systems. This was as much about information governance and a lack of data sharing agreements than the capability of the technical systems.

Scotland has a long-established data record linkage process at the national Information Services Division (ISD) now part of Public Health Scotland. This has allowed summary records from one type of healthcare service to be linked with records from other services at an individual person level. Recently, the linkable information has been expanded to include records from social care services. This gives, for the first time, an information resource linking individual-level records across the health and social care landscape—a resource for both local and national levels. Tools that provide interactive visualisation of the analysed data have been designed for use locally. Alongside, the development of the Source Tableau Platform (Public Health Scotland—ISD 2020b) has been national investment in localised analytical expertise (*Local Intelligence Support Team—LIST*) to ensure that the increasingly sophisticated resources can be used well to support local decision-makers in planning, commissioning and delivery of services (Public Health Scotland 2020a). A Data Sharing Agreement specifies who will use the data, who can get access and for what purpose, and sets out the process for authorisation and any restrictions. More information can be found at the ISD website (Public Health Scotland 2020c).

Analysis of healthcare cost data in Scotland shows that approximately 2% of the population account for 50% of the resource spent by health and social care partnerships (Healthcare Improvement Scotland 2017). These 'High Resource Individuals' (HRI) generally have complex needs. A novel 'High Health Gain' (HHG) prediction tool calculates the risk of a person becoming, or continuing to be, an HRI in the next 12 months. The tool builds on the experience from the Scottish Patients at Risk of Readmission and Admission (SPARRA) risk prediction tool (Public Health Scotland—ISD Scotland, n.d.). These tools are used to identify patients who may benefit from earlier interventions and preventative care.

50.2.5 Workforce Development and Contracts

Workforce capacity is perhaps the biggest challenge facing health and social care in Scotland. The National Workforce Plan sets out commitments and planned investment over the next five years to develop multidisciplinary capacity in the face of an ageing workforce and anticipated staff turnover (Scottish Government 2019c). Even prior to COVID-19, it was evident that workforce plans must address multiple considerations: incorporate innovations (technology, medicines, medical advances), the impact of Brexit, access to affordable housing, financial realities, perhaps most acutely experienced by social care and the third sector.

The Health and Care (Staffing) (Scotland) Act gained Royal Assent on 6 June 2019. The Act is the first legislation in the UK to set out requirements for safe staffing across both health and care services and most clinical professions. This includes placing a duty on the NHS and social care providers to make sure that there are suitably qualified and competent staff working in the right numbers. What this means in terms of service provision and ultimate accountability remains to be tested.

An important example of contractual change is the new General Medical Services contract for general practitioners in Scotland (Scottish Government 2017a). Introduced as the '*most significant reform of primary care in more than a decade*', it aims to transform elements of Primary Care Services through greater multidisciplinary working and creation of new roles and arrangements to improve access for individuals and communities (Burgess 2019). New primary care roles include community mental health professionals, community link workers, advanced practitioners and physiotherapists to see patients as a first point of contact (Audit Scotland 2018b). Notably, as we will touch on in the final section this 'reform' made no provision for making greater use of technology to improve access for patients (Thompson, Melting Pot 2020b).

50.2.6 Regulation and Standards

There has been no change to the regulatory framework for professional practice, or in the established professional accountabilities. Guidance on clinical and care governance for integrated working was published (Scottish Government 2015b). Integrated National Health and Social Care Standards *My Support My Life* were introduced in April 2018 to replace the previous sector-specific National Care Standards. The new standards endorse the personalisation agenda and seek to provide better outcomes across all care provision in Scotland (Scottish Government 2017b).

50.2.7 Service Transformation

Integration authorities are approaching service transformation through quality improvement and by engaging the public, service users, politicians and professionals in redesign of services, with varying degrees of success (Stewartet al. 2019; Mead et al. 2017). Proposals which are '*major*' require a period of formal public consultation lasting for a minimum of three months (Scottish Government 2010c). Scottish Ministers are responsible for deciding which proposed service changes will be approved, something Stewart et al. (2019) argued make it even more political and challenging to deliver major change in Scotland. Between 2010 and 2019, only 11 consultations on major service change were undertaken (Thompson 2020a). This makes it more important to share challenges and co-produce solutions. The Scottish Parliament's Health and Sport Committee, however, found a lack of consistency in stakeholder engagement across integration authorities. While some areas of good practice were cited, concerns were raised over engagement being '*tokenistic*', '*overly top down*' and '*just communicating decisions that had already been made*' (Scottish Parliament 2017).

Scotland has long had a strong record in quality improvement as set out in the Healthcare Quality Strategy (Scottish Government 2010d) and delivered through the Patient Safety Programme and a series of National Collaboratives that ran between 2005 and 2011 (Mead et al. 2017). From 2006 to 2016, cross-sector improvement was mainly facilitated by the Joint Improvement Team which had a focus on personal outcomes, co-production, Technology Enabled Care and the Reshaping Care for Older People Programme (Hendry 2016). From 2016, the lead responsibility for improvement support for integration passed to Healthcare Improvement Scotland, through their Improvement Hub.

50.2.8 Sharing Good Practice

Learning together and sharing good practice has been iterative over many years through local, regional and national improvement networks and collaboratives. Some are care group specific, for example, Focus on Dementia, while others focus on specific interventions such as Technology Enabled Care, strategic commissioning or specific parts of the care continuum such as primary care. Two examples are illustrated below:

Living Well in Communities is a portfolio of improvement programmes which aim to support people to spend more time at home. The portfolio spans people living with frailty or experiencing falls in the community; anticipatory care planning; intermediate care and reablement; hospital at home; and neighbourhood care. Results and case studies are available on the ihub portal and reports.

Improving together: A National Framework for Quality and GP Clusters in Scotland (Scottish Government 2017c) sets out the role of GP clusters introduced from 2016/17, and the national support to enables them to drive improved outcomes. Case studies are available in the national evaluation report (Mercer et al. 2019).

Several publications including Audit Scotland (2018b) (Baylis and Trimble 2018), Healthcare Improvement Scotland (https://www.healthcareimprovementscotland.org/) and the ALLIANCE Scotland (https://www.alliance-scotland.org.uk/) highlight local examples of practice. Many more examples support the refreshed guidance on the key elements required to integrate community services and improve outcomes (https://hscscotland.scot/resources/) along with presentations from annual conferences. Recordings, presentations and topic resources are also shared through the International Centre for Integrated Care—the home of the International Foundation for Integrated Care in Scotland—in their Integrated Care Matters webinars (https://integratedcarefoundation.org/ific_hub/ific-scotland-webinars).

50.2.9 Monitoring Experience, Outcomes and Impacts

The limitations of quantitative data alone for monitoring have become better understood in recent years, and the potential contribution of qualitative information in assessing outcomes for people, families and communities is now widely recognised. (Kumpunen et al. 2019). This is reflected in Scotland's National Performance Framework (https://nationalperformance.gov.scot/) which describes the outcomes and indicators that track progress in achieving the Scottish Government's purpose and values. First launched in 2007 and refreshed in 2016 and again in 2018, the framework reflects the values and aspirations of people in Scotland and is aligned with the UN Sustainable Development Goals (Scottish Government 2019a).

It sets out nine broad measures of national well-being which are underpinned by indicators for integration. These draw on a range of data sources, including local and national surveys of care experience. Each integration authority publishes an annual report of their progress against nine health and well-being outcomes and the national care standards. These local reports are available for public scrutiny on Health and Care Scotland (https://hscscotland.scot).

In their report on 'Health and social care integration; update on progress', Audit Scotland commented: 'Although some initiatives to integrate services pre-date the Act, there is evidence that integration is enabling joined up and collaborative working. This is leading to improvements in performance, such as a reduction in unplanned hospital activity and delays in hospital discharges'. They also highlighted significant local variation in performance against national indicators and state there is much more to be done (Audit Scotland 2018b). A summary of performance across six national indicators taken from Audit Scotland Report is shown (Box 50.4).

Box 50.4 Summary of Findings as Presented in Exhibit 5 Pages 18/19, Audit Scotland

National indicator	National performance 2014/15 to 2017/18
• Acute unplanned bed days	The number of acute unplanned bed days has reduced since 2014/15
• Emergency admissions	The number of emergency admissions has risen each year since 2014/15
• A&E performance	The number of A&E attendances has marginally increased since 2014/15, but achievement of the four-hour waiting time target has declined since 2014/15
• Delayed discharge bed days	Delayed discharge rates have fallen since 2016/17[a]
• End of life spent at home or in the community	A gradual increase in the percentage of people's time spent at home or in a homely setting at the end of their life since 2014/15
• Proportion of over 75 s who are living in a community setting	There has been a slight increase in the percentage of individuals aged over 75 who are living in a community setting

[a] Due to changes in data collection, comparable data is only available for two years

Benefits since introducing Highland's lead agency model in 2012 were not covered in the Audit Scotland Report but are reported in a number of publications (NHS Highland 2019; Mead et al. 2017; Westbrook 2017).

50.2.9.1 Key Trends and Analysis

Admissions to hospital have gradually increased over the last 20 years (Fig. 50.1). On elective activity, the shift towards day case and away from inpatient treatment has continued year on year since 1999/00 with day case numbers rising by 23% across the period. Emergency admissions to inpatient care have risen by 28% over the same period (Public Health Scotland—ISD, Scotland 2019b). Notably, this is similar to the 29% rise in the population aged 65 and over though it should not be assumed that population change alone explains the rise.

For many patients admitted to hospital, their stay is relatively short—in 2018/2019, around one in five inpatients was admitted and discharged on the same day and just under half (46%) of the total were in hospital for one night or less after admission (Public Health Scotland–ISD, Scotland 2019b).

The chart below highlights how length of stay for emergency admissions of older persons, in particular (in this case, age 75 and over), has changed in recent years. Using an index year of 2008/09, it shows a rise of over 30% in the latest year shown in the numbers staying one day or less—and a fall in the number who are staying 15 days or more (Fig. 50.2).

The Reshaping Care Programme tracked trends in hospital and care home utilisation by older people. The work delivered some impressive results: 10% reduction in hospital bed day rate following an emergency admission for people aged 75+, 2009/10–2014/15 despite increasing number of older people (Hendry et al. 2016). These trends have continued and, for example, by 2017/18, each day there were around 1866 fewer beds occupied by older people following emergency admission

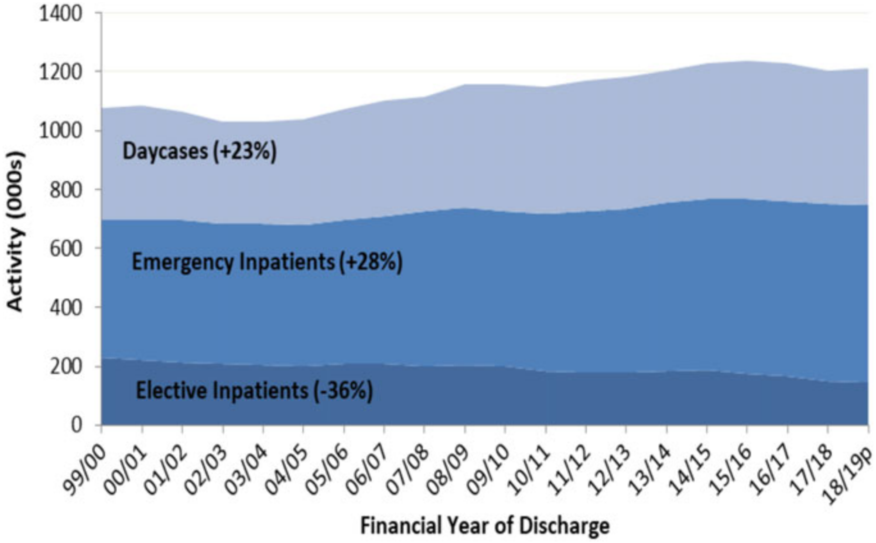

Fig. 50.1 Trends in day cases, emergency and elective inpatients 1999/2000 to 2018/19

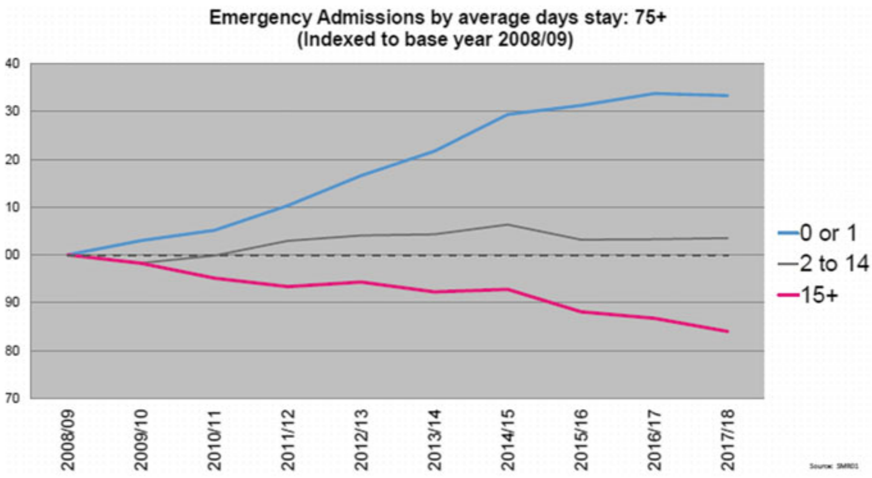

Fig. 50.2 Emergency admissions by average days stay 2008/09 to 2017/18. *Source* SMR01: personal communication P Knight

to hospital than would have been 'expected' had the 2008/09 rate continued in line with population ageing. And, in 2017, there were 7213 fewer older people in care homes each day than would have been 'expected' based on the 2009 rate and demographic trends (Knight 2019). This represents significant institutional care costs avoided, releasing resource for investment in community alternatives.

In line with changing practice, a reduction in length of hospital stay and an increased focus on community services and intermediate care, the average number of available staffed beds for acute specialties has reduced by 6% in the last five years. Despite this reduction in bed capacity, the percentage occupancy has remained relatively stable and was 87% in 2018/19 (https://www.isdscotland.org/Products-and-Services/Transforming-Publishing-Programme/).

As demands continue to rise, there has been a sharper focus on reducing delays in discharge from hospital. A more challenging target was introduced and saw the bed days associated with delayed discharge in 2018/19 reduced by 2% from 2016/17 when the new recording system was introduced. The estimated cost of delayed discharges reduced by £10 million from £132 million in 2015/16 to £122 million in 2017/18, adjusting for changes in daily bed day costs (https://www.isdscotland.org/Products-and-Services/Transforming-Publishing-Programme/). However, the data for 2018/19 shows around one in 12 hospital beds was still occupied by people whose discharge has been delayed, albeit with significant variation across the country. As part of the response to COVID-19, there was a system-wide approach to quickly reducing delayed discharges with various actions undertaken by health boards. These actions have not yet been fully described, and it remains to be seen what implications they had on outcome and whether they can be sustained post-COVID-19.

50.2.10 Summing up the Second Horizon

The implementation of the Public Bodies (Joint Working) (Scotland) Act, 2014, is still at a relatively early stage. By nature, implementation is multifaceted, incorporating a range of local experience and interventions in varying contexts. There are many positive examples of change and some emerging evidence of impacts. Clearly, however, analysis of system trends needs to acknowledge the increasing complexity over time associated with ageing and multimorbidity. In that context, even just 'standing still' may be a significant system achievement.

The Scottish Government's former Director for Health and Social Care Integration commented that easily measured factors, such as hospital activity data, are a '*very thin way of understanding healthcare with the quality of that care not necessarily captured'* (Fooks et al. 2018). There is also a continuing challenge to track changes in community interventions such as intermediate care for which there is currently no systematic national data collected. A further challenge in assessing progress is that the scale, complexity and lack of agreed definition of integrated care make evaluation including around any economic impact very difficult (Nolte and Pitchforth 2014). This is particularly the case when considering population health and addressing inequalities, not least because they need to be considered in both a national and local context and over a long period. Progress towards this, the third horizon, is explored in the next section.

50.3 The Third Horizon

The policy context on inequalities is complex, and in common with many countries, progress has been elusive and hindered by a decade of austerity (Marmot et al. 2020). In 2018, the gap in premature mortality rates between the most and least deprived areas in Scotland increased to its highest point since 2008. Relative inequalities have widened over the long term (Scottish Government 2020b). In the most affluent areas of Scotland, men experience 23.8 more years of good health and women 22.6 years compared to the most deprived areas. The life expectancy of people with learning disabilities is substantially shorter than the Scottish average. Gender-based violence is unequal, with 17% of women and 7% of men having experienced the use of force from a partner or an ex-partner at some point in their lives. Inequalities extend to literacy and numeracy skills in young people where the education attainment gap is also widening.

While health and care services make an important contribution to population health, the impact of the wider determinants of health and well-being is even more powerful (Marmot et al. 2020). Integration authorities must work more closely with their community planning partners from education, housing, employment, criminal justice, business, leisure, digital through to the environment if progress is to be made. The Scottish Index of Multiple Deprivation 2020 is a tool for identifying the places where people are experiencing disadvantage across different aspects of their lives. It focuses on data zones of around 800 people in neighbourhoods to allow consideration of local conditions such as poor housing, a lack of skills, poor public transport infrastructure and access to connectivity. This data can help target resources to areas with greatest need to improve the lives of all local people.

Place-based approaches are emerging as a way of encouraging a clearer focus on prevention and early intervention to improve population health (Naylor and Wellings 2019). The science of population health is still evolving but will be supported by Scotland's new national public health body—Public Health Scotland—charged with improving and protecting the health and well-being of all of Scotland's people to achieve the vision of a Scotland where everybody thrives. Launched in April 2020, it was immediately confronted with the challenge of how to mitigate both short- and longer-term impacts of the COVID-19 pandemic on individuals, families and communities.

This section describes some examples of place-based and citizen-led health initiatives that represent our most ambitious third horizon. Clearly, all this will need to be closely reflected upon as we move through recovery from COVID-19 and beyond.

50.3.1 Self-management and Social Prescribing Partnerships

The ALLIANCE leads My Condition My Life (https://www.myconditionmylife.org/) a national campaign and fund to promote support for self-management. Many self management initiatives and networks have been established across Scotland. For example, in Highland, Let's Get on With It Together (LGOWIT) hosted by the Highland Third Sector Interface has been active for almost ten years. The partnership of public, private and third sector (voluntary) organisations supports people living with long-term conditions through local officers, a dedicated website with a range of resources and a self-management guide co-written by local people living with long-term conditions and professionals.

Social prescribing is increasingly being used across Scotland with a wide range of community-based partners and activities (ALLIANCE 2017). An example, thought to be the first of its kind in the UK, is a partnership with RSPB Scotland where GP Surgeries across Shetland prescribe nature as part of the care plan. Scotland's House of Care Programme also embraces local assets and opportunities for social prescribing (https://www.alliance-scotland.org.uk/blog/resources/house-of-care-learning-report/. The Links Worker Programme introduced a new role into GP practices. Links workers support patients living in challenging circumstances to cope with issues like loneliness, mental health problems, addictions or debt.[4] The approach evaluated well and is being extended across Scotland to enhance relationships between the multidisciplinary team and community partners (Smith and Skivington 2016).

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[4] The GP at the Deep End is a collaboration serving the 100 most deprived practice populations in Scotland, with 86 of these practices in NHS Greater Glasgow and Clyde.

50.3.2 Anticipatory Care Planning

This is a person-centred, proactive, '*thinking ahead*' approach, in which professionals have collaborative conversations with individuals and their carers to identify personal goals in the context of their situation and health conditions. It builds on a decade of work in one GP practice in Highland who reported that the cohort with an anticipatory care plan had significantly fewer hospital admissions, days in hospital and associated costs than a matched control group (Baker et al. 2012). The approach has spread across Scotland levered through improvement support and an enhanced service in primary care aligned with polypharmacy reviews (https://www.polypharmacy.scot.nhs.uk/polypharmacy-guidance-medicines-review/). More individuals and carers can now make more informed choices and express their preferences for future care and place of care. Working with national IT providers enabled a summary of the ACP—Key Information Summary (KIS)—to be shared with emergency services so the right decisions can be made at a time of crisis and reduce avoidable emergency hospital treatment.

In Tapsfield's study, 65% of deaths in patients with anticipatory care plans were at home or in the community, compared to only 27% of deaths in those without anticipatory care (Tapsfield et al. 2015). In their larger study, they found 79% of those who had an advanced progressive illness had a KIS and started a median of 45 weeks before death (Finucane et al. 2020). For people with frailty and/or dementia, the anticipatory care plan discussions took place a median of 32 weeks before death, compared to 25 weeks for people with organ failure, and only six weeks for people with cancer. The odds of dying in the community compared to hospital were 3.7 times higher with a KIS than without one. Across Scotland, in 2017/18 there was a further 12% increase in the number of people with a KIS in place. This achievement contributes to progress in the national indicator that tracks time spent at home or in a community setting in the last six months of life. Over the nine years, 2010/11 to 2018/19 the indicator has increased from 85.3 to 88.1% (Public Health Scotland-ISD 2019c).

50.3.3 Compassionate Communities

Work by the Carnegie UK Trust identifies how kindness and everyday relationships can effect change and support the well-being of individuals and communities (Ferguson 2016). Connected Scotland is the Scottish Governments' strategy for tackling social isolation and loneliness. Published in December 2018, it highlights the power of kindness and the collective responsibility to build stronger connections to ensure communities are more cohesive (Scottish Government 2018b). Across Scotland, many community initiatives are beginning to tackle loneliness and social isolation. Two examples include work in Highland and Inverclyde: The Reach Out Initiative highlighted that 67% of people aged 65 years and over in Highland feel lonely (NHS Highland 2016). *Highland Compassionate Communities* is a partnership between NHS Highland Public Health, Age Scotland and the Life Changes

Trust that evolved from the Dementia-Friendly Communities Collaboratives. Information on this and other examples of Dementia-Friendly Communities in Scotland can be found on Life Changes Trust website (https://www.lifechangestrust.org.uk/).

Compassionate Inverclyde, an award-winning social movement, started with conversations about what matters most to local people: kindness, helpfulness and being neighbourly. The evaluation offers rich insights and describes examples of improved personal, relational and community outcomes experienced by many thousands of people (Barrie et al. 2018).

50.3.4 Housing

The importance of thinking about where, and how, citizens live as they grow older is seen as increasingly important. Security, connectedness, activities and purpose are critical elements of a good place and a good life (Scottish Government 2018a). The housing strategy cuts across many areas of policy and practice such as fuel poverty, dementia, social isolation and connectivity—all essential to enable Scotland's growing population of older people to age safely in place and independently at home for longer. Fit Homes is an innovative partnership between NHS Highland, Albyn Housing and a housing manufacturer to create modular housing. These homes incorporate high levels of technology which can be rapidly constructed and transported to new locations to meet changing need. The technology is used to closely monitor residents who have high levels of care needs and trigger appropriate action when a problem is identified. Although currently being undertaken as a research project, work is ongoing to consider how it can be replicated (https://attoday.co.uk/fit-homes-key-independent-living/).

50.3.5 Neighbourhood Care

From March 2016 to March 2019, 12 teams in five areas tested the Buurtzorg model of neighbourhood nursing, adapted for the context of integrated teams. The teams applied five core principles:

- Putting the person in the centre of holistic care
- Building relationships with people to make informed decisions about their own care, which promotes well-being and independence with active involvement of family, neighbours and the wider community, where appropriate
- Everyone, including support functions, enabling person-centred care at the point of delivery
- Small self-organising, geographical-based teams and
- Professional autonomy.

In rural and island areas, workforce challenges are particularly pressing and are driving the development of new roles and integrated working. One example is the creation of a health and social care support worker role to sustain access in remote areas in Highland. An evaluation revealed that a multidisciplinary team approach and more ‘dispersed’ models of provision could be delivered in ways that both communities and healthcare professionals found acceptable (Munoz et al. 2018). Further examples relating to remote, rural and island settings are highlighted in Dayan and Edwards (2017) and through the Scottish Rural Medicine Collaborative (SRMC)—https://www.srmc.scot.nhs.uk/.

50.3.6 Summing Up the Third Horizon

While Scotland’s health is improving, the gap in health outcomes between the most and least advantaged groups in society is widening. Integration authorities and their community partners must go further and faster on local prevention and early intervention to transform lives and communities. Almost a decade ago, the Christie Commission called for significant changes in the way public services are delivered including a move towards preventative and assets-based approaches. Since then, there has been almost year-on-year publications of policies, strategies and plans all geared towards integrating care, improving health and reducing inequalities. Intuitively, there should be a virtue in multiple policies which are mutually supportive. However, addressing population health and inequalities against a backdrop of rising demand and financial pressures is complex and remains largely elusive.

Now all these complex challenges will need to be viewed through the prism of COVID-19. For instance, the use of technology for homeworking, shopping, online banking, social-connectedness and remote consultations has been critical to Scotland’s response to the pandemic. However, it has exposed further inequalities with some 800,000 people across Scotland who lack access to digital solutions. This might be through lack of IT equipment, connectivity, capability, affordability or motivation to learn or be taught. The Scottish Government’s Framework for Decision-Making in COVID-19 includes a commitment to renew the country and build a fairer and more sustainable economy and society (Scottish Government 2020a). There are other related initiatives such as ‘No one left behind’ actively looking to address digital inequalities (https://www.scotlandis.com/blog/no-one-left-behind-digital-scotland-covid-19-emergency/).

In the final section, we explore some of the lessons learned in Scotland’s journey to integrate care and close with a case study which illustrates the transformative power of disruptive innovation.

50.4 Lessons Learned and Reflections on Scaling up

50.4.1 Lessons Learned

There have been various reports on lessons learned and insights around integration in Scotland. These mostly point to issues of leadership, culture, workforce challenges, sharing practice, difficulties with evaluation and the challenging financial context (Audit Scotland 2018a, b; Fooks et al. 2018; Baylis and Trimble 2018; The Scottish Parliament's Health and Sport Committee 2017; Dayan and Edwards 2017; Mead 2017; Mead et al. 2017).

We have distilled some key learning from these reports and from our own experiences:

1. There are no magic bullets for achieving ambitious, sustainable system change.
2. Successful transformation requires co-ordinated efforts across the whole of government, the whole of the health and care system, and at every level, and with citizens.
3. No single change framework can capture all the key elements to be addressed.
4. Nurture creative, flexible and resilient leaders at all levels to inspire and empower people to change policy, practice and behaviours.
5. Every community is different. Understanding the local context and readiness for change is important.
6. Invest time in building trusting relationships and strive to understand different cultures and what underpins varying behaviours and levels of co-operation.
7. Start with realistic conversations on the values and outcomes that matter to individuals and communities as the main drivers and agents of change.
8. Use information and stories on the quality and experience of care to influence hearts and minds and be open to being influenced.
9. Understanding data on relative inequalities can help target resources to areas with greatest need.
10. Co-produce a compelling vision and narrative about improving lives and a better, more sustainable, future.
11. Involve citizens and people who use services in co-designing future models of care.
12. Be prepared to cede power and control to other organisations, communities and individuals.
13. Investment needs to align with new models and approaches.
14. Stay curious, keep learning together, and look beyond boundaries for insights and solutions. Be prepared to fail fast, flex and adapt.
15. Embrace disruption and external challenges as opportunities for innovation to change pace.
16. Adopting technology and new ways of working is complex. Change needs to be co-produced, using quality improvement, and supported by the right leadership and peer support.

17. In ordinary circumstances, changes will take longer than initially expected but in crisis situations the pace and scale of change may be transformational. It remains to be seen whether such transformation goes from strength to strength or return to previous ways.
18. If hard-won gains are to be sustained, they need to be carefully planned and supported by well-timed communication, training and ongoing engagement.
19. Accepting new ways will only make sense if anticipated improvements can be evidenced and any unintended consequences managed.
20. Stick with it—this is a marathon not a sprint. Some things may appear to get worse before they get better. Be ready when opportunities present themselves.

50.4.2 Scaling Up the Gains—A Case Study

The global COVID-19 pandemic triggered unprecedented rapid scale-up of remote video consultations, across primary and secondary care, known as Near Me in Scotland (Greenhalgh et al. 2020a, b), and started to overcome some unsurmountable problems (Gray 2020, and Box 50.5).

Commenting on the wider use of remote consultations, Professor Trish Greenhalgh, Nuffield Department of Primary Care Health Sciences, Oxford University, said:

> *Until a few weeks ago, unless you lived somewhere remote, it was easy to pop to the hospital or the GP. With COVID-19, if you are a patient and you go to a GP surgery or you are a doctor and you see patients face-to-face, there is a high risk of infection. Suddenly the relative advantage of virtual consultations has changed dramatically. I cannot think of any comparative situation in the history of the NHS. This is such a complex innovation, changing the way we relate to patients and the workflows of the NHS. This is not just about video and telephone consultations, but also what is known as the total triage system, where a patient can't just phone up and book to see a doctor, they can't walk into the surgery to ask for a prescription. This is a radical and complex innovation, but the relative advantage is huge*. (Health Foundation 2020).

The use of remote consultations will be critical as we move through the phases of the pandemic and beyond but there will no doubt be further work to capture the learning and continue to win hearts and minds regarding changing the way we access services (Thompson, Melting Pot 2020b).

Box 50.5 Use of Video Consultations in Response to COVID-19

- Background

Attend Anywhere, a well-established video consulting platform developed in Australia, was procured by the Scottish Government's Technology Enabled Care (TEC) Programme in 2017 to improve access to services. Pharmacists in Highland were early adopters and led to *Pharmacy Anywhere* being developed in partnership with the Health Foundation's Innovating for Improvement Programme (Morrison 2018). This proof of concept led to the creation of NHS Near Me supported by the national TEC Programme, initially for hospital outpatient appointments in NHS Highland.

An initial focus was in response to public protest in 2017 in the far north of Scotland around discussions around changes to services (Thompson 2020a). Through these discussions, it emerged some people were having round trips of over eight hours for short 5–10-min appointments. The board of NHS Highland and the public were united in tackling this and work began in earnest with communities and clinicians to co-produce changes (Thompson 2020a, b, c).

- Co-design

Through the co-design process with patients and the public, the name was changed to Near Me to reflect its use at home and recognising the potential use across wider health, social care and public sector settings (Morrison 2019).

- Use of Near Me pre-COVID-19

Although Near Me was made available across Scotland, until the end of 2019 the most significant uptake remained in the north of Scotland—Highland c60 consultations per week and Grampian c30 per week—still a mere drop in the ocean www.tec.scot.

- Evaluation

Nevertheless, interim evaluation was positive, in terms of both the functionality of the video consulting platform and the experience of patients and clinicians. The report commended the quality improvement approach adopted in Highland and recommended this as a way forward to support wider roll-out (Greenhalgh et al. 2020a, b).

From early 2020, the plan was to scale up Near Me across Scotland focused initially on hospital outpatient appointments. In April 2019, a target had been set that by March 2020 there would be >1000 consultations per month on the Attend Anywhere platform. That work was just two weeks underway when the outbreak of COVID-19 hit Scotland in early March.

- Use of video consultations during COVID-19

The priorities for the roll-out of Near Me quickly changed to scale up video consultations including for primary care to allow as many people as possible to have remote consultations from their own home. In a matter of weeks, all

GP practices were equipped and use across secondary and primary care expanded.

Interest from all professionals continued to grow. Across a 10-day period in April 2020, over 2680 allied health professionals joined webinars in the drive to hear from front line practitioners around how they were using video consultations. Feedback was positive with plans to expand to nursing, midwifery, other professionals, and multi-disciplinary teams. In June it was made available to all community pharmacies across Scotland. It is also being used in the third sector and being adopted for use in ITU settings to enable virtual 'visiting'.

In terms of the numbers, prior in March 2020, there were around 300 video consultations per week using the Near Me system; by June, there were almost 17,000 every week, with around 150,000 in total https://tec.scot/. *Although much has been achieved in a short space of time, much more is still to be done*. Recognising the rapid increase in use, the Scottish Government prepared a vision (see here: www.nearme.scot/views) that 'all health and care consultations in Scotland are provided by Near Me whenever it is appropriate'. To seek views, a public engagement exercise got underway on 29 June which included an online public survey, views sought from professional bodies including a survey and wide range of stakeholders contacted and invited to feed back.

Finding ways to engage with service users who are not online during the pandemic has been challenging, and options to address this are being considered. Resources, reports and plans are available at https://tec.scot/digital-health-and-care-in-scotland/video-enabled-health-and-care/.

50.5 Reflections

This overview describes the three horizons in Scotland's journey to integrate health and social care over the past two decades. Only time will tell if we fully realise the potential from the legislation and manage to build on and sustain the gains. Few would argue that the pace and scale of integrated care need to increase now. Now more than ever we need all partners to work together towards a common goal. In the fullness of time, there will be so much more to reflect on and to share. Our journey of discovery continues. We hope this case study provides some useful insights on our experience and is a source of inspiration to others embarking on a similar journey.

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Innovative Payment and Care Delivery Models: Accountable Care Organizations in the USA

51

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51.1 Integrated Care in the USA

Examining the past and current state of health insurance and care provision helps in understanding recent attempts to foster integrated healthcare delivery in the USA. Most strikingly, high fragmentation among payers characterizes the US healthcare system. A number of different, and only partly complementary, insurance systems exist. Most citizens under age 65 are covered by private insurance, which comes in two ways: Employer-sponsored group contracts predominate among workers in larger firms and their families, while direct purchase insurance covers individuals who are not offered insurance through their employers. The first option is community rated, but the second was traditionally subject to risk rating and medical underwriting. The latter was changed by the Patient Protection and Affordable Care Act (ACA) in 2010, which introduced a third option, the so-called *health insurance marketplaces*. The marketplaces offer more standardized insurance products, partial community rating, and public subsidies for low-income individuals.

The USA also has public payers in the form of Medicaid and Medicare. Medicaid is primarily run by the states and covers low-income individuals who meet certain requirements. In the context of the ACA, the coverage has been expanded to

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more of the population depending on the state. Medicare is run by the federal government and primarily covers people of 65 years and older and people with disabilities. While Medicare's beneficiaries account for 18% of the US population, the program's expenditure is the second largest item of the federal budget, adding up to $600 billion a year. Medicare on average contributes between 26% to more than 40% of providers' total gross revenue (Aspen Publishers 2015; Cunningham et al. 2015); for many providers, it may well account for more than 50% of their business volume.

The US healthcare system has a history of continuous organizational change (Bazzoli et al. 2004; Vogenberg 2019). Cracks in the system and fragmentation have spurred both large-scale health reforms and individual entrepreneurial initiatives. The result is by no means a perfect healthcare system. From 1980 to 2018, national health expenditure as percentage of US GDP almost doubled, from 8.9 to 17.7% (CMS 2019b), while access and quality have seemingly not improved to the same extent (Manchikanti et al. 2017). Fragmentation also still prevails, and issues that were already discussed 30 years ago, such as community accountability or patient outcomes, remain subjects of debate. A by-product of this history is a large number of experiments, making the USA probably the largest laboratory for healthcare delivery reform in the world. Many of these attempts have failed, while others have endured longer than anyone would have predicted and have been adapted to the changing environment. Kaiser Permanente, Mayo Health System, and Geisinger Health System are just three of the largest and best-known examples of innovative healthcare delivery but not the only ones from which we can learn. The many failures can teach valuable lessons, too.

The era of *managed care* began in 1973 with the US Congress passing the Health Maintenance Organization Act. This act popularized the term "health maintenance organization" (HMO), removed many state restrictions, and mandated that employers with more than 25 employees that provided health insurance include at least one HMO option. Over the following two and a half decades, various forms of managed healthcare delivery prospered. They proved, among many other things, two facts. First, capitation is a powerful incentive to make organizations more efficient, as it reduces care volume and eliminates unnecessary services—and occasionally more than just the unnecessary ones. Second, health reform cannot succeed without patient acceptance. Patients value the freedom to choose their providers and rank (perceived) care quality higher than cost containment. Thus, a consumer backlash—triggered also by patient opposition to reduced formularies, red tape, and pre-authorization requirements—brought the managed care movement to a halt by the mid-1990s. Negative perceptions stirred up in the media overshadowed the positive aspects highlighted in scientific assessments (Greene 2003). As a result, the terms "managed care" and HMOs were stigmatized and remain basically taboo in health reform. This being said, today almost all the care delivered in the USA includes some elements of managed care, though these elements are not pushed as aggressively as they had been by the original HMOs.

Today, the structure of the provider market illustrates, to some extent, outcomes of this history. The boom of managed care fostered the consolidation of service providers. To provide service along the full continuum of care for populations in defined areas and create countervailing power against large insurers, providers merged. In 2019, most of the roughly 5,000 community hospitals were in a hospital system (almost 3,500), which is defined by the American Hospital Association as either a multi hospital or a diversified single hospital system. About 1,700 hospitals were part of a network, meaning that a group of hospitals, physicians, and other healthcare providers come together to deliver integrated care to their community. The system affiliation does not exclude a network participation. There is a mix of public (18%), private not-for-profit (56%), and private for-profit hospitals (25%) (AHA 2019a). Physicians are mostly organized in groups with varying degrees of economic and legal integration. They contract with hospitals, insurers, employers, and the federal and state government. As hospitals still rely mostly on attending physicians—hospitalists have gained popularity but are not common—physician groups are important players in the market. The past also saw recurring cycles of vertical integration, such as hospitals buying physician groups, followed by waves of disintegration.

51.2 Integrated Care in Practice: Accountable Care Organizations

51.2.1 Problem Definition

Quality, costs, and more recently patient outcome and experience are pressing issues for US healthcare reform. Efforts to address these issues by means of integrated care delivery and innovative payment models are mostly driven by the Centers for Medicare and Medicaid Services (CMS) and the Center for Medicare and Medicaid Innovation (Innovation Center), agencies within the US Department of Health and Human Services (HHS). CMS administers the Medicare program and the federal part of the Medicaid program. The high relevance of Medicare spending makes providers very sensitive to CMS's policy changes. And with the baby boomers hitting retirement age, the importance of Medicare looms ever larger. Many of CMS's reform efforts can be linked to goals that are known as the Quadruple Aim: improving the experience of care, increasing the provider satisfaction and the health of populations while reducing per-capita costs (Bodenheimer and Sinsky 2014). These aims conflict with traditional, fragmented delivery structures and fee-for-service (FFS) payments, which are still the norm for reimbursing providers.

In early 2015, HHS made a bold announcement, stating that it would drastically reduce traditional FFS spending (HHS 2015). While in 2011 almost all traditional Medicare spending was FFS, the agency's goal was to reduce the share to 70% in 2016 and 50% by 2018, replacing FFS with alternative payment models. In 2018, the agency said that 90% of the remaining traditional Medicare payments would be tied to value, patient experience and quality measures. According to the Health Care Payment Learning and Action Network, in 2017 41% of US healthcare payments flowed through FFS without any link to quality or value and about 25.4% were FFS payments with a quality or value component, such as pay for performance, pay for reporting, or pay for structure. Population-based payments such as condition specific, comprehensive, and integrated finance and delivery systems accounted for 3.8%. The remaining 29.8% amounted to alternative payment models built on FFS architecture, which payers believe will be increasingly used in the future and will improve, among other things, the quality and affordability of health care (HCPLAN 2018). CMS's goal is broader than just reforming the Medicare payment scheme; it aims also to incentivize private players in the market to foster patient-centered insurance and care delivery. While just a declaration of intent, this policy statement received considerable attention from providers.

Another trend has strongly influenced CMS's reform efforts. Over the last decade, the importance of social determinants of health for health outcomes has been increasingly recognized. Social determinants of health are defined by the World Health Organization as "the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life" (WHO 2020). The interest in addressing social determinants of health is also growing by policy makers (Horwitz et al. 2020). HHS described to "create social and physical environments that promote health for all" as one of the four goals in Healthy People 2020, a set of goals determined once a decade to improve the health of all US citizens (HealthyPeople.gov 2020).

51.2.2 Description of the ACO Model

One of the most discussed alternative payment models is the accountable care organization (ACO). According to CMS's definition, ACOs "are groups of doctors, hospitals, and other healthcare providers, who come together voluntarily to give coordinated high-quality care to their Medicare patients" (CMS 2015). ACOs have been conceived as a means for achieving the Quadruple Aim of improving population health, provider satisfaction, and the experience of care while containing costs and focusing on defined patient populations. Their payment system creates the corresponding incentives. The FFS scheme remains in place, but providers are evaluated financially with regard to a financial performance benchmark. The benchmark reflects former expenditure for the assigned population as well as expenditure trends. In the Medicare Shared Savings Program (MSSP), savings (one-sided option) or savings and risks (two-sided option) are shared to varying degrees between providers and Medicare, mimicking incentives of a capitation-like system. Payments depend on quality targets. The shared savings are multiplied with a quality score that can reach a maximum of 100%.

ACOs can also serve patients from the private (non-Medicare) insurance market, but the largest push fostering this model came through the ACA and CMS's subsequent targeting of the Medicare population. While private insurers can steer their enrollees toward their dedicated ACO—for example, by charging higher co-pays for physician visits outside of the preferred network—Medicare does not impose such restrictions. An algorithm assigns patients to a specific ACO if the data suggest that the preponderance of a patient's primary care services is delivered by a provider contracted with the ACO. The ACO is then accountable for the patient's care quality and costs, but the patient may also choose providers outside of the ACO. There is no requirement for an ACO to be a fully integrated company. In addition, purely contractual arrangements between participating providers to coordinate care processes and share risks and benefits are possible.

In consequence, a broad range of institutional arrangements has emerged. Muhlestein et al. (2014) have sketched out a taxonomy of ACOs, identifying at least six different setups characterized by their degree of integration across outpatient and inpatient care, the complexity of services covered, and the degree of centralization. On a general level, ACOs are either led by hospitals, physician groups, or fully integrated health systems.

Besides the MSSP, CMS also offered the pioneer ACO model, a two-sided option, putting providers on a faster track for taking on larger risks and cutting down on the relevance of the standard FFS share of their revenues. But by the end of 2015, 16 of the 32 organizations that had signed up in 2012 had left the program, mostly converting to the less ambitious MSSP. CMS thus has closed enrollment for this type of ACO. Reasons for the high dropout rate are its considerable financial uncertainty, implementation challenges, new information technology, etc. This matches with the trend in the MSSP. In April 2015, a bit more than three years after the start of the program, 401 ACOs operated under the one-sided regime, and only three under the two-sided regime.

A more recent alternative arose as an add-on to the MSSP. The ACO investment model addresses difficulties faced especially by smaller ACOs, particularly those in rural and underserved areas, which had struggled to come up with the investment budget to implement required changes of processes and information technology. This model pre-pays shared savings and thus tries to solve the problem of front-end investments with delayed payoffs. But CMS remains active in trying to promote new and ambitious ACO approaches. Building on the lessons from the pioneer ACO models, a new two-sided option was promoted under the label Next Generation ACO (NGACO) model administered by CMMI, starting in 2016 with 21 participants. A key goal was to provide participants with better predictability of financial outcomes (CMS 2016). The second evaluation report for the NGACO model from CMS found that the model was associated with a modest and statistically significant decline in Medicare's gross expenditures, and a non-significant increase in Medicare's net spending after accounting for CMS' shared savings payments to the NGACOs (CMS 2020b).

51.2.3 The CMS ACO Program Pathways to Success

In December 2018, CMS announced a new final rule to redesign the MSSP for ACOs called Pathways to Success (CMS 2018b; DHHS 2018). Pathways to Success includes both basic and enhanced levels for ACO participation. The new program accelerates the timeline for ACOs to assume greater financial risk after two or three years in a non-risk bearing basic level (A and B), depending on whether an ACO is "low revenue" (physician-led) versus "high revenue" (likely health system or hospital-led). Under the former MSSP model, ACOs could spend up to six years in a non-risk bearing model (Table 51.1).

Pathways to Success allows additional waiver opportunities for ACOs to pursue, which provide protection to ACOs from the legal risks of ACO formation that would normally be prohibited given Stark law, anti-kickback statutes, gainsharing, and beneficiary inducement prohibitions. The new program permits greater flexibility for telehealth, including telehealth services provided at a patient's home. The program also allows more flexibility for ACOs to offer patient incentives under certain circumstances and with appropriate controls in place.

Pathways to Success also requires ACOs to provide all Medicare FFS beneficiaries (not just those beneficiaries who are assigned to the ACO) seeing an ACO's provider with notification through written, emailed, or portal communication of what it means to be seen by a provider in an ACO.

Finally, the new program includes additional revisions to benchmarking methodology. For example, benchmarking now includes regional, not just national, Medicare FFS adjustments in ACO financial benchmarking and financial performance evaluation in the first year of ACO participation. The intention here is to allow for the methodology to have more accurate performance comparison for ACOs performing in the same region.

Table 51.1 Risk levels and associated rates and limits under the pathways to success regime

Risk level	Shared savings rate	Shared loss rate (%)	Loss sharing limit (lesser of)		Reward sharing limit
			% Medicare revenue	% of benchmark	% of benchmark
Level A	40% × quality score	N/A	N/A		10
Level B	40% × quality score	N/A	N/A		10
Level C	50% × quality score	30	2	1	10
Level D	50% × quality score	30	4	2	10
Level E	50% × quality score	30	8	4	10
Enhanced	75% × quality score	40–75	N/A	15	20

Source CMS (2018a), Champagne et al. (2019), Benstetter et al. (2020)

51.2.4 Impact

A much-debated issue is the benchmarks beeing used to establish savings or losses. As Douven et al. (2015) point out, the original version of the MSSP had created unintended incentives. The financial benchmark was defined for a full three-year contract cycle and referred to a weighted cost average of the attributed population over the preceding three years, giving the highest weight to the most recent year. This has created situations in which inflating costs pre-enrollment paid off heavily during enrollment periods. What's more, very successful ACOs ended up being punished, as their benchmarks became the more challenging the more they had saved. With each new version of ACO models, the benchmarking, as well as the risk adjustment schemes, have become more sophisticated to minimize these drawbacks. The weights have been adjusted to capture more of the long-term cost structure, and past savings are taken into account to avoid unintended penalties.

Additionally, as discussed earlier, among other modifications, the Pathways to Success program now includes regional FFS spending adjustment for ACO benchmarks in the first year of ACO participation, rather than only national adjustment, to afford more appropriate financial performance comparisons with ACOs in closer geographic proximity. CMS also included an allowance for the methodology to include an up to 3% upward risk score to reflect changes in health (with no limit on risk score decreases) when no similar health status adjustments were made within agreement periods previously under the prior MSSP ACO model. Even with these modifications, analysts believe it is unclear exactly how these changes will play out for ACOs (Gusland et al. 2019; Broome 2019). There has also been some public commentary about the difficulty ACOs have in attempting to replicate CMS benchmarking methodology (DHHS 2018). This is important given more clarity around the methodology could allow ACOs to more accurately project financial performance within a performance year to make adjustments in real time as needed.

It is still too early for a judgment on success or failure based on financial or quality indicators. The experience is too recent and brief. Too many different models have emerged. High shares of new entrants and dropouts obfuscated the results. And only a few providers and Medicare beneficiaries have participated. However, preliminary assessments can be made. The high turnover rate from the pioneer ACO model indicates that, while many ACOs can realize savings, not all providers are successful in this respect (Casalino 2014).

51.2.5 Preliminary Results

In 2019, CMS released the performance results for the sixth year (2018) of Medicare's flagship ACO program. Over the last years, the progress of this program has generally shown good quality of care and outcomes and modest but, over time, increasing cost savings compared to CMS benchmarks. Net savings per capita have more than doubled to $73 in 2018 compared to $35 in the prior year. These increased savings occurred probably due to a larger adoption rate of "downside" financing risk, with the participation in downside risk doubling from 8 to 17% in 2018. ACOs who accepted the downside risk were more likely to achieve shared savings than those who only accepted the upside risk, suggesting that greater financial responsibility is associated with a stronger commitment in transforming health care. Table 51.2 shows the performance of MSSPs compared to the benchmarks in the history of the program. Remarkably, the program's net savings per capita have doubled since 2017. Net program savings exceeded $739 million (approximately $73 per beneficiary), and gross program savings compared to benchmarks increased to $1.7 billion. Another notable aspect is that there is no relationship between ACO size and achievement of shared savings. However, larger size physician-led or integrated ACOs had a greater likelihood of achieving shared savings compared to hospital-owned ACOs. This association could not be found by hospital-owned ACOs, suggesting that the number of beneficiaries plays a more crucial role for physician-led ACOs, maybe due to economies of scale or access to financial resources. Considering the experience level, bonuses increase the longer an ACO has been in MSSP. Performance Year 5 and 6 ACOs were significantly more likely to gain shared savings compared to ACOs in their first Performance Years (Gonzalez-Smith et al. 2019).

To qualify for shared savings, ACOs must meet quality standards. CMS established 23 measures, covering four domains: patient/caregiver experience, care coordination/patient safety, preventive health, and chronic care (mental health, diabetes, and hypertension). Performance is captured through a mix of surveys, claims data, and other data sources (CMS 2019a). Early findings indicate that participating institutions do improve on these indicators. As McClellan et al. (2015) point out, the data do not suggest that there is a correlation between financial and quality performance. Furthermore, all results must be considered in the context of overall Medicare volume. In 2018, Medicare ACOs generated $739.4 million in total net savings across 548 ACOs (AHA 2019b). Still, total savings in 2018 were just about 1/1000 of the total Medicare budget ($750.2 billion, CMS 2020a). While the number of covered individuals has grown considerably, as of July 1, 2019,

Table 51.2 Medicare shared saving program accountable care organizations participation and savings from performance year 2012–2018

Performance year	Participated ACOs	Percent achieving savings compared to benchmark (%)	Percent receiving shared savings bonus (%)	Net program savings per capita
2012–2013	220	54	24	−$21
2014	333	54	26	−$9
2015	392	52	30	−$30
2016	432	56	31	−$5
2017	561	60	34	$35
2018	548	66	37	$73

Source Gonzalez-Smith et al. (2019)

ACOs nationwide still serve less than 11 million Medicare beneficiaries (Verma 2019). Provider participation is also still voluntary, suggesting that selection effects may confound some of the successes.

51.2.6 Dissemination

The ACA brought large momentum on various levels, changing the landscape for insurers as well as for providers. One should not underestimate the impact that the Medicare ACO programs also brought to the private market (Berenson and Burton 2012). While fragmentation continues to be a key challenge for healthcare delivery and for the health system in general, reforms such as the ACO programs give reason for optimism. The CMS-led programs have shown that ACOs can improve quality and contain costs. Even so, no ACO template has emerged; successful models still need to be identified and scaled up, and knowledge needs to be shared. At this point, too little is known about the actual changes successful (and unsuccessful) ACOs made in their care for patient populations. CMS needs to continue improving its benchmarking and transparency around benchmarking calculations, and incentivizing providers to embrace new approaches while not overtaxing their ability to implement them. At the same time, unintended side effects, such as growing market power on the provider side, must be addressed.

51.2.7 Lessons Learned and Challenges Ahead

Critics dismiss ACOs as repackaged HMOs, but there are key differences. CMS has taken a strong stance in favor of patients having free choice of providers; they are not limited to providers within their ACO and can leave if they are unhappy with their ACO. Furthermore, HMOs tried to reduce utilization through restrictive formularies and strict control of access. Today's approach aims at more patient-centered care, especially in primary care, while also paying attention to population health. There is at least some hope that this will live up to expectations and show concepts like the Quadruple Aim and ACOs are more than just buzzwords. What may make a big difference, in contrast to the situation 20–30 years ago, is the ability to create and analyze large data sets. These can help to identify patients at risk and effective preventive services and then measure the quality of the care patients receive. "Big data" is a buzzword itself, and many providers grumble about feeling the pain of these new technologies while receiving few of the promised rewards. But the promise in this field is enormous, so optimism seems appropriate. Still, there are concerns, especially with regard to the considerable investments required to take advantage of big data, which may overburden smaller or independent providers, and/or providers in underserved areas, thus again driving even more consolidation of services and/or lack of opportunity for participation in underserved areas where resources are already stressed. The noise in the marketplace is incredibly overwhelming, and sometimes confusing, for providers, particularly those that do not have large systems supporting them. It is difficult to keep up with the ever-changing programs, federal regulations, and measures, among other areas. And, at times, there is lack of alignment across public (federal and state) and commercial programs and measure expectations leading to additional burden for providers to overcome. Beginning with the Performance Year 2019, CMS requires all Medicare-eligible clinicians, and thus including ACOs, to use electronic health records, who meet the 2015 certification standards (CMS 2019a). This could be a first step in the right direction to improve interoperability between providers, and capture the necessary patient data for better population health management.

Further consolidation among providers would be worrisome, as the USA has produced strong evidence that regional markets dominated by few large health systems tend to result in higher prices due to market power (Gaynor and Town 2012a,b; Cutler and Scott Morton 2013). Various forces are driving consolidation in the wake of the ACA. Providers need to leverage large investments and need to cover a share of the population sufficiently large to enable them to operate efficiently. As more risk is passed on to them, they need more patients to spread this risk among. Several provisions of the ACA favor the formation of large local and regional entities and have triggered a new wave of mergers and acquisitions in the US hospital market (Pope 2014), adding up to 457 deals affecting 999 hospitals between 2010 and 2014 (AHA 2015). However, it is not clear, if the mergers can be causally attributed to the formation of ACOs or if other factors have driven this trend (Gee and Gurwitz 2018; Neprash et al. 2017).

High administrative costs are another concern. Driven by, among other things, extensive contract management and billing needs, they are one of the causes of the high healthcare costs in the USA (Himmler and Jugl 2016). ACOs may not be able to dampen this. These sorts of concerns, along with the worry that inertia will triumph and healthcare delivery will change much less than expected, can lead to skepticism about ACOs' long-term potential (Marmor and Oberlander 2012; Burns and Pauly 2018). As Casalino (2014) puts it: "The fledgling ACO movement involves two large risks. The first is that it will fail. The second is that it will succeed, but for the wrong reasons" (p. 1750). ACOs, in other words, may endure not because they provide better quality or lower costs but because they have become dominant players in the market.

Another aspect of ACOs likely to receive attention is the fact that physician-led ACOs have been more successful in reducing costs than their hospital-led counterparts (Introcaso and Berger 2015). This may indicate a dilemma for providers. Hospitals still run a largely volume-driven business model. For them, the incentives to reduce admissions are mixed, especially if they cannot adjust capacity and thus reduce costs on the same scale. Additionally, reducing internal costs may not be enough for hospitals aiming at improving their margins as value-based care models continue to evolve that require attention to be placed on reductions in total cost of care for purchasers and payers.

There are also implications for ACOs in light of the growing Medicare Advantage (MA) marketplace, and in particular the additional program flexibility and options MA plans have that ACOs do not have at their disposal to attract new and retain existing beneficiaries. More and younger Medicare beneficiaries aging into Medicare tend to opt into MA plans rather than remaining in FFS Medicare. Over 30% of all Medicare beneficiaries enroll in MA plans, with projected growth to 41% by 2027, and nearly 100% of beneficiaries currently have access to an MA plan (Patel and Guterman 2017). This potentially impacts patient risk profiles for ACO versus MA plan populations and how CMS measures and rewards each for the care provided to their respective populations.

Another consideration facing total cost of care models, like ACOs, is that focusing on improvements and efficiencies in medical care and the delivery system may not yield longer-term health improvement for individuals or communities. Horwitz et al. (2020) found that investments in social determinants of health are disproportionately made by Medicaid expansion states, in the Bundled Payment Care Improvement Initiative or in ACOs. Health behaviors, social and economic factors, and physical environment influence 80% of a person's health status; only 20% is attributed to clinical care (County Health Rankings 2014). ACOs (and providers in general) are beginning to focus on immediate social needs to assist in care delivery and remove barriers to care, for example, arranging for transportation with a private vendor or community service for patients to get to provider appointments. However, filling an immediate social need does not necessarily address underlying social determinants toward better long-term individual or population health. Further, it is not the primary role nor core competency of the health delivery system "writ large" to tackle topics related to social determinants of health, leaving ACOs and other providers looking to community agencies and local, state, and federal policy makers to fill gaps and drive societal policy change to better support healthy individuals and communities.

51.2.8 General Outlook of ACOs and the Impact of the COVID-19 Pandemic

The impact of the COVID-19 pandemic on ACOs will not be understood for some time. ACOs in the USA are already advocating for CMS to take into account pandemic-related costs in the financial reconciliation for the 2020 performance year (King 2020; Castellucci 2020). It could be that certain ACO costs will temporarily decline, e.g., postponed elective high-cost surgical procedures and postponed lower-cost preventive care and wellness visits, while costs for caring for COVID-19 patients may significantly outweigh these temporary reductions. Further, as annual wellness, chronic care, and preventive visits are postponed, ACO quality and patient experience may decline, as providers will be more focused on immediate COVID-19 needs, rather than identifying and filling care gaps. Postponement of needed care, particularly for those with multiple complex chronic conditions, could also lead to an eventual "boomerang effect," with worsening health status leading to costlier longer-term care needs.

CMS has extended quality reporting deadlines and relaxed rules on telehealth and other regulatory areas, providing some more flexibility in care delivery in the very short term to providers. However, in the longer term, given the overall economic strain the USA is experiencing, increasing federal deficits, and economic pressure on employers, it is unclear at this time what the financial and other impacts will be on ACOs and the delivery system generally. There may be a movement for the federal government and other private payers to reduce pricing as a quick way to alleviate healthcare costs, or shift more financial risk in the shorter term, rather than relying and iterating on value-based care models to deliver on the promise of longer-term cost reductions.

Additionally, the role and contributions of public and community health in the ACO model, and healthcare delivery in general in the USA, have been largely fragmented or absent. As CMS and CMMI introduce the next set of value-based care models, for example, direct contracting, the role of public and community health may be reconsidered and strengthened to better position more effective community-level healthcare delivery, and more specifically, a better, more coordinated response to future pandemics (Nacoti et al. 2020).

ACOs are unlikely to be a panacea. However, together with many other reform initiatives that have been proposed—such as the patient-centered medical homes or linking payments to value—they highlight both the relevance and the potential of integrated approaches to healthcare delivery in the USA and beyond.

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Case Study—Community Capacity for Health: Foundation for a System Focused on Health

52

Marlene Raasok and Mark Seland

This case study offers information, experiences and insights from a five-year journey to develop a community focus for health. Perspectives are provided on strategies *to optimize community capacity for health as the foundation for integrated and sustainable systems focused on health.*

52.1 The Challenge Before Us

It is more than 70 years since Tommy Douglas (Premier of the Province of Saskatchewan) championed better health and health care, the genesis of the Canadian Medicare system we have today. Unfortunately, the "RESET Button" imagined by Hon. Dr. Bennett has not been found, at least not within the current construct of the Canada Health Act (CHA) and the provincial healthcare funding structures and legislative frameworks (Fig. 52.1).

The Lalonde Report, **A Perspective on the Health of Canadians** (Lalonde 1974), began discussions in Canada to look broadly at health and health care. The Foreword to a Senate Report describes the challenge: "we must change our way of thinking and recognize that good health comes from a variety of factors and influences, 75% of which are not related to the health care delivery system. …we must become proactive and support communities, cities, provinces, territories and a country in producing citizens in good health, physical and mental well-being and productivity" (Keon and Pepin 2009).

The Canadian Medical Association (CMA) continued this dialogue with Town Halls regarding views of Canadians on social determinants of health (those factors outside an individual's genetics and outside healthcare services that influence the

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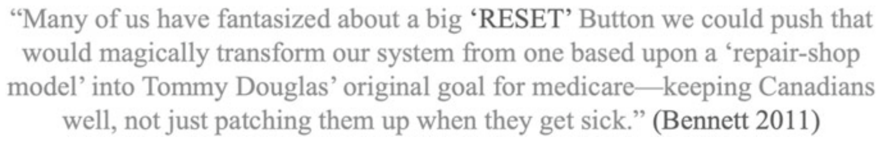


"Many of us have fantasized about a big **'RESET'** Button we could push that would magically transform our system from one based upon a 'repair-shop model' into Tommy Douglas' original goal for medicare—keeping Canadians well, not just patching them up when they get sick." **(Bennett 2011)**

Fig. 52.1 Imagine a medicare "RESET Button"

health of populations and as further defined in Fig. 52.5). The CMA's report with recommendations for inter-sectoral action demonstrated the medical profession's ethical duty to their patients to work toward a society in which everyone has opportunities to lead a healthy life (CMA 2013).

In a report to the Federal Health Minister, **UNLEASHING INNOVATION: Excellent Healthcare for Canada** (Naylor 2015), the document's Foreword underscores the continuing challenge: "Because our mandate was healthcare and that in itself was overwhelming, we did not delve into broad determinants of health or strategies for community-wide health promotion. However, readers will note that our recommendations point strongly towards empowering patients with their own health information, and towards modes of reorganizing healthcare systems to put much greater emphasis on keeping Canadians as healthy as possible, including better integration of healthcare and social services."

This is the call to action: get at *health*, and by extension, reduce people's need for "sick care" and the ever-increasing costs of healthcare services.

This case study provides experiences and insights of Airdrie's journey to develop community capacity for *health.* At the end, the authors discuss key elements of a "RESET Button" for an inter-sectoral approach for healthy/healthier individuals with direct correlations to improved system performance and sustainability.

52.2 Healthy Communities: National and Provincial Contexts

The Ottawa Charter for Health Promotion, co-sponsored with the World Health Organization, describes Health Promotion (HP) as a comprehensive, multidisciplinary approach (WHO 1986). It encompasses five action strategies (build healthy public policy, create supportive environments for health, strengthen community action for health, develop personal skills for health and re-orient health services), supported by three HP strategies (to enable, mediate and advocate).

Actions related to developing healthy communities in Canada draw from this charter.

- A framework developed by the provinces of British Columbia, New Brunswick, Ontario and Quebec describes five building blocks for a healthy community initiative: community/citizen engagement, multi-sectoral collaboration, political commitment, healthy public policy and asset-based community development (BC Healthy Communities 2011). Their approach identifies action on determinants of health and targets benefits at individual, organization, community and regional/provincial/national levels. Impacting healthcare costs is not a specific focus.

- The Public Health Agency of Canada calls for action by local communities, "to innovate so that the healthy choices are the easy choices" (PHAC 2017, p. 43).
- In 1986 in Alberta, the mandate for public health moved from municipalities to health authorities (now Alberta Health Services—AHS). AHS has developed an "Alberta Healthy Communities Approach" with a five-step process (Alberta Healthy Communities Approach). AHS resources include a healthy workplace development tool, practices for comprehensive school health and strategy kits for physical activity, healthy eating, tobacco, alcohol (Alberta Healthy Communities Hub). Implementation has occurred with a variety of focused community initiatives.

Momentum to develop healthy communities is now challenged by financial pressures. A review of AHS states: "the message that these studies create is consistent and clear: Canada's high rate of spending on health care does not correlate with higher relative performance on key international measures" (Ernst and Young 2019, p. 9). The challenge to AHS is to focus on continuous improvement of health performance while also reducing costs immediately and for the long term.

Strengthening integration of care is necessary to create cost-effective healthcare delivery. These changes will not be sufficient, however, to sustain the system or improve individual and population health, well-being and productivity.

Alberta's Chronic Disease Prevention Action Plan 2015–2018 (AHS 2016) illustrates the importance of looking to health-related factors and disease prevention in addressing future system sustainability: "Between 2009 and 2011, 58.1% of deaths in Alberta were attributed to cancer, ischemic heart disease, stroke, chronic obstructive pulmonary disease, type II diabetes, and hypertension. Currently, one in three Canadians aged 65–79 have three or more chronic diseases…chronic disease rates are increasing faster among Canadians aged 35–65 years and over, and children currently experience chronic diseases that were previously only seen in adults" (p. 10). … "currently, chronic diseases account for 53% of the total health care costs in Canada" (p. 11).

Many decision makers view financial allocations to health and wellness as additive to the public healthcare system versus a re-allocation. As discussed in the Naylor Report, it is time to widen our thinking and encourage re-allocation of funds currently focused on healthcare services.

This is the context in which this community's journey for health takes place. As a community, Airdrie chose to focus on improving health and inadvertently may be showing the way to the "RESET Button." Indeed "*Keeping Canadians well, not just patching them up when they get sick*" (Bennett 2011).

52.3 The Journey Begins in Airdrie

Airdrie, Alberta, Canada, is a city of 70,000 in 2019 with 100,000 projected by the early 2030s. It is close to Calgary (25 km to the south). Calgary is one of two major urban centers in the province and is the location of the hospitals serving this community. Publicly funded health care in the community is planned with the Calgary Zone of Alberta Health Services. Local services include primary care, community care, mental health and addiction services, urgent care and emergency services, and continuing care. Airdrie also has a range of social services operated by nonprofit agencies and funded by the city, non-health government ministries and donors. The authors have been part of this journey since the beginning as members of Abrio Health (initially Airdrie & Area Health Benefits Cooperative).

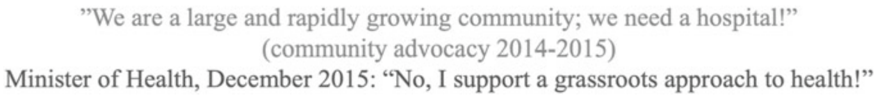
The quotes in Fig. 52.2 launched our journey. For 2016, the question became, "what is a grassroots approach to health?" Consultants were hired with seed funding from the city and private donors. Initial priorities included improving service coordination in the community and improving system performance. Solutions focused on inputs (too many physicians; need for team-based structures) and processes to integrate community-based health and healthcare services across needs-based segments.

Parallel to this, community leaders came together to form a backbone for community-based work, the Airdrie & Area Health Benefits Cooperative (AAHBC). This organization began to champion a bold community vision, "Own Our Own Health, Becoming Canada's Healthiest Community" to galvanize community action.

By late 2016, we began to learn the magnitude of the Minister's challenge. Work in 2017 and beyond has involved community engagement to understand needs and research to identify strategies to develop a healthy community with healthier citizens. The organization was very aware of evidence showing that healthy individuals and communities correlate to reductions in preventable disease and increased financial sustainability of healthcare systems and the RESET Button.

52.4 Community Plan for Health

The quotes in Fig. 52.3 came from a year-long engagement which informed the first community health plan.



"We are a large and rapidly growing community; we need a hospital!"
(community advocacy 2014-2015)
Minister of Health, December 2015: "No, I support a grassroots approach to health!"

Fig. 52.2 Community request 2015

Leaders of Abrio Health began with a conviction to build on the community’s “can do” attitude and that a sustainable healthcare system could be achieved through community-based changes supporting improvements in both individual and family health. After significant research, Abrio Health recommended the community to investigate Blue Zones Project®.

To learn if the foundations of success were present within the community, Blue Zones Project, representatives came to Airdrie in May 2018 to share methods and results. More than 600 citizens were engaged. Particularly significant to the community’s support and ability to proceed were two factors: First, they would have a comprehensive methodology with evidence and experience in more than 50 locations. Second, the community, through Abrio Health, could act on momentum with a decision to move forward with this organization, cementing local ownership.

Concurrent with the decision to move forward with the program, two changes took place to strengthen the environment for collective impact.

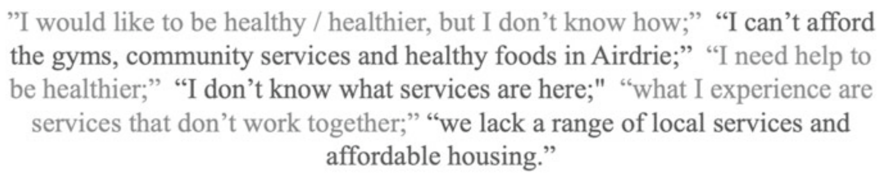
First, a new name was developed for AAHBC to move away from a focus on the organization to focus on a “movement” within the community: *Abrio Health (Brio meaning “Great things are happening here, in Airdrie*).

Second, the updated Community Health Plan (Abrio Health 2019) recommitted to the vision with a more complete description of the desired future:

- *Vision*: Own Our Own Health, Becoming Canada’s Healthiest Community.
- *Mission*: A healthy community culture where health = physical + mental + psychosocial health, where we connect health and healthcare efforts, where social determinants of health matter, and where individuals can own their own health.
- *Outcomes and Shared Benefits*: Community engagement, well-being, health outcomes, efficiency and resource utilization, economic benefits.

The Community Health Plan had *four interconnected strategies*:

- Connecting the Dots for Health, with Blue Zones Project as the framework for driving multi-sector impact on health determinants with measurable correlations to reductions in need for healthcare services
- Meeting Needs in New Ways for innovations to connect, reconfigure and enhance community health and social services and healthcare services
- Digitally Connecting and Engaging Individuals and Our Community



”I would like to be healthy / healthier, but I don’t know how;” “I can’t afford the gyms, community services and healthy foods in Airdrie;” “I need help to be healthier;” “I don’t know what services are here;" “what I experience are services that don’t work together;” “we lack a range of local services and affordable housing.”

Fig. 52.3 Community input 2018

- Supporting Our Community Plan with partnerships and vehicles for community leadership.

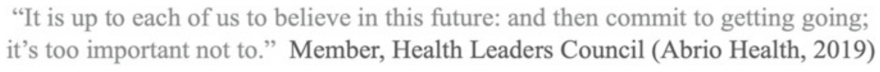
This Community Health Plan continues to guide our work, with annual updates to the community. Momentum is building as indicated in support for this plan, Fig. 52.4.

52.5 Aspirations Advanced by Blue Zones Project

Blue Zones Project is a community-led health improvement framework designed to make healthy choices easier by permanently improving our living environments. Established in 2010, Blue Zones Project is based on research by Dan Buettner, a National Geographic Fellow who identified five cultures of the world—or blue zones—with the highest concentration of people living to 100 years or older. Blue Zones Project incorporates Buettner's findings and works with cities to implement policies and programs that will move a community toward optimal health and well-being. The community was impressed by changes to improve health status and reduce healthcare costs across communities in the USA (some examples, Blue Zones Project 2016, 2018; Weiss 2018; Sears et al. 2013).

The program has *four integrated components*:

1. An evidence-based methodology. Blue Zones Power 9® principles promote healthy behaviors through simplicity and connections to what matters for healthy living, addressing stakeholder expectations to learn what matters for health. As illustrated in Table 52.1, Power 9 principles align with modifiable factors for chronic disease prevention.
2. An all-in approach to community engagement to transform a community’s environment for health (one’s life radius), delivering on the community desire for broad community engagement. The methodology integrates evidence-based expectations that support environmental changes across three areas: policies, including built environments, food and food systems, alcohol and tobacco policies, and smoke-free environments; places including faith-based organizations, schools, worksites, grocery stores and restaurants; and people, with strategies to engage individuals about their health, including the personal pledge, and for interpersonal connections and to create momentum with a broad range of community and civic organizations, like Purpose Workshops and Moais®.



“It is up to each of us to believe in this future: and then commit to getting going; it’s too important not to.” Member, Health Leaders Council (Abrio Health, 2019)

Fig. 52.4 Community aspiration, health plan 2019

Table 52.1 Alignment of Blue Zones Power 9 principles with risk factors for chronic disease

Blue Zones Power 9 (grouped in 4 categories)	Modifiable risk factors for chronic disease
Move naturally	Lack of physical activity, stress
Right outlook: Downshift, purpose	Stress, mental well-being
Eat wisely: 80% rule, plant slant, wine @ five	Nutrition, obesity, mental well-being
Connect: Loved ones first, belong, right tribe	Stress, mental well-being

Table 52.2 Alignment of Blue Zones Project's policy, places, people interventions with risk factors for chronic disease

Blue Zones Project intervention areas	Modifiable risk factors for chronic disease
Policy: Built environment, food, alcohol and tobacco	Physical activity, nutrition, obesity, stress and mental well-being
Places: Faith-based organizations, grocery stores, restaurants, schools, worksites	Nutrition, physical activity, stress and mental well-being
People: Engagement activities, personal pledge	Stress and mental well-being, loneliness

As illustrated in Table 52.2, addressing policy, places and people also aligns with modifiable factors for chronic disease prevention.

Following a Foundation Phase where the community is assessed for strengths, challenges and opportunities, a blueprint is developed in conjunction with community leaders using well-being indicators (denominators for change). This blueprint is the roadmap for change that guides transformation activities for multiple years. Defined methodologies (certification tools and improvement targets) for each area galvanize shared accountability toward the goal of becoming a Certified Blue Zones Community®. Specific time frames drive a sense of urgency and facilitate milestone completion.

This approach drives multi-sector engagement and empowers informal connections and "networks for health." These are keys to such health issues as mental well-being, loneliness and social isolation for persons living with challenges or for informal caregivers and aging adults. This multi-sector framework also means that what adults experience at work, in the community, and the grocery store aligns with what their children would experience in a school.

3. Measurement for individual, organizational, community and system learning: Blue Zones Project measurement methodology will bring meaning to targeted outcomes in the Community Health Plan. Their Simulation Model to project future impact on healthcare utilization and costs was of major interest. Representatives shared possibilities for impact in this community based on their rich data set of outcomes across 50 communities and health indicators and healthcare utilization by Airdrie residents. Their model projected reduced healthcare service utilization, improved productivity in local workplaces and enhanced regional economic development totaling over $100 M (CDN) annually, as early as seven years after implementation.

4. Implementation through community-based leadership. Each community has a steering committee of local leaders and sector work groups that are responsible to lead implementation of the blueprint for their respective areas and monitor success toward the goals of becoming a certified community.

These possibilities, combined with the systematized process for Airdrie residents to own their health improvement, were compelling for the community, and the overwhelming consensus was to proceed. Abrio Health has entered into a contractual agreement for Blue Zones Project® by Sharecare.

52.6 Blue Zones Project Airdrie Implementation

Blue Zones Project Airdrie was announced June 2019. "*Own our Own Health, Becoming Canada's Healthiest Community" becomes tangible: "Becoming Canada's First Certified Blue Zones Project Community."*

Airdrie would be the first implementation of this comprehensive health improvement initiative in the context of a single-payer, publicly funded healthcare system. Airdrie is recognized as an innovation project and contemplates three collaborators: The City of Airdrie for its municipal leadership, local policies and responsibilities related to the built environment; Alberta Health Services (AHS) for its healthy community policies and expertise and information regarding healthcare outcomes and costing; and Alberta Blue Cross (a nonprofit wellness organization and health insurance provider) as the measurement partner and healthy workplace thought leader.

This innovation project will deliver:

- A Canadianized adaptation of pledges, policy menus and reporting language integrated into certification materials
- A measurement methodology adaptation for Canada, with all data collected remaining within Canada and applicable to Canadian healthcare systems and
- A demonstration in Airdrie for the benefit of this community, with learning for potential application of this methodology beyond this community.

Implementation began on September 2019. The *Foundation Phase* (typically 8–10 months) involved hiring and training a *local* team, adapting materials, developing local leadership groups, and engaging citizens and organizations to identify priorities for action.

The first phase ends with a community blueprint for action. A community-wide launch will mobilize implementation, the largest community engagement in this city's history. The *Transformation Phase of community-led action follows* (approximately two years) with progress measurement guiding and nudging action. This ends with an assessment regarding completion of blueprint requirements for certification. Planning for sustainability will be ongoing through implementation.

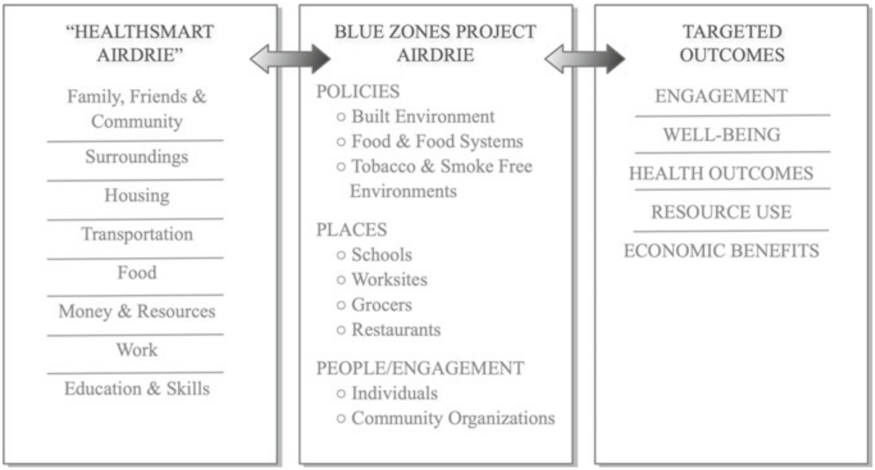


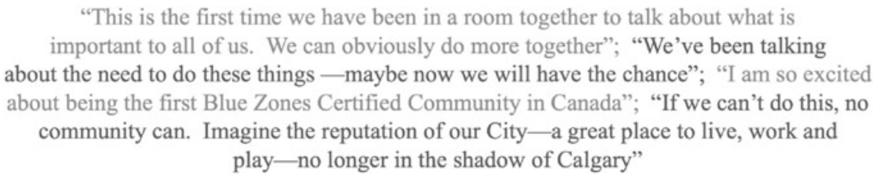
Fig. 52.5 HealthSmart Airdrie imapcts blue zones project Airdrie

The local team will build on work in Airdrie to engage citizens in understanding implications of Social Determinants of Health (SDOH). In 2018, the city, in collaboration with Abrio Heath and their proposal to the Federal Government's national Smart Cities competition, began to socialize a framework for SDOHs, HealthSmart Airdrie (Airdrie 2018). Figure 52.5 provides a description of the eight SDOHs included in HealthSmart Airdrie. During the Transformation Phase, the team will examine linkages between these elements as one input into Blue Zones Project Airdrie. They will also document community assets (formal and informal) to populate an inventory of resources, organized by categories reflecting HealthSmart Airdrie. This will support action to enhance community capacity for health.

Measuring population well-being occurs through a community-wide survey, unique to, and comparable with, the program implemented in 50 other communities. This includes elements shown to have the greatest impact on well-being: purpose, social, financial, community and physical. This assesses impact of change initiatives, resulting in a Community Well-Being Index (CWI) score. Recent work by Sharecare with Boston University continues to support the use of the CWI to monitor community progress and the social determinants of health.

Airdrie's initiative is funded by partners (funding from the city; in-kind by Alberta Blue Cross), community granting bodies and private donors who believe in the importance of developing healthy communities as the base for a sustainable healthcare system.

As of November 2020, physical *distancing* measures related to the COVID-19 *pandemic* and shifts in priorities of local businesses have made it impossible to continue with Blue Zones Projects Airdrie.



"This is the first time we have been in a room together to talk about what is important to all of us. We can obviously do more together"; **"We've been talking about the need to do these things —maybe now we will have the chance"**; "I am so excited about being the first Blue Zones Certified Community in Canada"; **"If we can't do this, no community can. Imagine the reputation of our City—a great place to live, work and play—no longer in the shadow of Calgary"**

Fig. 52.6 Community engagement and momentum 2020

However, the first four months of learning and input through *Blue Zones Project Airdrie* had an impact as illustrated by comments in Fig. 52.6: Learning has been significant and will guide future community work

52.7 Abrio Health Experiential Insights

Our first insight: Challenges of implementing a grassroots approach for community health have been many, and we know there will be more.

We have moved from planning by the organization and bringing plans to the community to being community driven (from/with/by the community). At the same time, individuals and organizations are busy with their own work; potential collaborative projects have been perceived as getting in the way of their own priorities or mandates. This is changing with time as the community's aspirations and opportunities become clearer, but requires consistent engagement, shared learning, striving for mutual value and time to build /rebuild relationships and trust.

Our second insight: *Organizational theory about aligning structure–process–outcomes applies, but with differences.*

Community aspirations are needed to inform structure, with frameworks and supports for community work. Together, they guide processes for engagement and change. The resulting cycle for healthy community development is illustrated in Fig. 52.7.

1. *Community Aspirations for Health*. Discussion over *four years* created focus, increasing trust and community readiness for change.
    - The vision, "Own Our Own Health, Becoming Canada's Healthiest Community," mobilized initial action and the desire to be Canada's first Certified Blue Zones Project Community.
    - The mission is informing our language and work.
    - Outcomes informed the choice of Blue Zones Project, with its ability to bring meaning to shared benefits.

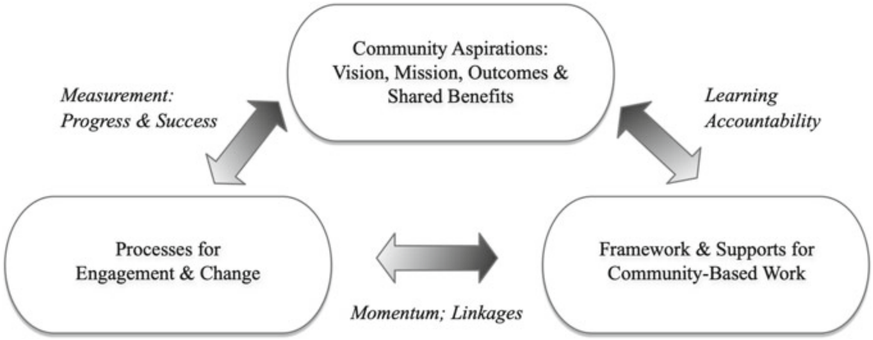


Fig. 52.7 AbrioHealth, healthy communities development cycle

2. *Framework and Supports for a Community Focus on Health.* Airdrie, like many communities, did not have infrastructure for community-wide action related to health. Today, this includes:

   - *A community-based organization* as a catalyst and support for activities toward the vision. Abrio Health provides strategic engagement and advocacy, ability to create contracts and partnerships for community development, and capacity for fund development for community-focused initiatives.
   - A *Community Health Plan* to create momentum, linking community initiatives across four strategies. It is a point of interface for all community initiatives and creates shared understanding, a key component for collective impact. Critical to this plan was stewardship for development by the Partnership Committee, with continued oversight by the Health Leaders Council (committees of community and health leaders).
   - *A capacity to be data driven and technology-enabled* to inform planning and accountability and to optimize digital tools for individual and community health in collaboration with partners.

3. *Processes for Engagement and Change*. As described in Table 52.3, processes align with the five principles in Alberta's Healthy Communities Approach (Alberta Healthy Communities). Blue Zones Project's approach aligns with each principle, a factor in selecting the project as a partner.

Resources included the local Blue Zones Project team and a small staff for Abrio Health (CEO, Operations Director, Chief Technology Officer and consulting resources for areas such as fund development) plus Abrio Health Board volunteers and community members on committees. Abrio Health had initiated contact with academic partners to provide external perspectives to Blue Zones Project Airdrie implementation and learning for our journey.

Table 52.3 Alberta's healthy communities approach: alignment with processes underway in Airdrie

1. Community and citizen engagement	• Consultations to develop and sustain community health plans • Community involvement to engage Blue Zones Project and to co-create project results • Digital engagement tools, in development
2. Multi-sectoral collaboration	• Health Leaders Council oversight for Community Health Plan • Engagement of local organizations in project advisory mechanisms
3. Asset-based community development	• Community Health Plan with holistic view of community activities • All-in approach of Blue Zones Project (policy, places, people) with SDOHs, plus a multi-factored measurement framework
4. Political and system commitment	• Partners from the outset: City of Airdrie, Alberta Health Services and Alberta Blue Cross
5. Healthy public policy	• Blue Zones Project Airdrie Outputs: community-based policies to enhance capacity for healthy built environments, food and food systems, and tobacco and smoke-free environments • As a final analysis, the community will have a lens to capture implications for provincial policies that impact the ability of the City of Airdrie and community stakeholders to implement and sustain strategies for healthy communities

Our third insight: *Developing a system to measure results is multifaceted.*

1. *Implementing targeted outcomes in the Community Health Plan to measure progress and impact requires measures that come from the community.* Development work benefited from partnerships with ABC and AHS enabling access to and use of data, resources and tools allowing for scalability and spread across Alberta. Initiatives included:
   - Digitizing engagement tools
   - Developing mechanisms to collect and share well-being and health risk/outcome data with individuals in the community and aggregate these data for community learning and monitoring
   - Aggregating relevant secondary data related to health outcomes and health-care utilization
   - Refining and enhancing community simulation models to project longer-term impacts on healthcare costs and economic gain.
2. *The community is also learning that the dynamics of engagement and change to become a healthy community require the need to think about, prepare for and capture immediate, near-term and long-term gains.*

- *Immediate benefits* include community learning about local organizations, citizen perspectives about needs and new ways of thinking about health and configuring health and healthcare services. Creating safe places for input and learning, such as Blue Zones Project Airdrie engagement to date mobilize change.
- *Near-term (3–5 years) gains* come through tangible actions based on the blueprint for change and other developments that are occurring through the Community Health Plan.

  At the end of three years, the intent was that this community will have demonstrated a comprehensive process to mobilize a healthier community. *Engagement indicators* would show increasing participation of individuals and organizations for health and new policies for healthy environments; the *Community Well-being Index* would show change and allow comparisons with other Blue Zones Project communities; and there would begin to be movement in key *health outcome measures*. These results would inform community eligibility for Blue Zones Project Community Certification and planning for ongoing sustainability.
- *Longer-term gains (5–10 years and beyond) bring focus to the final two outcomes, efficiency and resource utilization and economic benefits.* These would come from the foundations for change established and sustained from the first 3+ years. The Simulation Model has the capacity to project impact for healthcare savings, business productivity and local and regional economic growth (and to update initial projections noted at the end of Section 5).

Our final insight: Determining the value of this initiative is based on a philosophy of action learning through a journey of change.

- The Blue Zones Project Airdrie team would monitor process-related feedback for ongoing improvement and learning for other communities.
- The Community Steering Committee would monitor progress and outcomes related to the blueprint, with the initial targets for policy, places and people interventions, to become a Blue Zones Project Certified Community (as outlined above).
- Abrio Health, through the Health Leaders Council, would monitor opportunities to integrate and support Blue Zones Project principles in other development initiatives, broadening impact and enhancing sustainability of community transformation objectives.
- The community recognized that making fundamental and sustaining change to shift environments and practices for health is a long-term journey. This project was designed to show changes in Airdrie at the end of the Transformation Phase. The hypothesis was that comparisons with US experiences would demonstrate likelihood for ongoing, positive change and guide future investment to sustain and deepen changes.
- Finally, development of an analytic simulation model would show the correlation between community health activities and policy changes with optimized

healthcare system utilization, improved health outcomes and ultimately decreased healthcare system costs. This would have been key to showing the validity and value of the Blue Zones Project approach in a publicly funded health care system.

52.8 Perspectives: Healthy Citizens, Sustainable and High Performing Systems—We Can Have Both WHEN….

The authors posit that the RESET Button for a system focused on health and wished for in the introduction to this chapter is beyond a single "button," but rather a "RESET DIAL."

Based on this community's experiences, the authors suggest that there are *five functions on the RESET DIAL which are interrelated and need to move strategically and concurrently for desired impact*. This DIAL embodies inter-sectoral actions as envisioned in the reports of the late 2000s and aspirations and actions for health system reform underway in pockets across this country.

This multi-function RESET DIAL is illustrated in Fig. 52.8.

Function 1, developing community capacity for health, is seen as a foundation for our desired future. Functions 2 and 3 reconfigure and integrate community-based supports and healthcare services for improved results. "White zone functions" underpin individual, organizational and system capacity for health: Function 4 optimizes digital tools across all initiatives, and Function 5 aligns federal and provincial expectations and funding for health.

Three factors are important if community capacity for health is to become a foundation for systems focused on health:

1. *Placing a priority on funding evidence-based and measurable health promotion and disease prevention initiatives.* In so doing, incentives (with funding) need to be provided for community-based initiatives that enhance capacity for health. The impacts of mobilizing action related to community capacity for health, and thereby impacting health care use and costs, are too important to be left to ad hoc demonstration initiatives supported by ad hoc funding.

Fig. 52.8 REST DIAL for healthy individuals and sustainable healthcare

Based on outcome data from Blue Zones Project's implementations and system-impact algorithms, it is possible for increased expenditures impacting health determinants to create opportunities for future *re-allocation* of resources currently in the system, not additive to the increasing costs associated with healthcare provision.

The demonstration initiative in this case study is one example of a comprehensive approach to transforming a community environment for health and moving toward an integrated health and healthcare system with improved performance.

2. *Implementing "loose, tight" system governance and working relationships*. "Loose relationships" encourage community engagement and ownership; "tight relationships" may be more appropriate for horizontal and vertical integration of care services.

Success in this case study has been this community's ability to develop a vision for health, organize for that and implement a major health improvement initiative. At the same time, the community sees itself contributing to the aspirations of this province and a healthcare system for "healthy Albertans in a healthy Alberta."

This experience aligns with work of the Tamarack Institute regarding the concept of "loose/tight working relationships," with loose relationships most helpful with high leverage opportunities for change (Cabaj and Weaver 2016).

3. Aligning cross-ministry policies that influence individual and community capacity for health.

An analysis of policy implications from local perspectives would have been undertaken concurrently with Blue Zones Project Airdrie.

Support and collaboration of the City of Airdrie, Alberta Health Services and Alberta Blue Cross for Blue Zones Project Airdrie have been key to community gains and learning for other communities. Abrio Health looks forward to continuing this journey with service transformation initiatives (Functions 2, 3 and 4) which leverage unique opportunities in this community.

SO—can there be a future with integrated systems focused on health and where we have both healthy/healthier individuals and improved health system performance? YES, WHEN all functions on the RESET DIAL work together for health.

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Switzerland

53

Séverine Schusselé Filliettaz, Peter Berchtold,
and Isabelle Peytremann-Bridevaux

53.1 Health Care in Switzerland

Switzerland includes three main linguistic regions (German, French and Italian) and comprises a population of about 8.5 million in 26 cantons (FSO 2019). It is a democratic federal state in which government responsibilities are divided among three levels: federal, cantonal ($n = 26$) and municipal ($n \geq 2500$). The Swiss healthcare system is highly decentralised, with each of the 26 cantons responsible for securing healthcare provision for their populations.

Cantons finance about half of hospital costs and are in charge of issuing and implementing the majority of federal health-related legislations; they also carry out prevention and health promotion activities (OECD and WHO 2011; De Pietro et al. 2015). Outpatient services are financed through the mandatory health insurance, which also covers half of the expenditure of inpatient services, using diagnosis-related group (DRG). Individual health insurance contributions are independent of income and are only subsidised if they exceed 8% of taxable income. There are around competing 30 insurance companies offering mandatory as well as private schemes to the Swiss population.

Ambulatory medical care is provided by primary care physicians and specialists working mostly independently in private practices, but also in group practices, in networks of physicians and sometimes in health maintenance organisations that rely on the principles of managed care; hospitals also provide regular general and

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specialised ambulatory care. Other outpatient care providers include mainly private pharmacies, an array of therapists in private practices and both private and public homecare services. Residents have direct and unrestricted access to primary care physicians and specialists. The important exception is those who have opted for an alternative health insurance plan (approximately two thirds of insured residents of Switzerland) (De Pietro et al. 2015), which offers lower premiums for those signing up to voluntary gatekeeping. Other therapists' care as well as medicines will only be included in the insurance scheme if prescribed by a physician. Inpatient care is provided by public and private hospitals that receive financial subsidies from the state if they are considered of "public interest".

In 2017, the costs of health system benefits have amounted to 12.3% of the gross domestic product, ranking second within the OECD countries. Total (public and private) healthcare expenditures were mainly devoted to ambulatory care (26.5%), inpatient hospital (19%) and long-term care (19.3%). Healthcare expenses are mainly financed by the mandatory health insurance (35.8%), by households (28.6%, e.g. out-of-pocket payments such as co-payments, deductibles, uninsured services and drugs, complementary private insurance) and by direct government spending (18.1%) (Andreani and Marquis 2019).

Because of the high level of decentralisation, governance of the system at the national level is weak (Quentin and Busse 2018). Several reform attempts have been made to strengthen the system governance and to build a national consensus on health care in Switzerland, but this has remained challenging (Cheng and Zeltner 2010). While consensus building has been successful with regard to hospital care financing, involving a shift from a daily-tariff system to a national DRG system ("SwissDRG") in 2012 (De Pietro et al. 2015), this has been difficult to achieve in other areas. In 2012, for example, both reform proposals that aimed to develop care integration, introduce population-oriented services and strengthen efficiency and cost containment, as well as a health promotion and prevention law, were rejected. In 2014, an initiative suggesting to replace the health insurance system run by more than 60 private insurers by a system run by a single public insurer was also rejected (De Pietro and Crivelli 2015).

In 2013, the Federal Council approved the comprehensive strategy "Health 2020" (Federal Office of Public Health 2013), which was the first overarching national health policy in Switzerland. Focusing on four domains (maintaining quality of life, increasing equal opportunities, raising quality of care and improving transparency), the overall objective of the "Health 2020" strategy was to prepare the Swiss health system for the challenges ahead, at affordable costs. Several disease-centred programs emerged from this strategy, such as the Addiction strategy, the Palliative care strategy and the Cancer strategy (von Wartburg and Näf 2012; Federal Office of Public Health 2015; Federal Office of Public Health and CDS 2018). This "Health 2020" strategy was replaced by the "2030 Swiss health strategy" (Federal office of public health 2019), which includes eight objectives broken down into political axes, one of which calling for the "Reinforcement of care coordination". This strategy builds upon a recent move towards care integration in Switzerland, with federal inputs such as the "Coordinated Care" project (von

Wartburg 2016; Federal Office of Public Health 2016) as well as the "Promotion of Interprofessional Collaboration in Health" programme (Federal Office of Public Health 2017). At the cantonal level, while only few cantons had already been building up strategies (see below), the Swiss Conference of the Cantonal Ministers of Public Health published in 2019 a guide to help cantons implement care integration (Berchtold et al. 2019).

53.2 Swiss Integrated Care in Practice

Integrated care in Switzerland can be traced to physicians' networks that were first initiated in 1992 (Réseau Delta in Geneva) (Schaller 2008) and amounts approximately to 75 networks including approximately 50% of all general practitioners (GP) in Switzerland (Berchtold and Peytremann-Bridevaux 2011; Hostettler and Kraft 2018). Networks work on the principle of GP gatekeeping, and almost all have contracted with health insurances funds in which they assume budgetary co-responsibility.

There has then been increasing interest towards programmes to strengthen coordination of care for patients with one or more chronic diseases (Peytremann-Bridevaux and Burnand 2009; Berchtold and Peytremann-Bridevaux 2011) with a 2013 survey identifying 44 small-scale programmes targeting chronic diseases or multimorbidity in 14 of the 26 cantons (Ebert et al. 2015; Peytremann-Bridevaux et al. 2015).

In 2015, the Swiss Survey of Integrated Care (SSIC) was jointly initiated by the University of Lausanne, the Forum Managed Care and the Swiss Health Observatory. The objective of this survey was to produce a comprehensive overview of integrated care initiatives in Switzerland. Integrated care initiatives that met the following four criteria were included: (1) presented some type of formalisation, (2) considered at least two different groups of healthcare professionals, (3) integrated at least two healthcare levels, (4) were ongoing during the survey period. Data from 155 initiatives were gathered (Schusselé Filliettaz et al. 2017; 2018; Gilles et al. 2020). While some results will be described thereafter, brief descriptions of several initiatives are provided in textboxes; they were chosen for the purpose of illustrating the heterogeneity of care integration in Switzerland.

Box 53.1 "Mental health & psychiatry", example

Integrated Psychiatry and Addiction Care Winterthur (IPW)

This public organisation started before 1990 and focuses on persons with mental health issues. It includes 15 regional settings offering inpatient and outpatient services by various professionals (physicians, nurses, social workers, pharmacists, other therapists). Together with the patients and their environment, IPW develops goals that are based on their possibilities and resources. Interprofessional processes between different professional groups are promoted: they include the referring physicians, other specialists and organisations. IPW also facilitates transitions when patients navigate back and forth between the community and inpatient services.

www.ipw.ch.

Box 53.2 “Physicians networks”, example

Pizol care

A physicians’ network founded in 2000 and including around 100 general practitioners, specialists with their own practices and hospital doctors, together with medical assistants, nurses, nutritionists and physiotherapists.

The network offers specific care/case management, disease management and medication management models. Guidelines as well as quality circles are used for quality improvement.

www.pizolcare.ch.

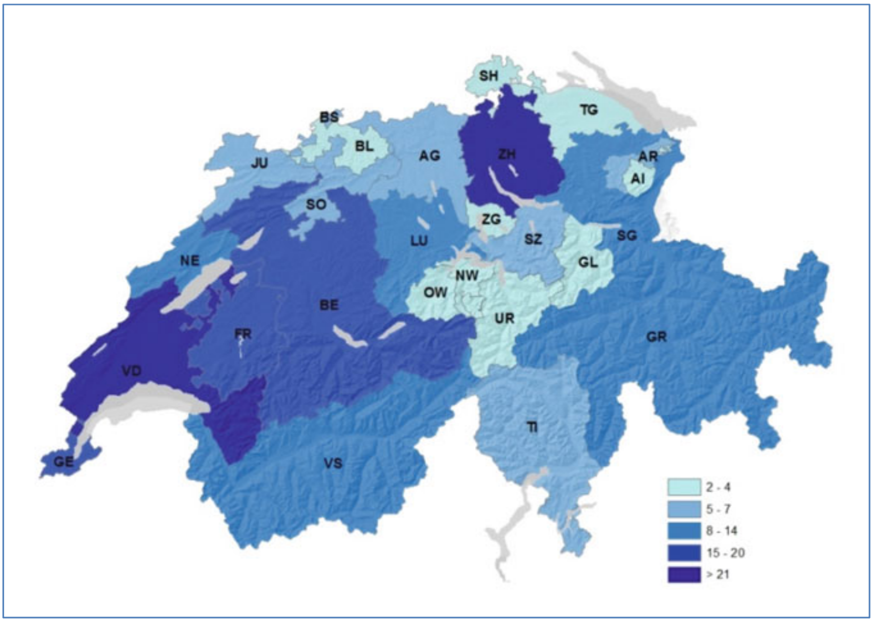
53.2.1 Number and Types of Integrated Care Initiatives

In most cases, initiatives were limited to cantonal borders. Indeed, only 25 of the 155 initiatives were active in several cantons, including two covering the whole country. While all 26 cantons had a least two initiatives, Zurich and Vaud had the highest number of initiatives, with 31 and 40, respectively (Fig. 53.1).

While the implementation of integrated care had been steadily raising since the 1990s (Fig. 53.2), upwards trends started later in the French/Italian-speaking region of Switzerland and eventually surpassed in 2012 the number of initiatives present in the German-speaking region.

The 155 Swiss initiatives were divided into the following six categories:

1. “Health centres”: Initiatives including several structures and levels of health care under the same governance, such as primary health care (physician or other), specialised outpatient care (physician or other) and inpatient acute care. This category does not include psychiatry or mental health initiatives (see below).
2. “Physicians networks”: Networks of general practitioners and/or family doctors and/or medical specialists, who develop/use guidelines and organise quality circles.
3. “Specific target groups”: Initiatives targeting more than one somatic condition or specific patient group (except psychiatry or mental health—see below).
4. “Mental health & psychiatry”: Initiatives targeting psychiatry (as a whole or a specific pathology) and/or mental health.
5. “Medicines”: Initiatives targeting treatment/drug management and/or reconciliation.



Source: Swiss Survey of Integrated Care

Fig. 53.1 Absolute number of initiatives per canton (n = 155). *Source* Swiss Survey of Integrated Care © Obsan 2017

6. “Transition & coordination”: Initiatives focusing on transition/coordination activities between several organisations/levels of health care, such as case/care management, interprofessional and interinstitutional care teams.

The implementation of the six categories of integrated care initiatives over the last 26 years showed heterogeneous trends (Fig. 53.2). The “Health centres” initiatives were the most frequent in 1990 and went through an almost four-fold increase until 2016. The first “Transition & coordination” initiative was launched in 1994 and intiatives in this category went into a much higher increase until 2016. Furthermore, while “Specific target groups” and “Mental health & psychiatry” initiatives were rare in 1990 and increased by more than ten-fold over the last 26 years, the number of “Physicians networks” remained very stable.

Box 53.3 “Specific target groups”, example

Wound care service, Regional Hospital of Mendrisio Beata Vergine

This outpatient clinic started in 2010. It is available both for patient admitted to the various wards of the hospital and for outpatients sent by external doctors, long-term institutions and homecare services. It pays particular attention to the continuity of care, through close collaboration with

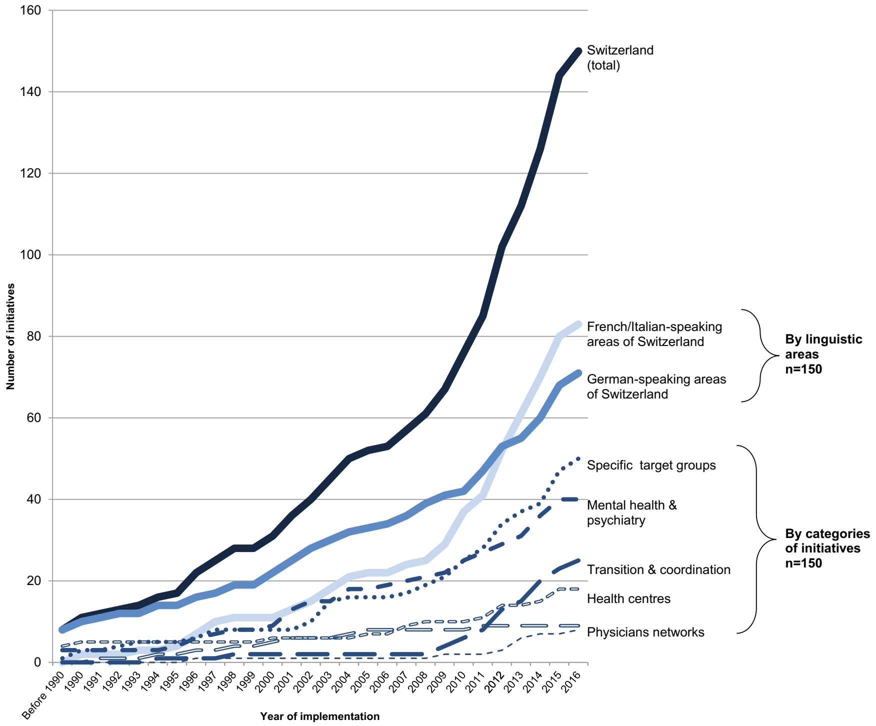


Fig. 53.2 Cumulative number of initiatives: Overall, by linguistic areas and by categories of initiatives (from before 1990 and 2016). Reprinted from Schusselé Filliettaz et al 2018, Fig. 53.2, with permission from Elsevier, License Nr. 4743740605260

patients, inpatient and primary care services: for instance with hotline for patients, telemedicine services and care/case management. It started in 2010.

www.eoc.ch/Ospedali-e-Istituti/Ospedale-Regionale-di-Mendrisio/Consulenze/Cura-ferite.html.

Box 53.4 “Health centre”, example

Cité générations

A private health centre built in 2012 and hosting more than 30 medical (family and specialist) independent practices, a pharmacy, a radiology, a short-stay medical unit, a physiotherapy and a nursing centres, an emergency service and two teams of the public homecare service.

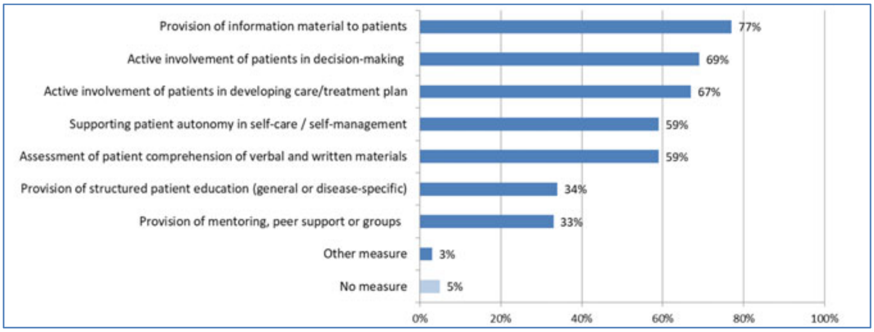
Most health professionals share the same electronic medical record, thus easily accessing patient's data and communicating with each other. Integrated pathways for specific diseases (eg. diabetes, hypertension) coexist with care/case management models for frail patients and with the implementation of interprofessional and interinstitutional coordination processes for complex needs patients.

www.cite-generations.ch.

53.2.2 People-Centeredness of the Initiatives

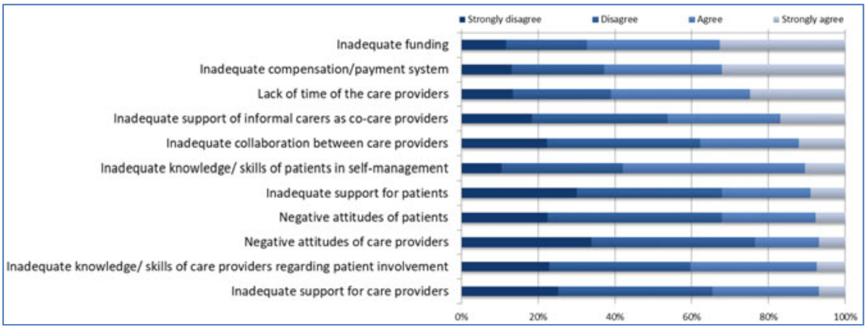
Except for 5% of the identified initiatives, all implemented different types of measures to encourage greater patient involvement in their own care (Fig. 53.3). In fact, the majority of initiatives provided information documents to their patients, and they also promoted active participation of patients in decision-making and in the development of care/treatment plans; structured learning and tutoring schemes were only available in one third of initiatives.

Respondents were also asked to report the extent to which specific difficulties hindered patient involvement or a patient-centred approach (Fig. 53.4). The majority of respondents (62.8%) reported inadequate compensation/payment systems as barriers; lack of time of the different care providers was also highlighted as a barrier by just over 60% of the respondents.



Source: Swiss Survey of Integrated Care

Fig. 53.3 Measures to involve patients, % of initiatives (n = 140–142). *Source* Swiss Survey of Integrated Care © Obsan 2017



Source: Swiss Survey of Integrated Care

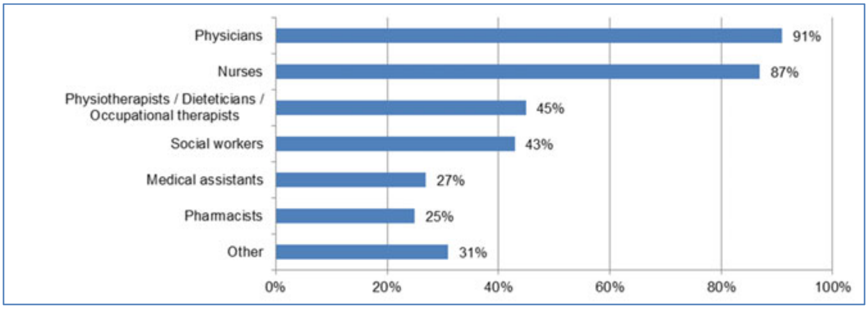
Fig. 53.4 Perceived barriers to patient centeredness, % of initiatives (*n* = 136–149). *Source* Swiss Survey of Integrated Care © Obsan 2017

53.2.3 Professionals Involved & Interprofessional Practices

Physicians and nurses were the most frequent professional groups involved in the initiatives (Fig. 53.5).

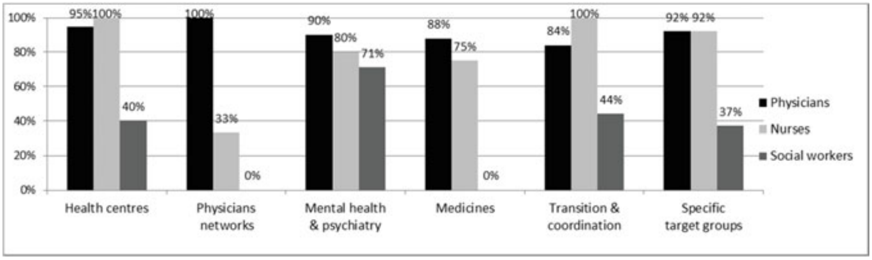
However, professional groups were diversely involved in the categories of initiatives. Figure 53.6 illustrates, for example, the involvement of physicians, nurses and social workers. It shows that social workers were involved in more than two thirds of the "Mental health & psychiatry" initiatives, but were absent from both "Physicians networks" and "Medicines" initiatives.

Meanwhile, initiatives included specific elements designed to foster teamwork and cooperation within and between professional groups. For example, three out of four initiatives organised regular meetings between health professionals and/or offered multi/interprofessional training.



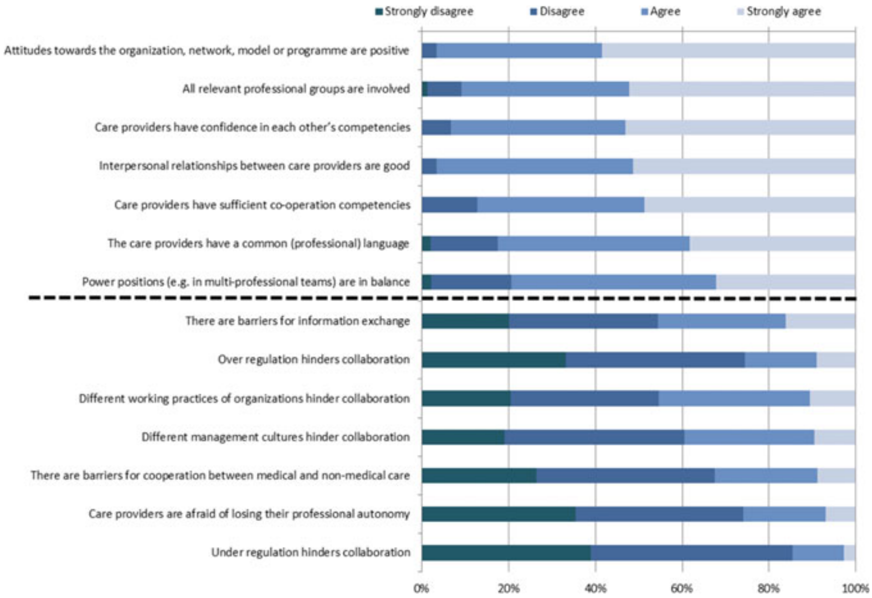
Source: Swiss Survey of Integrated Care

Fig. 53.5 Healthcare professionals involved, % of all initiatives (*n* = 155). *Source* Swiss Survey of Integrated Care © Obsan 2017



Source: Swiss Survey of Integrated Care

Fig. 53.6 Initiatives involving physicians, nurses or social workers, % by category (n = 155). *Source* Swiss Survey of Integrated Care © Obsan 2017



Source: Swiss Survey of Integrated Care

Fig. 53.7 Perceptions of collaboration between providers, % of initiatives (n = 144–153). *Source* Swiss Survey of Integrated Care © Obsan 2017

Despite of these measures, some barriers to interprofessional collaboration were highlighted (Fig. 53.7). For example, 45% of respondents still thought that interprofessional collaboration was hampered by difficulties in information sharing and by different work procedures between organisations.

53.2.4 Use of Clinical Information Systems

When asked about the use of clinical information systems in the initiatives, respondents mentioned three main communication tools: the electronic patient record, used in 77% of the initiatives; communication systems between healthcare providers, available in 58% of the initiatives; and email contacts between patients and providers, available in 44% of the initiatives. Other clinical information systems, such as electronic prescriptions, telemonitoring and teleconsultation, registries and on-line appointments, were available in one third—or less—of the initiatives.

Box 53.5 “Medicines”, example

Interdisciplinary therapeutic adherence program and risk management plan

This program started in 2013. It aims to support and to reinforce multimorbid patient medication adherence through a multifactorial and interdisciplinary intervention provided by a physician, a nurse and a pharmacist. Motivational interviewing is combined with medication adherence electronic monitors, and regular evaluations shared with involved actors.

https://dx.doi.org/10.1155/2015/103546.

Box 53.6 “Transition & coordination”, example

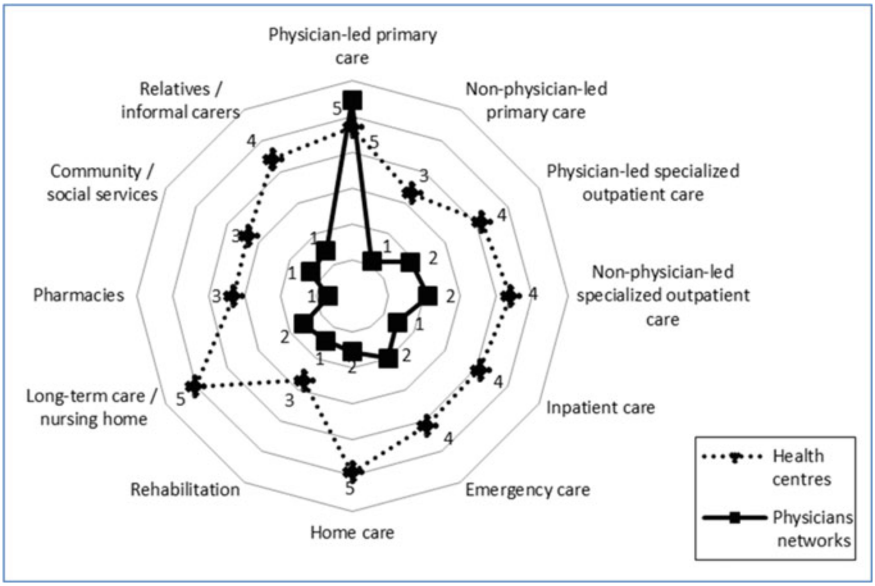
Association for health and social orientation (AROSS)

AROSS started in 2018 and aims to supporting elderly people in their choices, such as homecare, long-term care and social resources. AROSS also aims to support family carers and to coordinate action in favour of frail and/or dependent elderly people. AROSS professionals include physicians, nurses, occupational therapists and social workers, working in close collaboration with the actors already involved in the situation.

www.aross-ne.ch.

53.2.5 Integration Between Levels of Care

The levels of care between which the initiatives sought to improve integration are presented in Fig. 53.8. The latter, which presents two emblematic patterns, reflects the average number of times each level was integrated with another one: the larger the area covered, the greater the number and variety of levels integrated. The “Physician networks” mainly focussed on improving the integration of primary care by a physician with the other levels, while the “Health centres” targeted the integration of a broader range of levels within the health system.



Source: Swiss Survey of Integrated Care

Fig. 53.8 Targeted levels of care, average frequency by each initiative from the "Physician networks" category (n = 9) and from the "Health centres" category (n = 20). *Source* Swiss Survey of Integrated Care © Obsan 2017

53.3 Conclusion

This Swiss Survey of Integrated Care (SSIC) highlighted the existence of a number of integrated care initiatives. These results are encouraging and consistent with those obtained by other similar European projects (Nolte and Hinrichs 2012; Rijken et al. 2013; INTEGREO 2015; van der Heide et al. 2015; National Health Services Scotland 2017; SELFIE 2017; Borgermans et al. 2017).

The patterns of integrated care in Switzerland were rather heterogeneous: in the number of initiatives implemented in the various cantons and in the regions, in the chronological implementation of initiatives, in the number of healthcare professionals involved and in the healthcare delivery levels integrated. Because integrated care requires complex processes whose implementation remains highly context-dependent, this heterogeneity is probably very coherent with the Swiss federalist organisation.

This increase of care integration in Switzerland is probably due to a multitude of factors, such as: increasing burden of chronic diseases, multimorbidity and complex needs; increasing awareness of fragmentation and of the need for integration; interest of stakeholders in making their projects visible; better knowledge and skills of actors in the establishment and maintenance of integrated systems and increasing political support at the federal and cantonal levels.

However, a number of challenges remain in integrated care implementation, especially in terms of changes in organisation, practices and communication, as well as in resources for implementing and maintaining coordination activities. Integrated care also requires clear inputs from healthcare providers, patients and caregivers. Healthcare authorities must also show clearer and firmer political will that includes participative leadership, as much as they must develop an unequivocal vision about integrated care and the future of health care. Such a systemic approach, including change management, should allow a progressive but positive change in the organisation and provision of health care in Switzerland.

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Netherlands: The Potentials of Integrating Care Via Payment Reforms

54

The Case of Dutch Diabetes Care

Jeroen N. Struijs, Hanneke W. Drewes, Richard Heijink,
and Caroline A. Baan

54.1 Integrated Care in the Netherlands

This chapter provides insight in the potential of integrating care through payment reform in the Netherlands. We begin by briefly outlining the main characteristics of the Dutch healthcare system, which has been transformed into a system of managed competition in the past decade. We focus on health care, because our case study is situated in this setting. We then describe the implementation of the bundled payment for diabetes care as one main example of stimulating nationwide implementation of integrated diabetes care in the Netherlands. This case study is based on our previous work on integrated care and related issues, which we have described in detail elsewhere (de Bakker et al. 2012; de Bruin et al. 2013; Struijs 2013, 2015a, b; Struijs and Baan 2011; Struijs et al. 2010, 2012a, b 2015a, b; de Jong-van Til et al. 2013; Lemmens et al. 2015; Mohnen et al. 2015).

54.1.1 The Dutch Healthcare Reform in 2006: The Introduction of Managed Competition

In the past decades, the Dutch healthcare system has been gradually transformed into a system of managed competition in which market forces and competition play a prominent role (Van de Ven and Schut 2009). The introduction of managed

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competition provided a much more prominent role for the three market players in the system, i.e. the patients or consumers, the care providers and the insurance companies. The healthcare market consists of three interrelated subsidiary markets: the healthcare provision market, the healthcare purchasing market and the health insurance market (Fig. 54.1) (Van den Berg et al. 2014).

In the *health insurance market,* health insurers provide health insurance policies to all Dutch citizens. Since the introduction of the 2006 Health Insurance Act (Zvw), all health insurers are private companies and allowed to make a profit and pay dividend to shareholders (Scha¨fer et al. 2010). However, most health insurance companies operate on a non-profit basis. The content of the basic health insurance package to be offered by health insurers is determined by the government. Health insurers can however determine the content (and price) of any additional insurance packages, on which basis they can compete, in addition to the quality of care and the insurance premium. Following the 2006 reform, competition between health insurers led to all insurers incurring losses (Van de Ven and Schut 2009). Under the Zvw, insurers have an obligation to accept all applicants living in the Netherlands or abroad who are compulsorily insured under the Zvw (Van den Berg et al. 2014). To compensate insurers for enrollees with predictably higher care consumption and thereby to prevent risk selection, a risk equalisation scheme, which, through the Health Insurance Fund, distributes funds across health insurers on the basis of risk profiles of enrollees. Residents chose a health insurance policy with the insurer of their choice. They may change their insurer on an annual basis and about 6–8% of enrollees do so.

In the *health provision market,* healthcare providers deliver care services to services users. However, information on quality of care is still hardly available, although some websites, such as Kiesbeter.nl and VolksgezondheidEnZorg.info, provide basic information to inform consumer choice. The suboptimal information

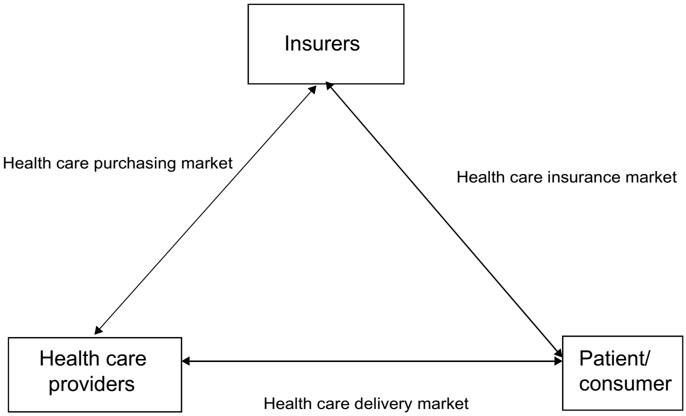

Fig. 54.1 Dutch healthcare system and its three interrelated markets. *Source* Scha¨fer et al. (2010)

on quality makes it difficult for the care consumer to make an informed choice regarding care providers. Besides GPs and other providers' advice, service users are increasingly using the Internet to look for information on care providers and quality of care.

In the *healthcare purchasing market*, health insurers aim to purchase good-quality services at competitive prices. In reality, purchasing services on the basis of quality remains a challenge, given the scarcity of robust information on care quality as mentioned above (Ruwaard et al. 2014), despite efforts by the government to make quality of care more transparent (Van den Berg et al. 2014). Possibilities for negotiating on the price of care were limited at the start of the 2006 healthcare reform, but have increased gradually over time. For instance, in 2006, about 7% of hospital care was freely negotiated, while in 2014, this figure was about 70%. For the remaining 30%, prices of hospital care rates are, at present, non-negotiable (Van den Berg et al. 2014). In pharmaceutical care, price negotiations between health insurers and pharmacies were implemented in 2012. Health insurers have restricted the reimbursement of pharmaceuticals to preferred medicines (mostly generics) in case a choice can be made between different brands. The price of GP services is negotiable for a small part only, and this is presently limited to multidisciplinary integrated care services [diabetes, chronic obstructive pulmonary disease (COPD) and vascular risk management (VRM)] are being negotiated, as we shall see below. Health insurers may also stimulate competition through selective contracting and substitution of care (e.g. services delivered by a nurse rather than a physician), although this option has not been implemented widely thus far.

54.2 Integrated Care in Practice

54.2.1 Problem Definition

The rising burden of chronic disease has been recognised as a challenge in the Netherlands, with for example about 4% of the population diagnosed with diabetes, and this proportion is expected to increase in the next coming decades (Van den Berg et al. 2014; Baan et al. 2009). This poses a major challenge to health services, in particular in combination with the rising prevalence of multi-morbidity, involving complex healthcare needs vis-a-vis a lack of coordination between different components and professional groups within health systems. In addition, there was evidence that the quality of care provided to patients with chronic disease was variable, with patients not receiving all the care they needed.

To address these challenges, the Dutch government initiated a range of policies. These included the introduction of integrated care programmes based on multidisciplinary cooperation in primary care, which sought to improve the effectiveness and quality of care and to ensure affordability. The first integrated care programme focused on diabetes care, based on the principles of a bundled payment, developed by the Netherlands Ministry of Health, Welfare and Sport (de Jong-van Til et al.

2013). The payment mechanism enables all the necessary services to be contracted as a single package or product. The aim of the new pricing model was to accelerate the implementation of diabetes care programmes, and those for other chronic diseases more widely. In 2007, groups of affiliated healthcare providers known as care groups began working with bundled payment arrangements for diabetes, initially on an experimental basis. In 2010, bundled payment for the management of diabetes, COPD and VRM was introduced as regular payment mechanism, although contracting under the previous pricing system involving is still permitted. By that year, there were about one hundred care groups operating integrated care programmes for diabetes, covering about 85–90% of all diabetes patients in the Netherlands (Mohnen et al. 2017) (see also Fig. 54.2).

54.2.2 Description of the Bundled Payment Model for Diabetes Care

In the Dutch bundled payment model, insurers pay a bundled payment to a principal contracting entity—the care group—to cover a full range of diabetes care services for a fixed period of 365 days. The care group, a new legal entity in the Dutch healthcare system, comprises multiple providers, often exclusively general practitioners (de Jong-van Til et al. 2013). By entering the bundled payment contract, the care group assumes both clinical and financial accountability for all diabetes patients assigned to its care programme. The contract is limited to general diabetes care provided in the primary care setting, that is services to manage the underlying disease and reduce risk for complications, and it does not include services to address complex complications that may arise. General decisions about services covered in the diabetes care bundle were made at a national level and, in 2007,

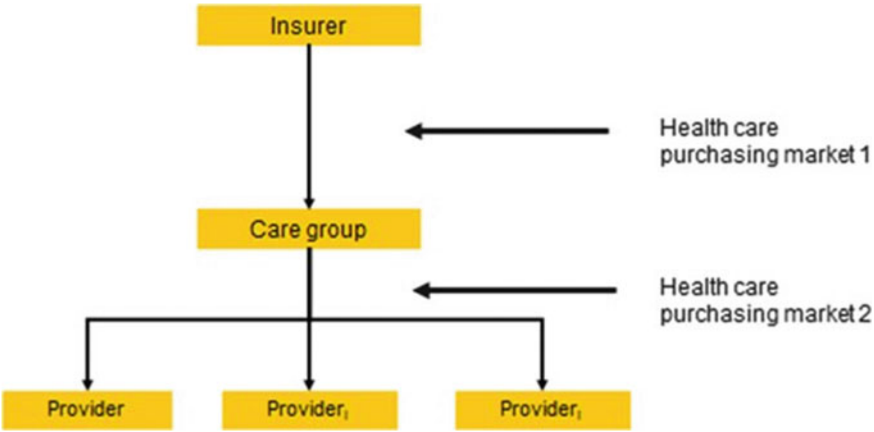

Fig. 54.2 Principle structure of the Dutch bundled payment model. *Source* Struijs et al. (2010)

codified in a Health Care Standard for type 2 diabetes (Dutch Diabetes Federation 2007). For the various components of diabetes care, the care group either delivers services itself or subcontracts with other providers (Fig. 54.3). Health insurers and care groups negotiate the price of the bundle, and the care group negotiates with the

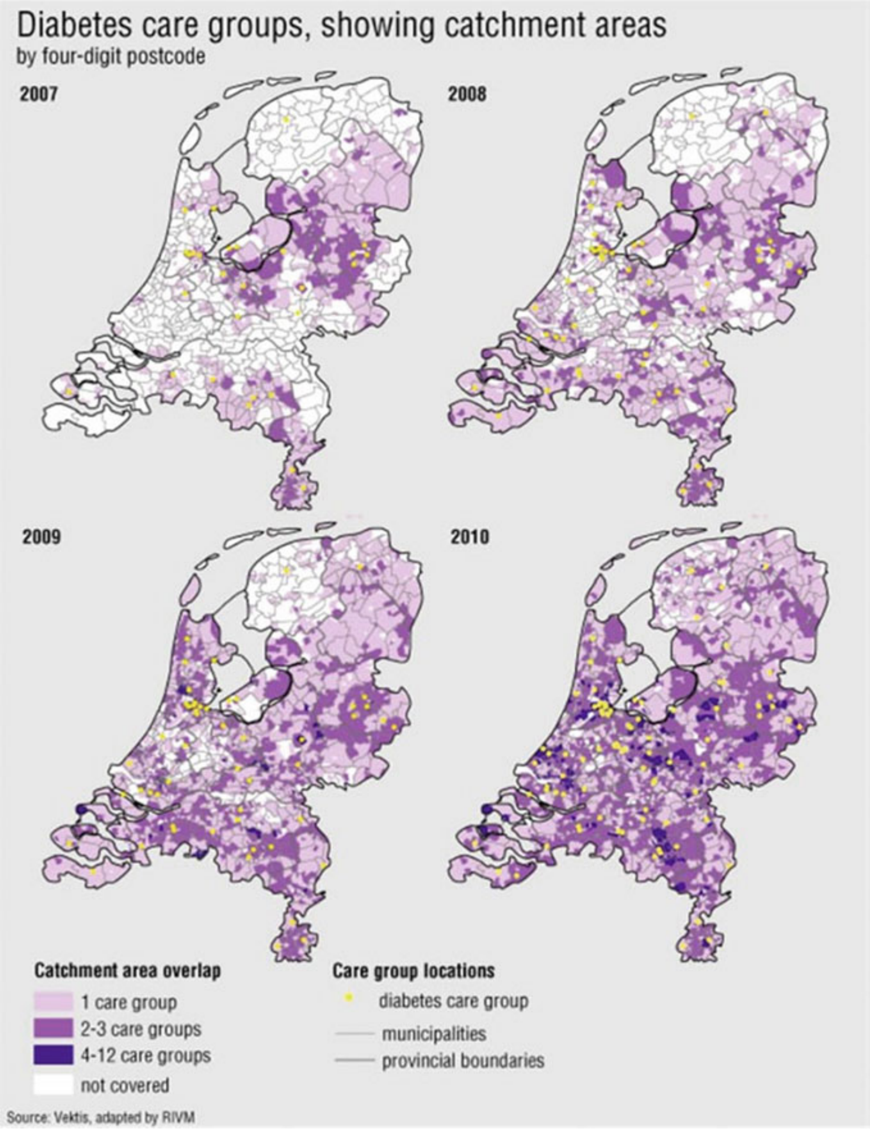

Fig. 54.3 Roll out of bundled payment model for diabetes care during 2007–2010. *Source* de Jong-van Til et al. (2013)

subcontracted care providers about fees for specific services. All services are covered under the basic insurance package for all Dutch citizens.

54.2.3 People Involvement/Service User Perspective

At national level, patient associations were actively involved in specifying the minimum requirements for optimal diabetes care. Patient associations agreed on the services described in the Diabetes Federation Health Care Standard (DFHCS), which sets the criteria on quality improvement (Dutch Diabetes Federation 2007). At regional level, patient involvement is mostly limited to care groups informing and consulting patients. Lemmens et al. (2015), in an assessment of patient involvement strategies employed by nine diabetes care groups, found that information was typically accessed through care groups' Websites, brochures or information letters provided upon enrolment into the care programme (Lemmens et al. 2015). They further reported that about half of the care groups also consult with patients through surveys, meeting with patient groups, or implementing patient panels. More direct forms of patient involvement, such as advising, co-producing and (shared) decision-making, do currently not appear to be regularly implemented by care groups. Lemmens et al. (2015) noted that there appears to be an implicit assumption among care groups and patient representatives that patient involvement is an instrument to improve (Raaijmakers et al. 2015) the quality of care and they are therefore committed to collaborate with each other but both parties found it difficult to translate this commitment into practice (Lemmens et al. 2015). At the same time, both groups expressed similar preferences regarding future themes for and shaping of patient involvement in the care group context, while there was agreement that several issues such as lack of evidence for effectiveness, differences in viewpoints on the role and responsibilities of care groups and perceived barriers for patient involvement would need to be addressed to take patient involvement to the next level (Lemmens et al. 2015).

54.2.4 Impact

The diabetes care groups were subject to multiple evaluations in terms of assessing the impact of the bundled payment on the healthcare delivery process, quality of care and medical spending (de Bakker et al. 2012; de Bruin et al. 2013; Struijs 2013, 2015a, b; Struijs and Baan 2011; Struijs et al. 2010, 2012a, b, 2015a, b; de Jong-van Til et al. 2013; Lemmens et al. 2015). These evaluations reported that care providers experienced improvements in the care delivery process due to the introduction of bundled payments and related care groups. Providers specifically mentioned that the coordination among care providers improved, as did protocol adherence, attendance at multidisciplinary consultations, and further training of subcontracted providers to facilitate protocol-driven work processes and the use of the electronic health records. For instance, a survey of providers in 2010 and 2013 found that, in 2013, some 89% reported that they perceived themselves to be working largely or completely in accordance with the Dutch Diabetes Federation Health Care Standard (DFHCS) compared to 79% in 2010 (Raaijmakers et al. 2015). It was also shown that in 2010, 3 years after bundled payments had been introduced, 66% of the care groups had implemented Web-based electronic health records (EHRs), requiring subcontracted providers to record their data (de Jong-van Til et al. 2013).

Studies further demonstrated that slight to modest improvements in outcome measures, such as percentage of patients with LDL-levels below target levels and percentage of patients with blood pressure levels below target level, were achieved during the first 3 years after the implementation of the bundled payment model (Struijs et al. 2010). In addition, fewer patients were found to have used specialist care that resulted in a reduction in diabetes-related outpatient specialist and inpatient diabetes hospital spending, but overall hospital care spending and consequently per-patient medical spending increased as compared to care as usual after a 2-year follow-up period (Mohnen et al. 2015). The observed increase in spending growth might have been due to the start-up costs of the bundled payment reform. Also, a 2-year follow-up period may have been too short to gauge the full impact of the bundled payment model as quality improvements within primary care tend to take time. Moreover, development and implementation costs were not included in these analyses, and such costs can be substantial. For example, Tsiachristas et al. (2014) demonstrated that development costs varied from €5891 to €274,783 while the implementation costs varied from €7278 to €387,879 across integrated care programmes (Tsiachristas et al. 2014). Key cost drivers were the duration of the development phase and the staff needed to develop and implement an integrated care programme. Overall, empirical evidence of the effects of primary care oriented bundled payments models is scarce, and most support is still based on conceptual grounds.

54.2.5 Lessons Learned

The implementation of the Dutch bundled payment model can be seen to have been a success for three key reasons, which can be summarised as follows (Struijs 2015a, b):

1. *The diabetes care standard was codified.* The DFHCS, agreed on by all national provider and patient associations, specifies the minimum requirements for optimal diabetes care and sets the criteria for improvements. By law, the bundled payment contract must include all services described in the DFHCS, which identifies *what* services to provide but not *who* delivers those services or *where* and *how* they are delivered (as long as these services are in congruence with national guidelines). This provided care groups with an incentive to adopt innovations and to reallocate tasks so that providers each do the work that best matches their qualifications with lowest costs.

2. *It fostered transparency through the use of electronic health records.* The EHR system made patient data available to primary care providers in real time and helped them to reduce duplicated services. Web-based EHRs also enabled care groups to benchmark the performance of care providers, who could then learn from one another. Struijs et al. (2012a) reported that the EHRs were used to generate accountability reports for insurers and to inform the public about care groups' achievements. This was seen by most providers to provide greater transparency and as the main achievement of the reform (Struijs et al. 2012a).
3. *It optimised the value of clinical expertise.* Being accountable for both cost and quality as a consequence of the bundled payment creates an incentive to offer effective care and prevent the utilisation of unnecessary care. GPs are incentivised to ensure that their patients receive the right type of care, delivered at the right time, at the right facility, by the right provider, and use their clinical knowledge to do so. For instance, Struijs et al. (2012a) found that following the introduction of bundled payments, diabetes patients with no abnormalities on their annual eye exam were switched to a biannual eye-exam schedule, consistent with Dutch clinical-practice guidelines (Struijs et al. 2012a), which increased the profit margins of care groups. Care groups also made use of various forms of task reallocation and task delegation both within primary care, but also from secondary to primary care as they have an incentive to steer to high-quality low-costs providers. For example, insulin-dependent patients without complications are increasingly being treated in GP practices instead of by specialists in hospital settings, which had been the case prior to introduction of the bundled payment.

Although the bundled payment model realised a more intensified and structured collaboration between care providers and demonstrated modest improvements in outcomes in the early stages after implementation, two main challenges remain (de Bakker et al. 2012). First, the care bundle was limited to primary care and included only to some extent specialist care, while medication was excluded from the bundle. Although this limited scope of the bundle was probably advisable in the early stages of implementation, as GPs were being urged to adopt bundles, it potentially encourages then to refer the more-complex (and more costly) patients to specialists (Struijs 2015a, b). As a result, an incentive for all providers to jointly reduce spending on diabetes care is still lacking, since specialists are not incentivised to do so as their payment model has remained unchanged. Moreover, the bundle does not include an incentive for preventing diabetes since the integrated care programme only commences following a diagnosis of diabetes.

Second, the single-disease approach is not in line with the complex healthcare needs of many diabetes patients with co-morbid diseases, and this may lead to new forms of fragmentation. Potentially, substantial parts of diabetes patients' healthcare needs are not related to their diabetes. However, an assessment of healthcare providers' views on multimorbid conditions found that the disease-specific approach to diabetes management had not yet resulted in problems for diabetes patients with co-morbid conditions (Struijs et al. 2012a).

54.2.6 Outlook

Considering the aforementioned challenges of the bundled payment model with regard to integration across the care pathway and single-disease approach, two new developments, which are currently being implemented in the Netherlands, are worth describing further: (1) the integration of primary, secondary and tertiary care for population subgroups, namely a bundled payment for pregnancy and child birth, and (2) the move towards population health management through the integration of services across the entire care continuum to address the needs of the whole population.

54.2.6.1 Bundled Payment for Pregnancy and Child Birth

Building on the diabetes care reimbursement model, this new bundled payment model seeks to encourage efficient outcome-focused pregnancy and childbirth care, which is currently hindered by the fragmented funding system. Like diabetes care, insurers will pay a single fee to a contracting entity to cover all services during the antenatal, delivery and postnatal phase for each pregnant woman. The contracting entity will be clinically and financially accountable for the services delivered to enrolled population. By eliminating current funding barriers, the Dutch Minister of Health aims to stimulate the collaboration between providers and settings in order to improve patient value. This bundled payment model will be structurally implemented on a voluntary basis in 2017 (Plexus 2016).

54.2.6.2 Population Health Management

Along with the developments in integrated care for single chronic diseases, it became evident that ideally the scope of integrated care needs to be expanded to bridge the gaps not only within the health system, but also between the health and social systems in order to provide truly population-centred services that improve population health (Struijs et al. 2015a; Steenkamer et al. 2017). In the Netherlands, several regional partnerships have emerged in 2013 in which care providers, insurers, and stakeholders such as municipalities and representatives of citizens participate (Drewes et al. 2015). These initiatives are based on a shared vision, following the Triple Aim (Berwick et al. 2008), with substantial investment in developing relationships between the involved actors in order to build trust for aligning organisations' scope and interest. This complex journey towards population health management is currently being evaluated by the Dutch National Institute of Public Health and the Environment. This evaluation will provide insight in the facilitators and barriers for implementing population health management in order to realise improvements in population health, quality of care and reduce spending growth.

Both the development of population health management and the implementation bundled payment for birth care are strong examples of 'integrating care' along and across the different domains, while at the same time revealing new but comparable challenges. First, both developments will need to create governance arrangements in order to achieve their aims. Whereas the bundled payment requires a contracting entity, this might not be the case within the population health management initiatives. How to best arrange these new governance arrangements, including public–private partnerships, which need to include elements of accountability, oversight and distributed leadership, while at the same time, considering the national, regional and local context is still widely discussed and yet to be resolved (Goodwin et al. 2014). These discussions also bring to the forefront conflicting interests of existing organisations and providers and the overall system-level goal of reducing spending growth.

Second, in both developments, questions arise about how to engage the population they serve. In population management initiatives, various strategies to actively involve the local community have already been launched, such as online 'communities', patient representatives as board members of health services, and even new entities led by citizens, which serve as integrator as described by Berwick et al. (2008). These tools and the definitions of underlying concepts vary considerably in scale and scope, and more insight is needed to ascertain what works for whom in what context to successfully involve the community (Goodwin et al. 2014; Ferrer, forthcoming).

Thirdly, there is an ongoing debate about the appropriate payment models. Although for birth care, a choice has already been made towards a bundled payment approach, involved providers are hesitant to adopt such a disruptive payment model (Struijs et al. 2016). Furthermore, discussions remain regarding the scope of the bundle and the number of modules within the bundle. Moreover, there is still debate within this field whether this is really a stimulus for integrated care or even a threat (Struijs et al. 2016). Currently, empirical evidence underpinning the effects of bundled payments on outcomes is scarce, and its support is mostly on conceptual grounds. With the population health management development, the debate on payment models is even more complex (Struijs et al. 2015b). By looking at initiatives experimenting with alternative payment models such as shared savings models (Hayen et al. 2015; Song et al. 2011, 2012; Chernew et al. 2011), lessons can be learned on how to shift financial and clinical accountability from payers towards (groups of) care providers (and potentially in the near future also citizens) in order to incentivise these providers to improve population health, quality of care and reduce costs growth.

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Designing Financial Incentives for Integrated Care: A Case Study of Bundled Care

55

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55.1 Introduction

The rise in chronic diseases poses a significant challenge to the health of populations, increasing overall health system expenditures worldwide (Thorpe et al. 2010; Wodchis et al. 2015). Health systems in many Western countries are oriented towards episodic and acute care, making them unprepared to address the multifaceted and complex needs of those with chronic diseases (Anderson and Knickman 2001). A significant challenge to the effective management of chronic diseases is the fragmentation of care between settings and healthcare providers (Tsasis et al. 2012). Fragmented payment structures, often separated by care sectors, have been highlighted as impediments to improving coordination and continuity of care for individuals living with chronic diseases (Mukamel et al. 2006).

A key enabler in the integration of care is the adoption of payment mechanisms that incorporate financial incentives that encourage or facilitate a connection between sectors and providers.

Existing models for paying for health services may not be well suited to promoting interprofessional coordination and organizational collaboration across the health system (Stokes et al. 2018). In activity-based payments, such as fee-for-service (FFS), providers are incentivized to produce high volumes of services, particularly for services and procedures with high net profit margins per unit of service. Under FFS, the provider is only responsible for the unit costs of services delivered, but not for patient health or overall treatment costs (DiPiero and Sanders 2005). It has been argued that traditional models of paying providers separately, by care sector, are not well suited for the ongoing management of chronic disease and

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coordination of care (DiPiero and Sanders 2005). Additionally, providers under these models of payment have a perverse financial incentive not to assist patients with non-medical needs, even if addressing these needs could improve overall health (Sutherland and Hellsten 2017). Payment models that implicitly or explicitly reward providers for providing linkages across the care sector can promote more integrated care (Crawford and Houston 2015).

Many countries are increasingly experimenting with new approaches to paying providers to incentivize more integrated care, and whose intended outputs are less cost, better health outcomes and improved experience. Indeed, financial incentives are used to influence the structure, process and outcomes of integrated care. To date, most payment schemes used in many high-income countries focus on the structure and processes of care. For example, in countries like the USA and the UK, payment incentives targeting general practitioners are tied to patient health outcomes (McDonald and Roland 2009). While most financial incentives in integrated care have targeted healthcare providers, various financial incentives have also focused on health insurers and patients (Korda and Eldridge 2011).

An approach that is currently gaining momentum amongst policy-makers and researchers is bundling care and service payments, across the care episode (Chen et al. 2015; Hussey et al. 2012; Struijs and Baan 2011). The Institute of Health Improvement defined bundled care as a structured way of delivering care for a defined patient segment/population that is based on a set of evidence-based practices, generally three to five. It is hypothesized that when these practices are performed collectively, they can improve patient outcomes (Resar et al. 2012). Others have also defined bundled care as a care delivery model that combines services from multiple providers and settings into a single episode of care, driven by evidence-based guidelines or practices (Jacobs et al. 2015). Often in bundled care models, a single payment provides coverage for health services required by patients within an episode of care. A lead provider organization is often responsible for ensuring the delivery of key elements of post-acute care transitions such as physician follow-up, discharge planning and home care (Wojtak and Purbhoo 2015).

This chapter draws on behavioural economics to examine empirical evidence of incentive effects on quality of care in integrated care. The chapter compares various versions of financial incentives all commonly labelled as ‘bundled care’. It is organized to answer the following questions about integrated financial incentives: What typologies of financial incentives currently exist as they apply to bundled care? Is bundled care cost-effective, particularly for patients with chronic conditions? What light can behavioural economic theories shed on the effectiveness and ineffectiveness of bundled care? Furthermore, a case study of the implementation of bundled care is provided for Ontario, Canada.

55.1.1 Models Based on Procedures and Diagnostic-Related Groups

The most common bundled care models have been based on a ‘triggering’ hospitalization’s diagnostic-related group (DRG). DRGs are deterministic algorithms that consider patients’ diagnoses and surgeries to assign each hospitalization to a unique DRG, and then each DRG has its own payment amount (Fetter 1991). Essentially, the DRG is a system of grouping patients with similar characteristics and comparable costs (Fetter 1991). Inpatient prospective payments based on DRGs have been implemented in many countries, including: the USA, England, the Netherlands, Germany, Finland and Sweden (Busse et al. 2011; Marshall et al. 2014; O’Reilly et al. 2012; Quentin et al. 2013; Scheller-Kreinsen et al. 2011). The number of and extent of policy objectives of DRG payments has varied widely across countries. Some of the policy objectives have included: increasing efficiency, improving quality, ensuring the fair allocation of resources or funding across geographical areas and across and within health care, encouraging the development of new cost-effective treatment pathways and improving the transparency of hospital funding, activity and management (Marshall et al. 2014).

An example of a DRG-based bundled care model is the Medicare Acute Care Episode (ACE) launched by the Center for Medicare in the USA in 2009 to bundle payments for orthopaedic procedures such as hip and knee arthroplasty (Froimson et al. 2013). Under ACE payment model, hospitals are prospectively paid based on the diagnosis of a patient’s illness and the average cost used by all hospitals in the USA to treat patients with a similar illness. In the early iterations of this model, Medicare provided a single bundled payment for all hospital services delivered to a patient diagnosed with a particular illness (Mechanic and Altman 2009). However, in 2016, the Comprehensive Care for Joint Replacement model was implemented to encourage hospitals, physicians and post-acute care providers to work together to improve the quality and coordination of care. The bundled payment and episode of care begin from the initial hospitalization through recovery, and up to 90 days post-discharge (Ellimoottil et al. 2017).

55.1.2 Single Condition Versus All-Inclusive Bundles

Episode-based bundles for single chronic diseases have been piloted across North America and Europe (Froimson et al. 2013; Dummit et al. 2018; Struijs and Baan 2011). An example of a single condition-based bundled care model is the Geisinger Health System (GHS) ‘ProvenCare’, which was launched in 2006 in the USA (Paulus et al. 2008). The ‘ProvenCare’ episode-based bundles provide payments to providers for patients with high prevalence chronic diseases, including diabetes, congestive heart failure (CHF), chronic kidney disease, coronary artery disease and hypertension. This model covers all inpatient hospital costs and post-acute care costs related to the condition for which the hospitalization was attributed, for up to 90 days, including complications (Paulus et al. 2008).

Further along the continuum of bundled care are models that provide coverage for all necessary healthcare needs, including institutional, residential and long-term care, as well as treating all the associated comorbidities. Models such as the Program of All-Inclusive Care of the Elderly (PACE) provide yearly capitation payments for a full range of chronic disease management services, rather than payments only for a single condition (Mukamel et al. 2007). The PACE model integrates funding and delivery of all Medicare and Medicaid services including a comprehensive list of long-term care (LTC) services. It is a community-based managed care programme for frail older adults (aged 55 and over), whose significant risk for cognitive and functional decline makes them eligible for LTC admission (Mukamel et al. 2007). At the core of PACE is an adult day programme that integrates services across the care spectrum. The programme is exclusively responsible for all their enrolees' care needs, through offering a comprehensive basket service, including: primary, social, mental, home care and LTC (Gross et al. 2004). In PACE, the governance structure is dictated by the availability of a parent or sponsoring umbrella organization, through which various programmes co-locate their services and share resources (Gross et al. 2004). In this capitation-based model of payment, all the programmes pool their budget under the governance of the PACE umbrella organization (Bodenheimer 1999).

More recently, in the UK, the Long Term Conditions Year of Care Commissioning Programme was developed to support the implementation of integrated chronic care services. The objective of the programme was to identify patients with chronic conditions, to provide holistic, person-centred, integrated health and social services by an integrated team, and to engage patients in the management of their care. A key objective of the programme was to redesign the funding of integrated care and incentivize care providers to work together by funding care for patients with chronic conditions using a capitated budget. Capitation payments, simply defined, are prospective, fixed payments to providers to care for a defined population for a defined period of time (Waters and Hussey 2004). A capitated budget is based on the needs of an identified population providing a per-person, average cost for a range of services over a fixed period. The budget generally covers all care for a group of people, including acute, community, mental health and social care costs. The national support team within the Long Term Conditions Year of Care Commissioning Programme encouraged the five early implementation sites to innovate within the broad programme objectives. Without following a prescriptive approach, the early implementation sites were encouraged to transform services in a way that matched their local care environment.

55.1.3 Event Triggering the Start of the Bundled Care

Determining the index event or the event triggering the episode of care is an important aspect of designing a bundled care model (Jacobs et al. 2015). Majority of the short-term episodic models piloted in the USA such as the ACE, ProvenCare Programme and Prometheus use patient hospitalization as the trigger or index event.

In this type of model, the episode of care begins when a patient is admitted to an inpatient unit for a specific condition (Chambers et al. 2013). In other models such as the Dutch Bundled Payment for Integrated Chronic Care, bundled care delivery is based on a single chronic condition (Struijs et al. 2012b). Insurers pay a single fee to a care group to cover a full range of chronic condition (i.e. diabetes, COPD or vascular disease) care for a fixed period (Struijs et al. 2012b). In early iterations of the model, care groups consisted of legal entities formed by multiple healthcare providers, who are often exclusively primary care providers. However later, the prospective bundled care model included the vertical integration of specialists (de Vries et al. 2019). The care group assumes both clinical and financial responsibilities for all assigned patients in the disease management programme (Struijs et al. 2012b). More specifically, the care group is responsible for the costs and clinical outcomes associated with the chronic condition for which the bundle is held (Struijs et al. 2012b).

In Canada, Ontario is undergoing a health system funding reform. In 2014, the province implemented new funding for systemic treatment, more specifically, chemotherapy and biotherapy (Kaizer et al. 2014). Funding for systemic therapy is overseen by Cancer Care Ontario, now an entity of Ontario Health, a provincial agency funded by the Ontario Ministry of Health (MOH), whose mandate includes planning, delivery, integration and coordination of cancer and renal services in the province (Evans et al. 2002). The funding model transitioned from a per-case and hospital-based remuneration to an episode-based approach, where funding flows into bundles of care. The bundled care episode is triggered at the initial consultation of patients with cancer (Kaizer et al. 2014). This model includes all patient-relevant activities that occur from patient referral to the start of the treatment or the decision not to treat. The core services included time-unlimited hospital-based chemotherapy treatments (Kaizer et al. 2014).

The MOH through Ontario Health also implemented capitated reimbursement for patients with end-stage renal disease requiring dialysis (Manns et al. 2007). In this model, patients receive care in dialysis clinics that are part of community-based groups or university hospital groups. The index event occurs when a patient first visits a clinic for peritoneal dialysis, where they receive care from a multidisciplinary team. This model of care includes care from a narrow set of predefined providers for over a year (Manns et al. 2007). It should be noted that physician renumerations are not part of the cancer or renal payments; rather, the payments relate to the delivery of renal or chemotherapy treatment over the specified period.

55.1.4 Short-Term Versus Longer-Term Models

Bundled care payments have been used to fund short-term procedure-based episodes such as the Medicare ACE programme, to comprehensive models such as the PACE model. Procedure-based models such as the ACE programme were a prototype for chronic care models such as the Bundled Payments for Care Improvement (BPCI) initiatives. Launched in 2013 across the USA by Medicare, BPCI provides time-limited coverage for chronic conditions (Jacobs et al. 2015; Dummit et al. 2018). The BPCI initiatives include four bundled payment approaches that cover short-term episodes of care. Model one is a retrospective payment for hospital and physician services provided during a hospital stay. Model four is a prospective payment for these services. Model two is like model one, but also includes 30–90 days of post-discharge care. Model three provides retrospective payment for post-discharge services only (Hussey et al. 2012).

When designing longer-term bundles for the management of chronic conditions, it can be challenging to select the appropriate time frames and the type of care providers to include (Jacobs et al. 2015). An example of a longer-term bundled payment is the Alternative QUALITY Contract by the Blue Cross Blue Shields of Massachusetts, implemented in 2009. In this model, a global budget payment provides coverage for all inpatient, out-patient and physician care (including pharmacy and mental health costs). A single organization is paid to cover any services required by the patient over a year (Chambers et al. 2013).

55.2 Bundled Care in Ontario: A Case Study

55.2.1 he Implementation Context

Over the last two decades, Ontario has taken an incremental approach to incentivize efficiency based on factors such as hospitals' relative volumes, input cost and complexity of cases. Ontario has also made use of activity-based funding payments at standard prices for specific hospital cases (Sutherland and Hellsten 2017). On the other hand, post-acute care sectors such as long-term care, home care and community services are funded through a mix of approaches. For example, long-term care is largely funded on a need basis determined by the complexity of their residents, while home care is largely funded based on an acuity-adjusted formula (Sutherland and Hellsten 2017). This constellation of different payment approaches and incentives spread across care settings results in no provider holding financial accountability for a patient's care or outcomes outside of the specific setting (Sutherland and Hellsten 2017). Integrating acute and post-acute care services in the context of these layered structures has therefore been particularly challenging for Ontario (Auditor General of Ontario 2015).

It was in this context that the MOH, following a readiness assessment, chose to pilot bundled care in June 2015, also known as Integrated Funding Models. Six pilot sites were selected with a range of medical and surgical patients (Ministry of Health and Long-Term Care 2015). Each programme consisted of partnerships across acute care and post-acute care sectors. The programmes determined their clinical focus and the specific set of services that a patient received for an episode of care, for a fixed period. Heterogeneity between programmes was influenced by programme participants' desire for accountability and localized control over decision-making. A recent qualitative interview of bundled care in Ontario showed that programme implementers went beyond policy-makers' original design, with a gap between programme implementers' and policymakers' conceptualization of bundled care (Embuldeniya et al. 2020). While the programme implementers appreciated the low-rules environment that the MOH had enabled, for example, allowing programmes to contract directly with home care providers, there were different nuanced approaches to bundled care. While the MOH approached the bundled care programmes through the lens of cost savings, the programme implementers approached it through the lens of cost avoidance (Embuldeniya et al. 2020).

Central to all the programmes was a bundled care coordinator who helped ensure smooth patient transitions. Each of the programmes had their own unique enrolment criteria for the specific bundles, including location of residence and age. This bottom-up approach created significant heterogeneity across programmes (Embuldeniya et al. 2018). Three of the programmes focused on patients admitted to the hospital with chronic obstructive pulmonary disease (COPD) or CHF, one on patients with urinary tract infection or cellulitis, one on stroke patients and one on patients undergoing cardiac surgery (Embuldeniya et al. 2018). As part of the approach, a single integrated payment was shared between the hospital and the home care agency for the episode of care. It should be noted that this payment did not include physician payments, drug cost reimbursement, long-term care or other community care sector costs.

55.2.2 Rationale for Integrating Acute with Home Care

Patients hospitalized for COPD and CHF were enrolled into the programme at hospital admission for a duration of 60 days across three pilot sites in Ontario. For each patient, the episode of care included: (1) a hospital-based care coordinator and a multidisciplinary team of providers who worked with the patient to develop a comprehensive discharge care plan to effectively manage the disease; (2) post-discharge, patients received care from a designated home care provider who worked with the team around patient needs; (3) shared electronic health information systems that facilitated communication across acute and post-acute care, including virtual specialist consults enabled through electronic technology; (4) 24/7 telehealth; and (5) a single integrated payment shared between the hospital and the home care agency for the episode of care.

The decision to integrate funding of home care with acute care for these select chronic conditions was multifold. Avoidable readmission of patients living with chronic conditions such as COPD and CHF is a significant driver of health expenditure (Van Walraven and Carl 1998). For example, evidence shows that almost half of hospitalizations for CHF are low risk and avoidable (Rich et al. 1993). With the recent expansion of home care, its integration to acute care has been proposed as a potential strategy to reduce hospitalizations (Landi et al. 1999). Home care can emphasize early identification of health exacerbations and decline, improve compliance with medications, promote preventative care and provide social support to patients (Landi et al. 1999). Another rationale is that through shifting some of the care from acute to home care, patients can be discharged to their homes sooner (O'Connor et al. 2015). The hypothesis is that through implementing an evidence-based clinical pathway that ensures the smooth transition of patients from hospital to home, acute length of stay is more likely to be reduced (O'Connor et al. 2015).

55.2.3 Characteristics of CHF and COPD Bundles in Ontario

There are many commonalities of the Ontario bundled care models with the BPCI and the ACE Medicare models implemented in the USA, which use the DRG system of grouping patients. The Ontario bundled care pilots that focus on CHF and COPD deliver episodic treatment for these single chronic conditions. This means that only services related to the treatment of each disease are prospectively funded through a lump sum payment. Although some of the pilots developed partnerships across acute, primary and home care, the payment only provides coverage for episodes of care spanning from acute to home care. These episodes are time-limited for 60 days.

Another characteristic of Ontario's bundles is that hospitalization for COPD or CHF marks the index event or the event triggering the beginning of the bundled care episode of care. Finally, although it is recommended that payment be provided to all providers within the bundle (Jacobs et al. 2015), physician payments are not included in the Ontario care model. There are many consequences to not including physician payments. For example, the Dutch Bundled Payment for Integrated Chronic Care is experienced substantial difficulty coordinating the necessary care with providers who were not initially included in the bundle (Struijs et al. 2012b; Struijs and Baan 2011). The importance of including physician payment in the bundles cannot be overstated, as they make majority of decisions about care provided to patients (Clancy 1989). Including their payment increases the likelihood of partnership with other providers also paid through the bundle. Most of all, it ensures both clinical and financial accountabilities in the care delivery (Jacobs et al. 2015).

55.3 Cost-Effectiveness of Bundled Care for Chronic Conditions

It has been argued that bundled care is best suited for acute conditions and procedures such as hip and knee replacement surgery. These are characterized by: (1) high volumes and short episodes of care; (2) clearly defined care pathways where there is room to reduce care variation through standardization; and (3) little follow-up care (Jacobs et al. 2015; Lewin Group 2015; Painter 2012). On the other hand, after discharge from the acute care setting, individuals with chronic care may require continuous management and longer-term follow-up (Coleman 2003).

Furthermore, for chronic conditions such as CHF and COPD, patients may require care from different health professionals across multiple settings (Brännström and Boman 2014; Coleman 2003; Garcia-Aymerich et al. 2007). Others argue that because chronic conditions form the bulk of unplanned hospitalizations (Hernandez et al. 2009), providers should be incentivized to avoid unplanned hospitalization rather than centre chronic care in acute care (McIlvennan et al. 2015). In many healthcare systems, hospitals have little direct financial incentives to reduce readmissions. However, in episode-based payments, particularly those that in bundled payments that cover post-acute care, hospitals are more likely to be invested in patient care post-discharge (McIlvennan et al. 2015).

55.3.1 Evidence of Cost-Effectiveness

There remains a paucity of rigorous evidence on the cost-effectiveness of bundled care for chronic diseases. Various measures have been used to evaluate the effectiveness of bundled care, some of these have included: healthcare spending such as acute care spending, healthcare utilization such as length of stay, quality metrics such as mortality and complication rate and unintended consequences such as whether hospitals avoided higher-risk patients (Agarwal et al. 2020; Collinsworth et al. 2020; Dixon et al. 2020; Ospina et al. 2017; Tsiachristas et al. 2015). Cost-effectiveness studies have also used natural units such as cost per exacerbations avoided or cost per deaths avoided (Boland et al. 2015; Dixon et al. 2020), while cost utility studies have used cost per quality-adjusted life years (Boland et al. 2015; Ospina et al. 2017).

To date, there has been mixed evidence on the cost(-effectiveness) of bundled care for chronic conditions like diabetes, cardiovascular disease and COPD (Boland et al. 2015; Struijs et al. 2012b; Tsiachristas et al. 2015, 2014). Furthermore, this evidence has been specific to the Dutch context (Boland et al. 2015; Struijs et al. 2012a, b; Tsiachristas et al. 2015, 2014). In the Netherlands, care is coordinated by primary care groups, often owned by general practitioners (GPs), who may deliver the care themselves or subcontract to other healthcare providers (e.g. other GPs, dieticians and specialists) (Struijs and Baan 2011). Thus, in comparison with the Ontario bundled care pilots, where acute and home care are bundled into a single episode and payment, in the Netherlands, services are bundled through primary care groups (Jacobs et al. 2015; Struijs and Baan 2011).

A study by Struijs and colleagues compared the costs of bundling care for diabetes management with usual care in the Netherlands (Struijs et al. 2012a). These costs included primary care, specialist care, allied professionals and other health system costs. Within a two-year follow-up, the overall healthcare costs of patients in the bundled payment group increased by €288 compared to those in the usual care group. The authors note that it was challenging to conclude whether the programme could show cost savings in the long term, attributing the initial cost increase to the ‘start-up phase’ (Struijs et al. 2012a).

Later evaluations of bundled care for chronic conditions in the Netherlands showed that there was mixed evidence on the overall healthcare costs by the type of conditions and intensity of services included (Tsiachristas et al. 2015; Tsiachristas and Rutten-van Mölken 2014). Tsiachristas and colleagues compared the cost-effectiveness of disease management programmes (DMPs) by the level of intensity of bundled care, as operationalized by the number of chronic care model components implemented (Tsiachristas et al. 2015). They found that the incremental quality-adjusted life years (QALYs) ranged from −0.032 to 0.038 across bundled care for COPD and cardiovascular disease (CVD) prevention. For primary CVD prevention, the difference in healthcare cost was €237, favouring the least comprehensive DMP in the first year, and €425 in the second year. For secondary CVD prevention, the difference in healthcare cost favoured the most comprehensive DMP in the first year (€–2340) and in the second year (€–66). For COPD care, when comparing the most comprehensive to the least comprehensive DMP, i.e. DMP with the least number of chronic care model components, healthcare costs were higher (by €1787) in the first year and slightly lower (by €24) in the second year (Tsiachristas et al. 2015). A detailed elaboration on bundled payment in the Netherland is provided in Sect. 6.17.

55.4 The Economic Theories Behind Financial Incentives as They Apply to Bundled Care

55.4.1 Principal–agent Theory

Financial incentives are often analysed and designed within the framework of the principal–agent theory. This theory can be applied to payment arrangement between the principal and the agent (Braun and Guston 2003). The patient receiving care and the healthcare payer are the principals, while the organization and individual provider delivering care are the agents. In bundled payments, agents can be expected to behave in ways that maximize ‘value’, i.e. optimize health benefits for the patients, while minimizing the total opportunity costs. These costs may include provider, administrative and patient opportunity costs (Conrad 2015). When analysing the effects of payment incentives in bundled care, one must consider the multiplicity of the relationships between the agents. This is particularly the case when patients require care from multiple settings and providers. One of the issues with applying the principal–agent theory to understanding bundled care is the assumption that the provider, the healthcare payer and patient have perfect foresight; i.e. they are aware of every state in the conceivable future. Under this assumption, the healthcare payer can design a bundled care contract that accounts for all possible scenarios, with the provider’s or organization’s incentives perfectly aligned, ex-ante (Bech and Pedersen 2005). Another gap of the principal–agent theory is its poor application to bundled care implemented in health systems where physicians are remunerated outside of the usual course of care and have a high degree of autonomy, but a relatively low degree of affiliation (Jacobs et al. 2015). As is the case for the bundled care model in Ontario where physician payments are not included. Although it is expected that both agents, the organizations delivering bundled care and the physician, must cooperate to jointly integrated care for patients, they respond differently to incentives (Conrad 2015). In the scenario where providers are remunerated with volume-based approaches such as FFS, it can be expected that as agents, the payment approach may misalign their objectives with those of the organizations' partnering to deliver bundled care. In the FFS example, they may behave in ways that increase the volume of patients discharged from the hospital, to try to maximize their net income (Dor and Watson 1995). Others have argued that even FFS could be used to promote more integrated approaches to care if the healthcare payer chooses to pay for services meant to achieve that goal. For example, clinicians could be rewarded for ensuring that patients at risk of chronic disease receive their full set of preventative services including care coordination with other providers (Jha 2019).

55.4.2 Transactional Cost Economic Theory

Unlike the principal–agent theory, transactional cost economic theory considers the impact of information asymmetry as it applies to payment incentives in bundled care. In this case, informational asymmetry occurs when the knowledge of the ex-ante or future context in which the bundled contractual payments are implemented is incomplete (Bech and Pedersen 2005). Imperfect information and knowledge leave gaps and missing provisions in payment contracts. A contract is usually a set of written agreements that stipulates a set of specific actions of compliance by the parties involved in the agreement (Brousseau and Glachant 2002). In bundled care, the contracting parties make reciprocal commitments—for example, a bilateral care coordination arrangement between a hospital and home care agency (Bech and Pedersen 2005). In this instance, the payment contract may outline that after hospital discharge, patients should have coordinated access to home care. However, the contract might not stipulate the specific home care agency or comprehensively list the types of services a patient should receive. Since individuals are assumed to be opportunistic, the consequences of incomplete contracts can result in contractual hazard (Richman and Macher 2006). Incomplete contracting is associated with increased transaction costs, such as the costs of developing, maintaining, monitoring and enforcing multiple contractual relationship (Bech and Pedersen 2005). In bundled care, the ex-ante transaction cost of searching for, drafting and negotiating a contract with multiple other agencies is minimized if the set of providers involved in patient care is reduced. Often in a bundled payment involving multiple agencies (e.g. acute and community-based care), the governance structure minimizes the transaction cost by predetermining the organizations involved in the contractual relationship, as well as the types and length of services delivered (Bech and Pedersen 2005).

55.5 Conclusion

Bundled care is a promising approach to improving care outcomes and reducing costs. Bundling care and payments offer an opportunity to align provider incentives with effective care delivery, while addressing cost inefficiencies. Although cost savings and cost-effectiveness of bundled care are appealing outcomes, the evidence is still emerging and mixed.

While there is evidence on the effectiveness of bundled care for acute conditions and procedures, it remains inconclusive whether bundled care, as it has been implemented in Ontario, will be effective/cost-effective. Evidence indicates that bundled payments may not be suitable for all conditions, especially for conditions with unclear clinical pathways such as COPD and CHF. Despite this, there remains considerable interest in the implementation of bundled care for chronic diseases (Boland et al. 2015; Dixon et al. 2020; Ospina et al. 2017; Tsiachristas et al. 2015).

Significant heterogeneity exists in the implementation of bundled care. This chapter sought to outline the different typologies of bundled care programmes, and as a case study, sought to highlight the implementation of bundled care in Ontario. There are several lessons for those considering adopting bundled care in their local context. Great consideration should be given to the duration of treatment (short term vs. long term), the type of condition (chronic vs. acute or diagnostic procedure), the event triggering the beginning of the bundle and the care context and providers included in the bundle. More particularly, physician payment should be included in a bundle, as physicians make most of the decisions about care provided to patients. Finally, for health systems considering the implementation of bundled care programmes, there must be widespread commitment and adoption from both payers and providers.

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Singapore

56

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56.1 Introduction

Singapore is a small nation-state situated at the southernmost tip of the Malayan peninsula, the most developed member of ASEAN, the Association of South East Asian Nations. It is the second densest nation in the world with a population density of 7866 persons per square kilometre and a total population of 5.7 million on a mere 725 km^2 of land (Government of Singapore 2019).

Having one of the world's highest life expectancies at birth (83.2 years) coupled with one of the world's lowest fertility rates (1.16), Singapore's population is rapidly ageing (Department of Statistics Singapore 2019). About 10.2% of the population is over 65 years of age, and that proportion could reach 50% by 2050 (United Nations 2017). The ageing population was recognised as a national priority as long ago as 1993 in the government's White Paper on Affordable Healthcare published in that year (Ministry of Health Singapore 1993).

56.2 History and Transitions

Since Singapore obtained independence in 1965, the healthcare system has evolved in multiple ways (Lee and Satku 2016) in the effort to improve the quality and efficiency of care delivery, and it has arguably delivered (Haseltine 2013). The manifold transitions are challenging to summarise in a succinct and yet clear manner but may be described as follows.

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Evolution The British left a healthcare system that was largely taxation-based, free at the point of care, and government run. Public hospitals and outpatient clinics (called dispensaries) were government departments. Over the first decades, the government started introducing limited co-pays and additional healthcare financing schemes, first Medisave (mandatory medical savings accounts for the employed) and then MediShield (healthcare insurance that was well subscribed even though it was opt-in), and then, finally MediFund (an endowment fund that offsets bills as a last resort) (Lee and Satku 2016). All schemes had limits on the amounts that could be used, and the need to co-pay for most services was well-guarded. Some private sector healthcare services, both mainstream and alternative (Traditional Chinese Medicine and others), gradually started.

Revolution Recognising that public healthcare facilities would be more agile and cost-conscious if they operated more as business entities, most of the public healthcare institutions were "restructured" by 1991, starting with National University Hospital in 1985. By 2000, the last two completed the transition, including a large psychiatric hospital. The restructuring changed the ecology substantially, with the institutions no longer needing to follow the Civil Service's "Instruction Manual" and able to hire and operate as private companies, albeit owned, supervised and directed to some extent by the government. Two other major government agencies were set up as statutory boards during this period by spinning off government departments, viz the Health Promotion Board and the Health Sciences Authority.

Devolution The next major transition was the grouping of more than 20 public healthcare entities into two large clusters in the effort to promote collaboration between primary, secondary, and tertiary levels of health care in 2000. Each cluster was tasked to coordinate services for better patient care. The clusters were primarily designed so as to divide equally their services and capabilities as much as possible (some services were not so neat; one cluster got most of the psychiatric beds and the other most of the paediatric). Each had a tertiary hospital and some secondary hospitals, polyclinics, and national speciality institutions. While there was a geography to their distribution (one was in the north and the west, while the other was concentrated in the denser southeast), patients were free to choose, and a significant proportion chose, services outside their own localities. Much authority was delegated down to the cluster headquarters to develop their focus areas and corporate distinctives. Clusters began to consolidate their common services, in particular aspects of information technology, finance and human resource management. The clusters were adjusted from time to time, with one hospital (National University Hospital) joining an academic health system with the National University of Singapore's medical and dental faculties, and two others eventually given their own regions to look after as more new acute hospitals were built. The initial two clusters became six regional health systems (RHSs) by 2011, each with a putative geographical region and anchored by a major acute hospital.

Convolution The care delivery ecology continued to become yet more complex with the establishment of the Agency for Integrated Care in 2009. This agency, formed from a MOH unit originally set up to facilitate care transitions from acute hospitals to nursing homes, was also tasked to facilitate the development of the RHSs and later to develop the intermediate and long-term care sectors (which included community hospitals, nursing homes, day care and day rehabilitation centres, and home care). Its remit later expanded to include mental health services, primary care, and social support for the frail and well elderly in 2013. In 2017, MOH announced the regrouping of the six clusters into three. The "regional health system" was clarified as going beyond the public healthcare institutions to include both private and "people" sectors for the sake of better population health. The Agency for Care Effectiveness (Ministry of Health Singapore 2020a) and the Agency for Logistics Procurement and Supply (ALPS 2020) were formed to centralise and focus health technology assessment and public sector supply chain management, respectively. Another agency, the MOH Office for Healthcare Transformation, was created in 2018 to help innovate and reshape Singapore's health system (MOH Office for Healthcare Transformation 2020).

56.3 Governance and Care Delivery

Governance and regulation of health and social care is split across multiple ministries, with the Ministry of Health (MOH) focusing on health care, while the separate Ministry of Social and Family Development (MSF) looks after social services. In addition, pre-hospital care is under the Ministry of Home Affairs (MHA); the public ambulance service is operated by the Singapore Civil Defence Force (together with the firefighting service). Government support for charitable social care services is under yet another ministry, the Ministry of Community Development, Youth and Sports (MCCY). MOH hosts the Ageing Planning Office which coordinates all planning related to the elderly across all ministries and supports the Ministerial Committee on Ageing chaired by the Minister for Health.

The model of care, until the past decade or so, has been focused on the acute hospitals and centres of excellence, with many patients seen by multiple providers and professionals in different facilities on the small island.

Health and social care are provided in a mixed ecology, with the public sector most prominent in the provision of acute and inpatient care, while the primary and social care is mostly provided by the private sector. Approximately 80% of inpatient beds are operated by the public sector, while 80% of outpatient attendances are at private clinics (Ministry of Health Singapore 2020d). The charitable sector (often called the "people sector" in Singapore) provides a significant proportion of intermediate and long-term care services.

In Singapore, “public sector” healthcare institutions are in fact private limited companies owned by the government through the Ministry of Health Holdings (MOHH). The “public sector” in Singapore has the best (and in some ways the worst) of both worlds. They receive substantial subsidies for their operations to offset the bills of patients who choose “lower classes” of accommodations and clinics and yet have the flexibility and agility of private corporations. They are however closely supervised by MOH and perform public services beyond the remit of normal private facilities (not least in the current circumstances of the COVID-19 pandemic).

56.4 Healthcare Financing

Singapore has long prided itself in the quality of its medical services and has been the destination of choice for health care from the region and beyond. The price of providing such cutting-edge care for an ageing population, however, has been escalating healthcare expenditure. In 2017, Singapore spent 4.4% of GDP on health care (World Bank 2019), and national healthcare spending almost doubled from S $11 billion in 2010 to SS$21 in 2016. Government subsidies given to Singaporeans increased from S$2.6 billion to S$5.6 billion over the same time frame (Ministry of Health Singapore 2019).

Singapore is still transitioning from its historical health financing roots based on savings and insurance for the occasional episode of care, to a longer-term health financing system more suited for longitudinal and integrated care.

Healthcare financing in Singapore is complicated, with a wide array of different funding mechanisms (Ministry of Health Singapore 2020b). Foremost, there are government block subventions that are provided to the public healthcare clusters to enable reduced pricing for the “subsidised” classes. On an individual level, insurance coverage comes from the government-mandated MediShield Plus and individually purchased add-on riders by private insurance providers. Direct payments for care services can be covered out-of-pocket with personal savings, or use the individual or a family member’s MediSave. Supplementation can come from charity donations and with targeted governmental grants and subsidies for specific activities and needs (e.g. grants for caregiver training, mobility devices, drugs, disability support, among others). MediShield was originally an opt-in health insurance scheme but was recently upgraded to MediShield Plus, a mandatory insurance system that covers the whole population.

The Community Health Assist Scheme (CHAS) deserves special mention, subsidising medical and/or dental care at participating medical and dental clinics. It started as a Chronic Disease Management Programme to subsidise a list of common diseases and gradually grew in both the conditions it subsidises and the population eligible. Today, this has become a significant funding mechanism for the primary care sector which was once largely out-of-pocket or insurance-funded. There are also special “Pioneer Generation” and “Merdeka Generation” schemes provided to older citizens of different age ranges for additional subsidies at public healthcare facilities.

Caregivers Training Grant (CTG)	$200 annual subsidy for caregivers to attend training courses
CareShield	New care insurance scheme with $600 for disabled elderly
ElderFund	$250 a month for needy and disabled elderly Singaporeans who are not eligible for CareShield
ElderShield (ESH)	Care insurance with $300/$400 per month for disabled elderly Singaporeans
Foreign Domestic Worker Levy Concession (FDWLC)	$60/month for families who hire a FDW to care for disabled family member
Foreign Domestic Workers Grant (FDW)	$120/month for families who hire a FDW to care for disabled family member
Interim Disability Assistance Programme for the Elderly (IDAPE)	$250/$150 for needy and disabled elderly Singaporeans who were not eligible for ElderShield
Merdeka Generation Package	$200 annual MediSave top-up, additional outpatient subsidies, MediShield Life premium subsidies
Pioneer Generation Disability Assistance Scheme (PioneerDAS)	$100/month for Pioneers with moderate disability. Additional outpatient subsidies
Screen for Life (SFL)	Subsidised screenings based on age and gender
Seniors Mobility & Enabling Fund (SMF)	Subsidises citizen seniors for assistance devices, consumables and transport

Patients who are indigent and unable to pay their bills are supported by the MediFund, a government endowment fund, and facilitated by medical social workers at each healthcare facility. There are also substantial sources of funding for development and improvement of healthcare services, for example, the Community Silver Trust Fund and the Tote Board Community Healthcare Fund dispense grants for specific projects.

Social service agencies receive subsidies from MSF and are supported by the National Council of Social Services. The health and social care sectors have come much closer in the past decade, for example, part of the Centre for Enabled Living, the agency supporting the social service agencies under MSF, was merged with the Agency for Integrated Care under MOH in 2013 (the remaining component was reframed as SGEnable to support services for the disabled), and MSF transferred its social aged care functions under the Senior Cluster Network and other programmes to MOH in 2018. Other services that cater to the elderly are been gradually transferred to the oversight of MOH, e.g. the Community Networks for Seniors (CNS) initiative.

56.5 Integrated Care in Practice

Singapore is an archetype of the ageing society and its attendant problems. In 1970, one in 31 Singaporeans was 65 or older. That proportion increased to one in eight by 2015 and is anticipated to be one in four by 2030 (Ministry of Health Singapore 2016b). It is also estimated that three in four seniors have at least one chronic disease, while over one in three has at least three (Chan et al. 2018).

In 2016, based on a study that projected one million diabetics in Singapore by 2050, the Minister for Health formally declared a "War on Diabetes" (Khalik 2016; Phan et al. 2014) and launched a multi-agency strategic plan to prevent, detect and manage diabetes (Ministry of Health Singapore 2018).

In 2017, MOH announced the key drivers for the continued development of the Singapore healthcare system, beyond the organisational changes above, neatly summed up as “The Three Beyonds”, viz “Beyond Healthcare to Health, Beyond Hospital to Community, and Beyond Quality to Value” (Ministry of Health Singapore 2017). This marked a major shift away from the reactive provision of care to the proactive prevention of disease (e.g. by reducing obesity through the HPB’s National Steps Challenge), from the acute healthcare facilities to settings where people lived and spent their daily lives, and from the focus on providing the most excellent of care to improving quality while increasing awareness of costs and ensuring value for money. The Agency for Care Effectiveness (ACE) was set up, and fee benchmarks were also introduced.

In the meantime, the private sector has grown in Singapore, which has long been a key destination for international healthcare seekers from the region. Besides looking after foreign patients, the private clinics and hospitals also catered to the better-off local residents. However, the “paying classes” in the public sector compete directly with the private sector, which subscribes to the same financing structure as the public sector except that it does not receive the subventions for the “subsidised classes” it does not serve. So, while it is common to distinguish between the “public sector” and “private sector”, it should be remembered that the public healthcare facilities are actually private limited companies which also operate within the larger private economy.

Lastly, the charitable “people sector”, known locally as volunteer welfare organisations or social service agencies, are supported by subsidies from both MOH and MSF for different purposes (“double-dipping” is strictly forbidden). They are supported by the aforementioned Agency for Integrated Care and by the National Council for Social Services.

At the announcement of the “Three Beyonds”, the Minister for Health made clear the intended strategy for developing the new health and social care ecology. In brief, it must be multidisciplinary and person-centric, focused on joining up both health care and social care seamlessly across different care settings, from acute to intermediate to long-term, and from primary to secondary to tertiary to community care. Developing this new care delivery system will require the right type of workforce, information technology and patient information management, and the right financing arrangements for better efficiency and effectiveness.

The key implementation arm of the Three Beyonds is the three regional health systems (RHSs), each of which has set up their own RHS offices or the equivalent. They have variously designed their patient care journeys or the equivalent and developed population health strategies.

Many community care programmes, or their pilots, have been launched and funded by various sources including MOH, AIC, and charitable foundations. MOH, in an effort to drive creation of integrated community care programmes, set out funding under six nation-wide priority areas (Nurjono et al. 2018a). Priority 1 focused on helping provides holistic case management for those with frequent hospital admissions; Priority 2 focused on smooth timely discharge from acute hospitals to homes through transitional care; Priority 3 focused on timely discharge of medically stable outpatient from hospital-based specialist care to primary and community care providers; Priority 4 focused on consolidating and reducing of appointments across multiple specialities; Priority 5 focused on health education or screening to prevent or slow down the progression of chronic diseases; and Priority 6 focused on strengthening of primary and community care through cross deployment of skilled workforce to partners. As the programmes matured beyond initial pilots, funding for Priorities 1 and 2 was merged under the Hospital-to-Home (H2H) programme, while funding for Priorities 3 and 4 was merged as the Outpatient to Community (O2C) programme.

There is much energy in the development of community care programmes. There are however many points of leadership and initiative and no clear lead agency for any one constituency, and there is still much work to be done to improve patient care navigation.

56.6 People Involvement

In 2014 and 2015, the Ministerial Committee on Ageing supervised a public consultation with some 4000 Singaporeans on how they think Singaporeans can age well. That culminated in a report called the *Action Plan for Successful Ageing* (Ministry of Health Singapore 2016a) that describes Singapore's aspirations:

- To provide *Opportunities for All Ages* “where everyone, including seniors, can continually learn, grow and achieve their fullest potential”
- To be a *Kampong* (local Malay for “village”) *for All Ages* to create “a caring and inclusive society that respects and embraces seniors as an integral part of our cohesive community”, and
- To be a *City for All Ages*, a “senior-friendly city” that is distinctive globally not just for its economic success but also as a model for successful ageing.

At the launch of the plan, there were already more than 70 initiatives and programmes in 12 areas, including “health and wellness, learning, volunteerism, employment, housing, transport, public spaces, respect and social inclusion, retirement adequacy, health care and aged care, protection for vulnerable seniors and research”.

The regional health systems and healthcare facilities also conduct their own feedback channels, some more traditionally and others through social media and other innovations (one hospital CEO used to invite the writers of letters of complaints to lunch).

56.7 Impact

Over the years, comprehensive evaluations have been done on some of the integrated care programmes under the MOH priority areas. These included the post-hospital discharge transitional care programmes for Priorities 1 and 2, and the right-site care and care consolidation programmes for Priorities 3 and 4. These studies covered both process and outcome evaluations. The process evaluations provided useful insights for understanding the programmes in the context for which they were implemented and the aspects that could be improved (Nurjono et al. 2018a, 2019, 2020). The outcome evaluations focused primarily on the programmes’ effect on hospital readmissions, utilisations, and charges, as well as mortality, which have been found to be positive (Ang et al. 2019a, b; Low et al. 2015, 2017, Wee et al. 2014).

The evaluation studies of these integrated care programmes in Singapore are limited. Many similar efforts might not make it to the public domain as published reports or peer-reviewed journal articles, and those that do might have publication bias of having significant positive findings. Outcome evaluations in the past have often been done retrospectively as they were not planned ahead of time from the start of programme implementation. As such, there have been reported difficulties in being able to gather relevant information for a rigorous outcome evaluation, particularly in cost-effectiveness analyses (Eh et al. 2020). Evaluation and understanding of long-term impact of integrated care programmes is even more limited.

56.8 Areas for Improvement

As a small city state, patients in Singapore are free to choose their health care from different hospitals and medical centres. Patients are not restricted by law or insurance to seek care only from the RHS of the geographical region that the patients reside in. As such, true integration of care needs to span the three RHSs. In the current state, much fragmentation still remains.

The use of information technology (IT) systems is key in achieving care integration through consolidating patient records and medical history and allowing flow and access across different care settings and institutions. MOH set out to achieve "One Patient, One Health Record" with the introduction of first the Electronic Medical Record Exchange (EMRx) across the public sector in 2004, and then the National Electronic Health Record (NEHR) since 2011 (IHIS 2020). By design, medical records of all public healthcare institutions were shared from the very beginning of the EMRx, but the practical use of its successor, the NEHR, by the private sector has been relatively low even after many years (Koh 2018). Transitioning from paper to electronic medical records could be difficult for some healthcare providers, particularly those from the older generation. Even those familiar with electronic medical records would have to transition to secure front-end management platforms compatible with the NEHR, necessitating cost, time and effort.

Within the three RHSs, different institutions and centres were also using different front-end management platforms, which are commercial or internally developed. This existence of such differences is partly because of legacy software platforms from before the formation of the RHSs in 2017, further limiting interoperability even within the same organisation. A common platform, named the Next Generation Electronic Medical Records (NGEMR), has been in the works and started partial rollout in two of the three clusters in early 2020. The full rollout within these two clusters is still years away as customisations continue, software kinks get ironed out, and staff adapt to the transition. It must also be expanded to provider partners of the RHSs and the third RHS.

Financial schemes and policies are keys in care integration to ensure appropriate incentives and reward for all providers. Singapore's public acute hospitals are heavily subvented to ensure the public receives affordable care. However, health care has shifted from acute episodic illnesses treated in a hospital setting to long-term care of chronic diseases in the community. As such, the financial schemes and policies have to be revised to ensure that appropriate subsidies and funding are applied to private primary healthcare sector and social service agencies (SSAs). Schemes such as the CHAS, Pioneer Generation, and the most recently introduced Merdeka Generation have components that give patients subsidised rates for chronic disease care in the community outside of the hospital setting. This is aimed at levelling the cost differentials of heavily subsidised public health care to reduce the financial barriers for continued care in the community.

The efforts to develop coordinated strategies to integrate care across the various partners within the RHSs are primarily led by the RHS offices within the clusters (Nurjono et al. 2018b). The administrative offices manage the block funding from MOH, including that for the various integrated care programmes, appropriately across the various partners. Some care partners in the community however feel less involved and are less in control within the RHS.

Public perception can be shaped by historical context and culture and can heavily affect the level of success in adoption of integrated care. Patients, particularly those from the older generation, often think that specialists are better than primary physicians (Lai et al. 2017). There is also be the perception that private health care always seeks to maximise profits (Lai et al. 2017). Because of the heavily subsidised care in the restructured hospitals and the perception that hospital-based care is superior and therefore "value for money" (Nurjono and Vrijhoef 2019), many continue to be resistant to step-down care in the community (Lim et al. 2018).

Many patients in Singapore are still passive and non-participatory in shared decision-making because "the doctor knows best" (Nurjono et al. 2019). There are also relatively few patient advocacy groups that are actively participating in codesigning of integrated care (Lai et al. 2017). A top-down approach in the design of strategies for improving care integration runs the risk of a disconnect between healthcare providers and healthcare users.

56.9 Learnings from the COVID-19 Pandemic

The COVID-19 response in Singapore has driven integration across not only health and social care, but across public, private and voluntary sectors. The rapid scale up of the whole-of-nation approach, led by a central taskforce, provides a clear illustration of the impact that integrated thinking and integrated approaches can have to solve what would otherwise be insurmountable challenges. This approach built on the experience of cross-government working on the War on Diabetes and Healthy Ageing, but at a far more rapid pace (days and weeks, compared to months and years). The pandemic showed that integration was not only of value when leveraged to address the needs and issues of ageing populations and chronic conditions but also across a multitude of acute priorities.

The Singapore integrated whole-of-nation response to the COVID-19 pandemic was built on the hard-earned lessons of the SARS experience. A Disease Outbreak Response System Condition (DORSCON) alert system was in place based on previous infectious disease threats and was the initial "playbook" that triggered measures across government, such as travel advisories and containment measures (Government of Singapore 2020c). The DORSCON approach requires measures that spanned government departments, business, schools, health care, transport, and so on and therefore requires a collegiate shared decision-making forum at Ministerial level.

Singapore had its first confirmed case of COVID-19 on 23 January 2020. The day *before*, a central planning multi-ministry taskforce was established to:

- Direct the national whole-of-government response to the novel Coronavirus outbreak;
- Coordinate the community response to protect Singaporeans and stay vigilant against the spread of the disease; and
- Work with the international community to respond to the outbreak.

The taskforce included the senior ministers from across government: health, trade, national development, education, communications and information, workforce , environment and water resources, social and family welfare, and transport (Ministry of Health Singapore 2020c). The taskforce met every day either face-to-face or virtually. This coordination and integration at a senior level was credited with enabling decisive and rapid decision-making in response to the epidemic.

Early on, the taskforce led coordination with focused objectives. Lawrence Wong, Co-Chairman of the COVID-19 taskforce, National Development Minister stated that “Every day, we are discussing, thinking through potential scenarios of how the virus can unfold and then developing new measures, adjusting and updating our measures” (Khalik 2016).

One of the first integrated approaches was around contact tracing of people who may have come into contact with COVID-19 positive individuals. This is an example of integrated multi-agency working, overseen by a single organisation, in this case the Ministry of Health. Hospitals, the police, volunteers from statutory boards, security officers, paramedics and the Government Technology Agency (GovTech) all collaborated and developed a shared pool of skills to enable effective contact tracing in the early phase of the epidemic. A Bluetooth App was similarly developed based on the insights from across the Ministry of Health, GovTech, SGUnited, and the private sector (Government of Singapore 2020a).

Singapore’s Comprehensive Medical Strategy for COVID-19 (Government of Singapore 2020b) linked up primary, community, and acute care in the common goal of deploying medical resources optimally to treat people appropriately and prevent the healthcare system from being overwhelmed (realigning capacity within days). The operationalisation of the strategy involved removing organisational structural boundaries (e.g. deploying acute staff into community facilities where appropriate), ramping up capacity, using technology as an enabler to integration, and building teams from different public and private sector organisations as well as volunteers. The Ministry of Health also worked closely with academics, such as those from the National University of Singapore Saw Swee Hock School of Public Health, to ensure that they had the latest scientific literature reviewed and synthesised to help inform decision-making (Teo 2020).

From learning around previous outbreaks, Singapore had established Public Health Preparedness Clinics (PHPCs) to be activated during public health emergencies to act as gateways to more acute care and to provide medication and subsidised care. PHPC are staffed by health professionals trained to coordinate the primary care response, following established protocols and linking closely to the hospital sector. The PHPC system was activated in February to care for patients with suspected COVID-19 infections and to support patient flow through integrated care pathways with community and acute healthcare facilities as appropriate (Primary Care Pages 2020).

Despite a proactive and integrated approach, Singapore faced a substantial challenge in its fight against COVID-19 from a surge in case numbers in the migrant worker community in early April 2020. Singapore has around 1,400,000 migrant workers, of whom some 284,000 construction workers are in high density accommodation such as dormitories (Ministry of Manpower Singapore 2019). Many of these construction workers are from India, Bangladesh, Sri Lanka, and Thailand (BBC News 2020).

The rise in cases highlighted the conditions of the migrant workers; some dormitories were reported to be unsanitary and crowded (Lim 2020). It also spoke to the gap in consistent care for migrant workers. Many relied on HealthServe, a subsidised clinic run by a charity, staffed with volunteer doctors and nurses. The capacity of the clinic had to be scaled back when a government directive was announced that restricted the work of individuals to one healthcare facility to reduce the risk of cross-infection. Although the directive was well-intentioned, the unavoidable consequence was a reduction in available volunteers and subsequent reduction in the provision of care (Geddie and Aravindan 2020). This may have hindered early warning of the growing case numbers in the migrant worker community, in the rapidly changing and intense situation ("the fog of war"). Once the surge in cases was identified, however, Singapore was swift in its integrated response.

Singapore set up a dedicated strategic inter-agency taskforce for the foreign worker dormitories, recognising that it was a "very major and urgent issue that requires active intervention" (Government of Singapore 2020b). The unprecedented approach was a herculean effort that incorporated public services, private sector, the army and the police force, to name but a few. Within days of identifying the challenge, Singapore coordinated the mobilisation of joint deployments at scale. For example, redeploying 387 officers from the police, Singapore Armed Forces and Ministry of Manpower into teams of nine, each team worked with one of the worker dormitories to bolster operational capacity and capabilities (Phua and Ang 2020). Teams focused on identifying infections, care coordination, reducing overall infections, ensuring workers have essential needs taken care of, and addressing concerns that arise.

It has been said that COVID-19 achieved more for migrant health care in a few weeks than the valiant advocacy groups have over decades, not because of the lack of effort on the part of the latter but because the realised urgency removed barriers they had been struggling with. It has led to the integration of wrap-around services which are both effective and efficient and a platform on which to continue to deliver care for this unique community group.

Underpinning these examples of integration over COVID-19 are several key enablers:

- Central coordination and chain of command.
- Clear objectives that must be achieved rapidly.
- Clear communication.
- Empowerment of local multi-agency teams.
- Use of technology and data in decision-making and operations.
- Rapid removal of barriers to achieving goals (through legislative, policy, or organisational means).

The government and its partners achieved a great deal during the COVID-19 epidemic. The opportunity is now to build on this experience to make integrated care "business as usual".

There are many insights and lessons to be learnt from the COVID-19 outbreak that would help in the advancement of Integrated Care in Singapore. The need for knowledge and skills in Public Health in general, and infectious diseases control in particular, parallels the need to break free of our traditional silos of specialities and care delivery modalities. One astute physician pointed out how COVID-19 shows us the need for capabilities in palliative care in every clinical service.

It is too early for the many research projects on the impact and implications of the COVID-19 outbreak to produce results but informal class discussions with postgraduate students (many working in health and social care) offered the following insights.

- There is a tendency in Singapore for our programmes to be rooted on, and developed by, the healthcare sector, leading to healthcare-centred programmes that are focused on meeting medical needs (and reducing the utilisation of public sector health care). Social services are added primarily to help reduce the burden on healthcare services. In the response to the outbreak, this pattern can also be observed in that many social support services were initially left aside to focus on the healthcare concerns. In Integrated Care, this is paralleled by the common preference of patients for specialists in preference to family physicians and for doctors in preference to other healthcare professionals, leading to uneven emphases and efficiencies in care provision, which can be further worsened by funding disparities and misalignment.
- The outbreak has brought issues of mental wellness and well-being to prominence, not least perhaps because the care providers themselves share in the feelings of isolation and distress which are no longer distant issues. The nature of the containment measures requires the buy-in and compliance of the population at large. In Integrated Care, the perspectives of patients and their caregivers are often considered, but they usually do not themselves participate in the design and implementation of programmes. More can be done, both for the management of the pandemic as well as in Integrated Care.

- Also, the need for teamwork and collegiality has never been more critical to the care community, and trust has been vital. The efforts to integrate our fragmented care delivery can be hindered by our fragmented healthcare *providers*. Beyond the collegiality and cooperation that would serve us well in Integrated Care, we should also consider how we can better integrate care as a single integrated system rather than closing individual gaps separately, creating in turn yet more foci of fragmentation.
- Care professionals generally have well-defined roles and responsibilities. Because of the urgent circumstances, we have had to deploy persons with minimal training into some tasks usually done by professionals and found they do quite well. We could rethink how we design and assign care responsibilities in Integrated Care; maybe some of our past assumptions could be revisited.
- There are many new informational flows needed to manage the outbreak. When information is shared haphazardly and upon request, it can become very chaotic. Information shared as it was collected in the source (and not as it is to be used in the destination) may fail to find its purpose. There should be oversight and coordination of the information flow, that is, to have a clear “information architecture” (not an *IT systems* architecture). The multiple initially disparate COVID-19 apps and portals provided by different agencies are another example.
- Anecdotally, there are instances of apparent gaps in our COVID-19 policy and measures, some due to the lack of clarity for those in the community as well as the healthcare facilities. The challenge, for the outbreak as well as for Integrated Care, is for the designers who must necessarily operate with the larger system at “37,000 feet” to understand the impact of their decision on the ground to make better decisions and for those on the ground to see the larger picture beyond their own trenches to understand them. Thus, for both COVID-19 and Integrated Care, there needs to be a mutual understanding and dialogue between the planners and the executors to produce good outcomes.
- Many things that were thought impossible or undesirable, from both providers’ and recipients’ vantage points, are suddenly possible and in demand, e.g. teleconsultation for care services. The key insight here is in the *choices*: before the outbreak, it was between “standard” and “substandard” care (hence the hesitancy), while now it is between what was called “substandard” care and no care at all. Programmes can be hampered by the urge to get it planned perfectly, but the needs on the ground are urgent.
- While the sentiment and trend are indeed towards community-based services, providers still generally prefer patients to use centre-based services rather than home-based, partly for the sake of their own convenience and efficiency. The limitations on movement prevent the elderly from coming to centres for day care and rehabilitation services, and providers must now prioritise these patients for (protected) home-based services, which prompts a reconsideration of what we really mean by care *in* the community.
- One of the classic steps in Change Management is the creation of a “burning platform” to energise and direct efforts towards a common outcome, which COVID-19 has provided that in spades. However, the well-known challenges of

our ageing and sicker population, rising healthcare costs, etc., have not done the same for Integrated Care. One of the major drivers for Integrated Care was the public sector bed crunch, which is important to the public sector but not necessarily so to other players. For Integrated Care to be driven across the whole care system, there must not only be a burning platform but the *right* burning platform that unites *all* parties.

- To respond to the outbreak, organisations had to overcome some of the classic hindrances to programmes (including lack of senior management support, top-down hierarchical thinking, lack of financing, lack of peer and partner cooperation, etc.). This experience hopefully could help when we resume our focus on Integrated Care.
- Programmes are often defined based on a specific target group of clients, e.g. the elderly in general or a disease-patient group in specific. Singapore's migrant worker COVID-19 story illustrates the dangers in missing out on groups of people in need but who fall below our radar. We have to go beyond the integration of care delivery as a goal in itself to the health of the whole population, to change our perspective from looking after the people in front of us to looking for everyone else who may be in need, not just our own citizens but all who live in our communities.
- The outbreak has led to extraordinary measures and their attendant extraordinary expenditures. Singapore's public sector has traditionally been very cautious when it comes to budgeting and accounting, preferring for example to reimburse providers for their actual or "norm" costs rather than for the value of their services to the society at large (e.g. in costs avoided elsewhere). This experience may hold lessons for how we value services, to think in terms of their outcomes and impact on society rather than on the costs incurred in their provision.
- Further to seeing the whole population as the recipients of care, we should also consider the entire community as carers, not just health and social care professional and providers. We would do well to learn from the current COVID-19 outbreak to regard Integrated Care not as a "from us the professionals to them the clients" but as a "we are all in this together" situation and design the care delivery *and receiving* system to foster this mutual collaboration.

56.10 Outlook

Singapore's healthcare system has evolved over the years, from its initial taxation-based governmental provision to a community of restructured public providers to a gradually morphing network of services to the current somewhat complex ecology of organisations that includes public, private, and "people" sectors providing different levels of health and social services. The inherent "philosophy of design" echoes the official MOH strategy of "many helping hands" for patients in the community.

Although the health and social sector still operate on what is essentially a fee-for-service economy (even government subsidies are somewhat based on the volume of care episodes), much funding comes from and through the government, either as subventions directly to the public sector or through grants to individuals and families.

Such a multipronged and seemingly chaotic ecology provides many opportunities for innovation and enterprise but at the same time encourages a certain amount of friction in the system as patients, their families, and providers must learn to negotiate their way to desired outcomes, and new, even excellent, interventions and programmes struggle to rise amidst a large field of competitors.

The contrast of the preceding health and social care environment with the very centrally coordinated and directed response to the COVID-19 pandemic is stark. The way forward will depend very much on how well Singapore learns from its response to the huge communicable disease threat in her immediate future to apply to the possibly larger non-communicable disease threat in the longer term.

The future will show how well we learn from the last insight above from the students: that *all* of us have to work together. Much of what we do in Integrated Care has traditionally been driven by *empathy* (an emotional connectedness with others), *reciprocity* (giving in exchange for receiving), and *charity* (where one gives to the less privileged), but the way forward must be built on *solidarity*, of being in the same boat and must have all hands on deck (Fong and Devanand 2020).

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Integrated Care in Norway

57

Monica Sørensen

57.1 Introduction

As in the rest of the Western world, demographic development and new technologies demand rapid and comprehensive changes in how the Norwegian healthcare system is organised and delivered. In the recent decades, policy development has focused on improving preventive and person-centred interventions, care coordination between primary and specialist care (The Norwegian Ministry of Health and Care Services 2008–2009; Romoren et al. 2011) and on increasing user involvement in clinical decisions (TMoHaSC 2019).

57.2 Norwegian Health and Social Care Services

In 2019, health expenditure in Norway was 9.4% of GDP. Although recent policy development has put much effort in strengthening primary care, only about 6% of this budget was used in primary care, which is half of the OECD average at 12% (OECD 2017, 2019a). Thus, insufficient resource allocation is considered a threat to the sustainability of Norwegian primary care services (OECD 2014). The public hospitals in Norway are organised into four regional health authorities and operate with a combined budget of about NOK 75 billion (2019) (The Ministry of Health and Care Services 2015).

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Box 57.1 Norwegian municipal health and social services

Municipal health and social services encompass: emergency medical services, dental health services, home care services, physiotherapy, occupational therapy, general practitioner (GP) service, mental health services, school health service, prenatal care, rehabilitation services, nursing home accommodation, day care, measures to combat alcoholism and drug abuse, environmental preventive health measures and user-controlled personal assistance.

Municipal health and social services are comprehensive and serve the population from birth to death (see Box 57.1 for what these services encompass). All persons registered as domiciled in a Norwegian municipality has the right to be listed with a regular GP. This right also applies to asylum seekers and their families when they are members of the national insurance scheme. The Norwegian Labour and Welfare Administration is responsible for a third of the state budget of Norway, administering programs such as unemployment benefits, pensions, child benefits and more.

Although Norwegian citizens enjoy one of the highest per capita health expenditures in the world (Ringard et al. 2013), many people with complex health and social care needs such as those with multiple long-term conditions (LTCs), substance abuse problems, mental health disorders and those living under social deprivation experience inadequately coordinated and disintegrated health care (Oxman et al. 2008). This is despite the same groups of people have the right to an individual care plan and a personal coordinator intended to safeguard their right to receive comprehensive, coordinated and individually tailored health and social services (and sometimes educational services) (The Norwegian Directorate of Health 2011, 2018; Ivan et al. 2019). It is the responsibility of the municipality to create routines, train employees and appoint coordinators for this scheme. However, only 0.6% of the Norwegian population has a tailored care plan, and there is a paucity of data providing information to estimate the size of the coordination and integration challenges for persons with the highest care needs. Siloed services, missing infrastructure for cross-institutional communication and erroneous spending on specialist care has received much of the blame (Norwegian Ministry of Health and Care Services 2018). As a result, national diagnose specific pathways (‘pakkeforløp’) for, among others, mental disorders and cancer have been implemented (Norway:Norwegian Directorate of Health 2019). These pathways are based on national and international professional guidelines and meant to strengthen service quality and access and facilitate safe and predictable care processes. As part of the service is the appointment of a care coordinator who organise all relevant health and social services for relevant users. Still, more than 50% of the people who are told by a doctor that they have a mental health problem feel that their daily activities or ability to work are limited, indicating that mental health and employment services could be better integrated (OECD 2019b).

The next sections give an overview of recent policy documents supporting Norwegian authorities' ambition to improve care integration and creating person-centred health services.

57.3 The Coordination Reform (2008–2009)

The Coordination Reform was effectuated in 2012 and aimed at improving cooperation between municipalities and hospitals and the cost-effectiveness of health care. Legislation and incentives followed the reform and required hospital trusts and municipalities to establish binding agreements in order to improve coordination and integration of healthcare services (Specialist Health Services Act (Spesialisthelsetjenesteloven) 1999; Municipal Health and Care Services Act (Helse-og omsorgstjenesteloven) 2011). The reform asserted that more money should be spent investing in preventive measures and more financial incentives and responsibility should be transferred from the specialist to the primary care. Incentives were also suggested for hospitals and municipalities to team up. Although the length of hospital stays is reduced following the reform (The Norwegian Directorate of Health 2015; Grimsmo 2013; Abelsen et al. 2014), earlier discharge requires tighter communication between care levels and institutions, and there are indications that the reform worsened communication across the two care levels and thus has led to reduced quality of care (Grimsmo 2013).

Three years following the Coordination Reform, in 2015, several audits of how well municipalities and hospitals collaborated were carried out by governmental bodies (The Norwegian Research Council 2016; Board and of Health Supervision 2016). One was a surveillance by the Norwegian Board of Health Supervision in 37 municipalities and 56 organisations where violence of law where found in 36 organisations. Most frequently, these breaches were related to inadequate communication between hospitals and municipalities, leaving patients without appropriate primary care services (Board and of Health Supervision 2016). The report also noted that the dialogue and planning of care services with the patient after discharge did not meet patients' expectations. Results from a second evaluation study by the Norwegian Research Council indicated that the impacts of the Coordination Reform led to more fragmented patient care pathways (The Norwegian Research Council 2016). The evaluation showed that municipalities felt they were not considered as an equal partner in dialogue with the specialist care regarding treatment decisions, and they often lacked necessary information about patient prescriptions. Increased municipal responsibility for patients unable to stay at home has also led to care units being rebuilt from single to shared accommodations, and long-term facilities for home-bound patients are reallocated to short-term stays for patients transferred directly from the hospital. Lastly, the Coordination Reform has been criticised for being more about transferring money than improving care for the most vulnerable patients (Grimsmo 2015; Monkerud and Tjerbo 2010).

Following the Coordination Reform, four recent policy documents provide a consolidated picture of the Norwegian government's future policy for the health and care services: the white paper *Primary Health and Care Services of Tomorrow – Localised and Integrated* (2014–2015)), the white paper on public health (2014–2015], *Care Plan 2020 and* the *National Health and Hospital Plan (2020–2023).*

The primary health and care services of tomorrow—localised and integrated (white paper 2014–2015).

The last white paper on primary health care reiterates the intentions of the Coordination Reform on coordinated, integrated patient pathways, more prevention and early intervention, more services close to where the users live and a larger proportion of the services provided in the municipalities (The Ministry of Health and Care Services 2015). It emphasises that to achieve these goals, strengthening municipal competence is needed and that the following main target areas for tomorrow's primary health care must be addressed:

- Quality of the services
- Fragmentation and isolation of services
- Coordination between the services
- User involvement
- General practitioners poorly integrated with the rest of municipal health and care services
- Lack of interdisciplinarity.

57.4 The White Paper on Public Health (2014–2015)

The national policy on public health emphasises to strengthen the facilitation of healthy choices (TMoHaC 2014). Anticipated results are increased individual responsibility for health and well-being and a more positive attitude towards lifestyle changes. These changes are expected to be accounted for by local community development and intersectoral cooperation, potentially creating a society that promotes quality of life for all citizens. Yet, inequality in health is a major challenge in Norway, and those with higher education and income generally live 5–6 years longer than those with lower educational attainment (Health and Institute Institute 2018).

Mental health and substance abuse prevention are other target areas of the white paper and foreseen as equally important parts of the public health work. However, mental health problems among children and adolescents are high and increasing among girls (Institute of Public Health 2016).

57.4.1 Care Plan 2020

The Norwegian Government's Care Plan 2020 followed the white paper on Primary Health and Care Services (The Ministry of Health and Care Services 2015). It envisages the state to assume a greater financial responsibility for ensuring that municipalities develop enough capacity and quality in the health and care services and are able to improve cooperation and coordination among the various primary care services.

Measures in the plan are designed to enable users to have greater influence over their own daily lives and more freedom of choice through new innovative solutions (e.g. through implementation of user-friendly welfare technology and digital solutions that allows patients to supervise their own health and meet healthcare providers from at home). The plan reiterates that care services must be designed and developed together with users, patients and close family members in cooperation with volunteers, non-profit organisations and private actors, and that services must be based on sound expertise, effective management, continuity of services and multidisciplinary cooperation (MoHaC 2015).

57.4.2 National Health and Hospital Plan, 2020–2023

The recently published National Health and Hospital Plan describes what efforts are needed to develop a more person-centred healthcare system over the next four years and how to realise services that is in harmony with Health Minister Bent Høie's slogan 'No decision about me, without me' in a sustainable way (TMoHaSC 2019). For example, key future desired scenarios are described:

- Patients and their next-of-kin participate actively in decision-making about their health care
- Co-design is the norm, and citizens can communicate digitally in a language they understand with their providers
- Patients experience integrated and coordinated services across specialist and primary care
- Health professionals support each other and agree on a united course of action for the patient.

In addition, 19 health partnerships will be established in Norway during 2020, partly inspired by NHS's Vanguard model (NHS 2017). These communities will have members representing the local hospitals, GPs, primary care institutions, municipalities and citizens planning and developing services together based on local needs. From being 'parts' of the system, municipalities and hospitals are envisioned to becoming 'partners' and work better together to improve care for the most vulnerable patients. Children and youth, persons with mental illness or drug addiction, frail elderly and persons with multiple LTCs are identified as prioritised groups for these health communities.

57.5 Reaching the Quadruple Aim in Norway

Attaining the quadruple aim, i.e. enhancing patient experience, improving population health, reducing costs and improving the work life of healthcare professionals involves shifting from a volume-driven system to a system that achieves outcomes that matter to patients and appears meaningful for healthcare workers (Bodenheimer and Sinsky 2014). Governmental strategies (TMoHaSC 2019; The Norwagian Ministy of Heath Care Services 2012; TMoHzC 2014–2015), reforms (The Norwegian Ministry of Health and Care Services 2008–2009) and legislations (The Norwegian Ministry of Health and Care Services 2012; Lov om folkehelsearbeid (folkehelseloven) 2011) generally include an ambitious number of ultimate goals and expectations regarding the development of integrated and person-centred care services. However, scant attention is usually paid to guidance in the processes of delivering such services (Reeves et al. 2010), the necessary underlying organisational capabilities and conditions (Evans et al. 2016) and the impact on policy development of patient-reported outcomes and needs. Although national surveys of patient experiences of hospital-based care are carried out regularly in Norway, it is questionable to what extent they inform service development. Taken together, these surveys demonstrate that patients are satisfied with the general communication with healthcare personnel. However, improvement is needed in regards to engaging patients in decision-making, informing and preparing patients for upcoming hospital discharge, coordination of care across hospital and municipal health services and the access of services (Bjerkan et al. 2014). Noteworthy, no similar surveys are carried out in primary care, and there is an urgent call for establishing routines for gathering and learning from municipal care experiences.

The Norwegian government wants healthcare professionals to operate according to patients' answer to the question: 'what is important to you?'. Patients generally prefer providers who have time to listen to their worries and questions, to know what is next in the care trajectory and who knows who is responsible for what (Institute of Medicine 2013). Although widely recognised as facilitating shared decision-making, care plans are not used to consolidate patient preferences and aspirations with those of the healthcare professionals or to align care across providers and levels of care. This can be reflected in the outcomes of the Commonwealth Fund International Health Policy Survey (2016), where Norwegian patients scored among the worst for indicators such as GPs spending time to explain things in a way patients can understand, GPs discussing lifestyle intervention or things that worry or cause patients stress, patients experiencing challenges with care coordination and gaps in hospital discharge planning (Osborn et al. 2014).

Doctors in primary and specialist care are stretching themselves to handle the tensions between quantity and quality and overcoming organisational shortcomings (Wærnes 2017; Gullestad 2017). In specialist care, an over-emphasis on clinical indicators, budget concerns and limited management recognition for quality of patient care have led to doctors feeling estranged and having their professional identity threatened. In primary care, Norway, as most other western countries, is experiencing a recruiting and retention emergency of healthcare professionals. Six out of 10 GPs and one out of six nurses consider quitting their job because tasks and responsibilities are increasing and the workforce reduction advances (Nilsen 2017; Thalberg and Sønstebø Svendseid 2019). Despite GPs having warned against increasing work pressure for several years, few measures have been initiated to improve their experience of joy and meaning in their work.

Mandated governmental cuts in the healthcare budget mean the continuation of approaching health and illness reactively is not sustainable. Numbers from 2015 show that the by far largest expense item on the Norwegian healthcare budget is curative and rehabilitative care (50%), while preventive and public healthcare services are offset with only a tiny fraction (3%) (NOK 2018). Thus, the visions set out in the governmental policy papers briefly described above for integrated, proactive and person-centred services are currently no more than visions.

57.6 Patient-Centred Healthcare Team in Tromsø

A promising initiative for the development of more person-centred care services has been introduced by The University Hospital in Tromsø (UNN) and Tromsø municipality. With a purpose of reducing hospital costs (7 mill NOK per 1300 patient per year), the initiative set out to lower the number of bed days by replacing acute care for elective care and increase the use of technology (Rumpsfeld 2019). The patient-centred healthcare team in Tromsø is co-financed by the hospital and five municipalities and offers people with long-term and complex health challenges comprehensive healthcare services based on patient preferences and goals. The model focuses on preventing acute illness, health education and meeting patients' preferences for care. Patient-reported outcome measures are developed from the project to guide service development and outcome evaluation. The team, consisting of a team of geriatric specialists, nurses from the district and the hospital, physiotherapists, occupational therapists, pharmacist and medical secretaries, identifies and assesses care needs early, provides support during discharge and follow-up, facilitates coordination and integrated services and provides home-based services by actively monitoring, supporting and caring for patients outside the hospital until adequate follow-up services are in place (Bergmo et al. 2016). The users are actively involved in the care and self-management process, which involves identifying individual goals, assessing home situations and facilitating personal tailored care plans and follow-up protocols.

Based on the team's experiences, the combination of patient-centred goal-oriented care, integrated care and proactive care have reduced target patients' use of high-level emergency care, increased the use of planned community services, the number of patients offered rehabilitation and substantially reduced mortality risk compared with propensity score matched controls (43% after six months) (Bergmo et al. 2016; Berntsen et al. 2019). Furthermore, only 3% of the patients handled by the team were readmitted within 30 days compared to official statistics from 2013 reporting that 12.7% of the patients over 67 years old were readmitted after a hospital stay in Tromsø (https://www.helsedirektoratet.no/statistikk/kvalitetsindikatorer/behandling-av-sykdom-og-overlevelse/reinnleggelse-blant-eldre-30-dager-etter-utskrivning). The team members agreed that coordination was the most important part of their work, which is a task they did not have prior to the introduction of the team (Bergmo et al. 2016). The coordination particularly involved prompt engagement of the appropriate professionals, arrangement of necessary meetings and communication channels that included healthcare personnel from community care services and the hospitals.

57.7 Outlook for the Future

Norwegians enjoy universal health coverage to a comprehensive set of healthcare services, and private healthcare spending rates are among the lowest in the world (https://www.gapminder.org/tools/#$state$time$value=2010;&entities$show$country$/$in@=nor;;;;&marker$axis_y$which=out_of_pocket_share_of_total_health_spending_percent&scaleType=linear&spaceRef:null;;;&chart-type=linechart). However, the price for the state is high and unsustainable (Kringos et al. 2013). An ageing population means more skilled healthcare personnel must be employed in the communities, and more money must be spent in primary care. One-third of every death in Norway is attributed to preventable risk factors, and the rates of hypercholesterolemia, hypertension, overweight and obesity are increasing. Furthermore, although receiving more attention in recent years, Norway witnesses high rates of mortality from mental health disorders and a high prevalence of harmful use of drugs/alcohol (Institute for Health Metrics and Evaluation 2016; OECD 2019c). Considerable efforts should therefore be put in place on early prevention of lifestyle diseases.

Among the five key primary care aspects (structure, accessibility, continuity, coordination and comprehensiveness), coordination has been identified as Norway's weakest dimension (Kringos et al. 2013). Since coordination of primary care is related to reduced potentially avoidable hospitalisations for conditions that can also be treated within primary care, money could be saved on prioritising strengthening of community healthcare actors, the skill mix of primary care providers, the collaboration within primary care and with secondary care providers and integration of more public health functions in primary care. Successful implementation of current national policies will also require strengthening of municipal leadership, quality management and improved resource allocation to practice-oriented research in primary care (Bjorvatn et al. 2019). Moreover, development of clinical guidelines and payment models that support healthcare professionals in multidisciplinary team-based practices and in developing good professional–patient relationships that respect patients' values and preferences will be necessary (Blozik et al. 2013; Hughes et al. 2013; Smith et al. 2012; Sondergaard et al. 2015; Bodolica and Spraggon 2014).

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Wales

58

Thomas Howson, Leo Lewis, and Helen Howson

58.1 Introduction

Wales is a westerly region of Great Britain (GB), which shares a single border with England to its east. With a population of just over 3.1 million people (2019), Wales is the United Kingdom's (UK) third largest constituent nation, representing a 4.7% share of the total UK population (ONS 2020). Once an industrial powerhouse, providing coal and steel to fuel industrial expansion globally, traditional industries in the region have since witnessed a period of significant decline, with Wales now considered the poorest of the four UK nations (determined by Gross Value Added (GVA) per head of population) (see ONS 2018a, b).

As with many other developed nations internationally, Wales has an ageing population, which is further hampered by a high prevalence of chronic disease, much of which remains a legacy of the country's industrial heritage (Lewis 2015). This is accompanied by falling fertility and birth rates (ONS 2019); leading recent predictions (ONS 2019) to suggest a 0.9% reduction in the nation's population size by 2048. Alongside this, for the first time in recorded history, life expectancy for both men and women in Wales has declined (ONS 2018a), whilst health inequalities and chronic disease burdens continue to grow.

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Publicly funded healthcare services in Wales are delivered by NHS Wales, which has witnessed significant change over recent years. Following political devolution in 1999, decision-making powers governing the provision of health and care services in Wales were decentralised from the UK central government, aligning with similar processes that occurred in both Scotland and Northern Ireland. This has led to divergence in both policy and practice relating to the way in which health and social care services are delivered throughout the four UK regions.

In 2009, NHS Wales undertook a further restructuring exercise to ensure services could most effectively meet the evolving health and care needs of its population. This transformed NHS Wales service delivery obligations from the responsibility of 22 Local Health Boards (LHBs) (aligned to local government boundaries) and seven NHS Wales trusts, to seven integrated Local Health Boards (Fig. 58.1) and three pan-Wales NHS Trusts (Public Health Wales NHS Trust, The Welsh Ambulance Service Trust and Velindre NHS Trust), as is seen today.

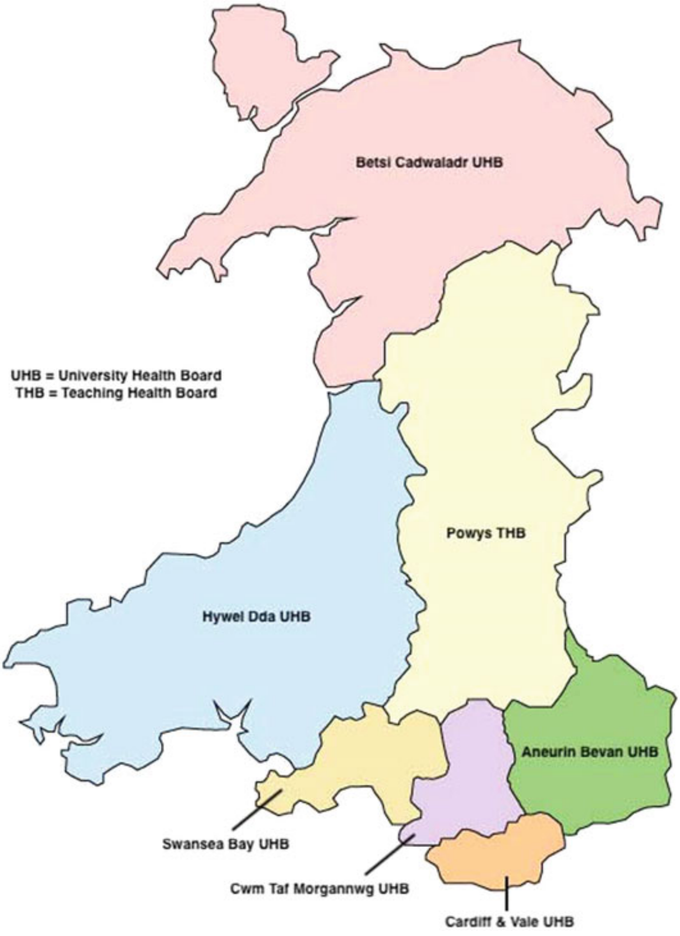

Fig. 58.1 NHS Wales Health Board boundaries

Currently, the Welsh Government spends just over 48% (£7.3 bn) of the £15 bn devolved national budget for Wales on Health, Wellbeing and Sport (Welsh Government 2016). NHS Wales employs around 90,000 staff, making it Wales' single largest employer.

58.2 Problem Definition

As with many other nations internationally, Wales faces a growing number of challenges in relation to the consistent and sustainable provision of high-quality health and care services. These, amongst others, include an ageing population, a growing burden of chronic disease, increasing public demand and expectations, staff shortages and recruitment issues (Bevan Commission 2016a, b; PRHSCW 2018). Alongside this, NHS Wales also faces wider operational and financial performance-related challenges, which have resulted in five of seven NHS Wales health boards being placed in enhanced monitoring or special escalation measures. Findings from the recent Parliamentary Review on Health and Social Care in Wales (2018) suggest that a root cause of many of these challenges might be problems arising from '*the fragmented system through which care is delivered*'.

58.3 Integrated Care Policy in Wales

Although there remains no single overarching policy document that outlines specific criteria for the implementation of integrated care in Wales, the notion and desire for more joined-up approaches to the delivery of Health and Social Care services have been voiced for many years. This aspiration has become increasingly prevalent in both policy and practice at national, regional and local levels, with a number of examples of this detailed below in Box 58.1.

Box 58.1 Welsh Integrated Care Policy and Interventions

- In 2003, the Welsh Assembly Government released its *Health*, *Social Care* and *Well-being* planning strategy (Welsh Assembly Government 2003), which aimed to support a more '*integrated and multi-disciplinary approach to local authority and NHS strategic planning for health, social care and well-being*'. This placed a statutory duty on public sector bodies to adopt partnership-working approaches when designing and implementing health and care services across Wales. This also led to the establishment of integrated health and social care partnership forums between local authorities, NHS trusts and local health boards, although these forums had no statutory basis.

- In 2009, Welsh Government restructuring of NHS Wales services led to the creation of seven integrated LHBs (see Fig. 58.1). This intended to provide a vehicle for more joined-up approaches in relation to the delivery of public health and healthcare services across the country.
- In 2011, the Welsh Government's five-year vision for the NHS in Wales (Welsh Government 2011) outlined the need for improvement and future proofing of NHS Wales services. This placed the requirement for more integrated approaches to health and care service delivery as one of seven core areas demanding greater attention.
- In 2014, the Welsh Government established a national Integrated Care Fund (ICF), which aimed to drive greater integration between social services, health, housing and third sector bodies in order to develop more effective and sustainable services. Although initially established on a one-year basis, the Welsh Government has continued to invest in the ICF, with £270 m made available to regional stakeholders up to March 2019 (see Welsh Government. 2019).
- In 2014, the Social Services and Wellbeing Act (Wales) also received royal assent. The Act, which came into force in April 2016, provided the legislative framework for the transformation of social services in Wales. This is guided by four inter-related principles or themes: people, wellbeing, early intervention and collaboration, aiming to promote '*stronger partnership working across all organisations to better support people in achieving positive outcomes*'.
- In 2016, the Welsh Government created seven statutory Regional Partnership Boards (RPBs). The purpose of the RPBs is to drive the strategic regional delivery of social services in close collaboration with health to provide greater integration and coordination between public sector bodies and all their services, together with engagement with the third sector in Wales.
- In January 2018, a Parliamentary Review on Health and Social Care in Wales (2018) identified the need to create one 'seamless' system of care across the country, by integrating all facets of the health and social care system; from primary and secondary care, to mental health and social care services.
- In June 2018, responding to the findings of the Parliamentary Review, the Welsh Government placed the integration of health and social care services at the forefront of their policy agenda, outlining ambitions of creating a '*seamless whole system approach to health and social care*' in the long term health and care strategy, 'A Healthier Wales*'* (Welsh Government 2018).

58.4 Integrated Care in Practice in Wales

A number of initiatives designed to strengthen the implementation of integrated care in practice are currently taking place across Wales. Some of these are supported by ICF funding (see Box 58.1), with others being encouraged through different means, such as the Bevan Exemplars Programme (discussed in further detail below). The following section sets out two examples of integrated care in Wales; one between health, social care and wider support services and the other within the healthcare system itself. Case study one describes an example of integration between organisations, citizens, patients and communities, whilst case study two details an integrated approach to palliative care for people living with heart failure, led by a hospital in collaboration with other primary and community-based organisations.

58.4.1 Integrated Care Case Study One: A Healthier West Wales: Proactive Technology-Enabled Care

A Healthier West Wales is an ambitious transformation project that seeks to radically change health and social care in the region over the coming years. Driven by the West Wales Care Partnership (WWCP), the approach has leveraged insight from the work undertaken by two separate, but linked Bevan Exemplar projects, one which looked at the provision of holistic care for people living with dementia and the second developing and testing an integrated health and social care support worker role. The ‘A Healthier West Wales’ project has sought to rise to the challenges highlighted by the Parliamentary Review on Health and Social Care in Wales (2018), utilising transformation funding provided by the Welsh Government to innovate in key areas, including new models of integrated care. The project is underpinned by £7.45 million of transformation funding and amalgamates a range of core regional priorities and initiatives into a single, comprehensive programme (see Fig. 58.2).

One element of the A Healthier West Wales approach is the Proactive Technology Enabled Care (PTEC) Programme. The underlying principles of the Healthier West Wales PTEC approach were designed upon a similar programme implemented in Bilbao, Spain, which demonstrated how care systems can be transformed by developing proactive and preventative services facilitated by new technologies. The Bilbao model of care is focused on the use of regional tele-assistance services to support people living in local communities. The model utilises risk-stratified data (inc. social indicators) to build a picture of need, enabling a proactive and integrated approach to care and support, by for example, calling up ‘at risk’ individuals and mobilising preventative health and social care services where necessary to avoid crises. This is supported by a 24/7 response to alerts and incoming calls, including from home-based telecare sensor alarms, which allows remote monitoring of the most vulnerable citizens.

Key to the success of the approach in Bilbao has been the building of alliances with local service providers, including NGOs and community groups, whilst the service itself operates as a public–private partnership. In Bilbao, 14% of the social

Fig. 58.2 A Healthier West Wales programme approach (Source: West Wales Care Partnership)

care budget is now spent on tele-assistance (compared to 1% in Wales), and far less resource has subsequently been required for domiciliary and residential care (29% of the social cared budget in Bilbao, compared to 83% in Wales).

The Healthier West Wales project is coordinated operationally by the West Wales Care Partnership and Delta Wellbeing, a multidisciplinary contact centre (health, social care and support sectors), who provide a 24/7, single point of access for service users. This partnership is responsible for coordinating the delivery of three main programme components (outlined below), each of which is designed to improve people’s well-being and reduce demand on the health and care system:

- Fast-tracked, consistent integration—providing a multi-agency crisis response service to support people in medical crisis and link them with local support and thus avoiding entry into the acute health system.
- Creating connections for all—developing services within communities enhancing the community connector role to facilitate the development and promotion of volunteering to champion independent communities through the ‘West Wales is Kind’ programme.
- Proactive, technology-enabled care—supporting people through enhanced technology to enable them to stay at home and connecting them quickly with wrap-around, responsive support within their community.

An independent evaluation, based on the Quadruple Aim approach, has been commissioned to examine the following aspects of the projects:

- Outcomes and performance measures for citizen/ patient and care system;
- Cost benefit analysis of transformation fund use and sustainability of outcomes and the model;

- New models of working including critical success factors, extent of shift to preventative services and applying the philosophy of Prudent Health and Care;
- Pace of change and has it varied according to population group, level of intervention, geography;
- Engagement and participation of workforce, citizens and patients;
- Governance arrangements, new guidance and policies.

Whilst the outcomes from the project are not yet available, the West Wales response to the COVID-19 pandemic demonstrated the ability for the model to be rapidly scaled up to provide both additional and enhanced services and support to many more people identified as vulnerable by Public Health Wales.

58.4.2 Integrated Care Case Study Two: Providing Palliative Care for Heart Failure Patients at Home

Heart failure (HF) is an increasingly common, expensive and unpleasant chronic disease. Whilst most people and their families would prefer to die at home (or in a place of their own choosing), some 81% of people still die in hospitals. This is associated with significant costs both emotionally and financially to patients, family members and health and care systems alike. Indeed, the costs of supporting HF patients in their last year of life in hospitals accounted for around 50% of the overall costs related to the management of the condition, which equates to roughly around 1% of the total NHS budget. Furthermore, quality of life for patients with HF is poor, with sufferers exhibiting high symptom burdens and frequently requiring admission to acute care settings, which also places significant demands on caregivers and health and care services.

Palliative care (PC) services can have a significantly positive effect on HF patient's quality of life. Such interventions can drive improvements in symptom control, support advanced care planning, increase access to care in the community and reduce hospitalisation rates. However, referral rates to these services are low, with only 4–6% of patients with HF being suitably referred, despite recommendations from the American Heart Association (AHA) and the National Institute for Health and Care Excellence (NICE) since 2005. Such poor referral rates are associated with a number of factors, which include

- Uncertainty relating to optimal referral time.
- Difficulty referring patients with longstanding relationships with invasive cardiac services.
- Difficulty for PC services to match the unpredictable disease trajectory of heart failure.
- Uncertainty regarding whether patients may still receive benefit from active treatments.

To address this, a supportive care project for advanced heart failure patients was initiated as a Bevan Exemplar project. The project aimed to develop a more prudent approach to health and care, through an integrated, cross-boundary, heart failure care pathway, which involved a co-specialty, multidisciplinary team. This included a palliative care consultant, a consultant cardiologist and specialist palliative care and heart failure nurses, operating in both parallel and joint clinics.

The purpose of the project was to provide a progressive model of advanced care planning and enable palliative care in the home, for example, through the use of subcutaneous Furosemide infusions. This approach allowed patients with an estimated prognosis of 1–2 years to be seen in individualised settings including hospitals, outpatient clinics, at home and in nursing homes or hospices, facilitating a more tailored and responsive approach to care throughout the unpredictable trajectory of the disease lifecycle. The emphasis on transitioning between specialities with overlapping input allowed for earlier referral, transfer of trusting relationships between patients and specialities and the ability to maintain access to the skills and expertise of both specialities.

Over 3 years, 101 patients were referred to the service; 60 patients are now deceased (mean time in service: 225 days), and 41 are still receiving ongoing care (mean time in service: 303 days). On average, the service helped avoid 12 hospital bed days for each deceased patient and 15.5 bed days for patients that remain on the care pathway. Death rates at home (which was the preferred place of death for the majority of patients) increased from 18 to 58%, whilst 90% of patients using the service would recommend the approach to other HF patients, and considered the care that they received both compassionate and coordinated. Alongside this, 80% of patients reported that symptom control was improved and that integration of care with the cardiology heart failure team was beneficial.

In 2017–2018, it was demonstrated how this approach ‘flipped’ the actual place of death so that 91% of patients being cared for under the home-based model died at home, and the remainder in local hospices. The avoidance of acute hospital admissions in the last year of life reduced overall costs, demonstrating a net positive impact both financially and in terms of patient and carer satisfaction.

A subsequent evaluation of the programme determined the model to be more prudent and highly sustainable, with a cost saving approximated to be in the region of £10,000 per patient referral. Key elements of the pathway included the strong co-speciality relationships, cross-boundary approach, multidisciplinary team working and use of electronic communication and virtual clinics. Furthermore, it is thought that a similar integrated model of care could be applied to support other advanced chronic condition pathways including the management of end stage renal, respiratory and liver disease.

58.5 Impact, Dissemination and Replication

From the evidence outlined in Box 58.1 and case studies presented previously, it would appear that Wales has set out strong foundations from which to build more effective integrated care approaches in practice. However, despite the legislative and political support for more effective integrated working, evidence suggests that there are a number of other significant factors at play, preventing Wales achieving its full potential and promise to achieve better integrated care.

In 2019, a report by the Welsh Audit Office (2019) concluded that '*the fund* [ICF] *has had a positive impact, supporting improved partnership working and better integrated health and social care services…. Despite positive examples, the overall impact of the fund in improving outcomes for service users remains unclear, with little evidence of successful projects yet being mainstreamed*'.

The report suggested that although ICF funding provided an impetus for greater integration between regional partners to co-develop services and more joined-up funding arrangements, aspects relating to the allocation and governance of funding have '*hampered regional delivery*' at a local and national level.

Transforming the way services are planned and delivered is not easy, and the barriers (and enablers) to change have been well documented (see Bagnall 2012; De Silva 2015; Bevan Commission 2016a, b). Evidence suggests that in order to systematically develop and apply innovative ways of working, in this case in integrated care, there is a need to also recognise and address the cultural, behavioural, leadership and the local environmental factors at play (see Miller 2016; Public Health England 2018; Timmins 2019). However, one of the biggest weaknesses in Wales' approach to delivering integrated care appears to be a predominant focus upon the strategic, organisational and management perspectives of integrated care rather than addressing the citizen/patient-reported concerns such as accessibility, care quality and coordination (Wales Audit Office 2019).

The Bevan Commission, the leading independent think tank for health and care in Wales recognised the significance of this through its Bevan Exemplar programme (see Bevan Commission 2016a). This aims to try out and test innovative ways to deliver a more Prudent Model of health and care in Wales, including integrated care, as demonstrated in the previous case studies. Over a 5-year period, the Bevan Exemplar programme has supported more than 200 initiatives, demonstrating a consistent 80% success rate, and many other impacts across a range of initiatives led by people at all levels within the health and care system (for example see Bevan Commission 2019). Whilst the success of these individual initiatives has been demonstrated within one area or part of the system, the ability to ensure these are adopted and spread systematically across Wales has been much more difficult to achieve. As a result, the Commission recently established, with Welsh Government support, a national *Adopt* and *Spread* programme (see Bevan Commission 2020).

The *Adopt* and *Spread* programme uses a '*living lab*' type approach to try out and test the adoption and spread of its Exemplar projects in live service delivery settings across health and care in Wales. This uses the original Exemplar to help support a number of 'adoptees' and assess how these different models of care perform when implemented across a variety of contexts. This will help to identify the critical factors or necessary conditions that enable (or otherwise) their successful adoption and spread.

Alongside this, the Welsh Government has provided each Regional Partnership Board in Wales with transformation funding to strengthen integrated care. This is further supported by additional funding for the establishment of regional Research, Innovation and Improvement Co-ordination Hubs (RIICHs). The purpose of this nationally coordinated network of hubs is to '*bring together all research, innovation and improvement activity within each regional partnership board footprint, focussed on supporting local innovation and partnerships which drive towards new models of care*' (Welsh Government 2018). This aims to support the coordination, collation, analysis and dissemination of research, innovation and improvement activity at a regional and national level.

Taken together, these actions will help to provide conditions conducive to secure and support the changes needed, as well as an ongoing learning environment to reinforce this.

58.6 Lessons Learned and Outlook

Drawing upon the experience of applying integrated care policy in practice from stakeholders across Wales, a number of important lessons have become evident, which are outlined below. These include strategic, policy and practical perspectives, all of which are important in enabling the delivery of more effective integrated care. If successfully translated into practice, these lessons from Wales, alongside wider international evidence, could provide the essential steps to drive positive change for people, patients and professionals alike on a larger scale.

- **A place-based approach**. There is a need to adopt a place-based approach to ensure that health and social care services respond directly to the needs of people in local contexts. This should value and utilise the knowledge, skills and assets held by people and communities themselves, whilst also encouraging their participation in the co-design and co-delivery of services. This should place people and their needs first, whilst also promoting behavioural change amongst managers, professionals and providers.
- **Investment in the workforce, investment in teams**. Transformational change requires a radical shift in thinking to ensure care is delivered by community-based teams and through inter-professional working. The ability to provide seamless care remains problematic due to siloed professional, operational and funding mechanisms.
- **Readiness for change**. Not everyone is at the same stage of 'readiness' for change or has the motivation or confidence to do so. Understanding this level of maturity is key to helping people and organisations take a different perspective on

issues, whilst also creating a sense of ownership over transformation processes. This will help develop greater momentum and promote a wider cultural movement for change, particularly with short-term mindsets and financial inflexibility.

- **Leadership and persistence**. In overcoming resistance to change, there is a need to co-create a clear vision and communicate the aims and purpose of new innovations to a wide range of stakeholders. Investing in the skills and competencies of leaders at all levels in organisations is important, alongside ensuring that the core focus of change is firmly centred on the needs of people and communities.
- **Engaging people and working the system**. It is recognised that whilst there is policy support for integrated care in Wales, this does not automatically translate into change across the people and organisations involved (e.g. procurement rules, regulatory frameworks and funding mechanisms). However, we know that people often make things work despite the system and 'where there is a will there's a way'. Therefore, encouraging and supporting people to work creatively, using their assets and insight, are imperative in such contexts.
- **Permission and support to act**. The work environment often constrains the ability to make changes, with rules, bureaucracy and overly hierarchical systems focused on process-driven regulation, rather than promoting a freedom to innovate and improve. Giving people 'permission' to fail and encouragement to change plays an important role in creating a supportive environment for effective transformation. Addressing these rules, effectively managing risks, and finding new ways of sharing power, governance and accountability require attention.
- **The Bevan Commission and Bevan Academy**. The ability to use an independent, credible and respected body to advocate, promote and support new ways of working is important. Drawing from and upon an independent and trusted source could also be used to help challenge the status quo, share best practice and build evidence for wider change, whilst influencing upwards to inform and drive policy.

58.7 Concluding Remarks

Wales has come a long way in its journey towards a more integrated health and care system for its people. It has integrated health boards with a one to one or one to many relationships with local authorities, and together, they have responsibility for population health, established legislation, developed policy and provided funding mechanisms to support such change. Yet what has become clear is that change will not necessarily happen by top down directives, but is dependent upon people making change happen, or not. Integrated care in Wales will happen when people can see it as the right thing to do and because they are encouraged, motivated and supported to do so. Change is not easy, but with the right environment and conducive conditions, change will happen because everyone understands the imperative to find better solutions together.

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Integrated Community Care—A Last Mile Approach: Case Studies from Eastern Europe and the Balkans

59

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59.1 Introduction

Most countries in Eastern Europe and the Balkans have inherited health systems based on the Semashko model of the Soviet Union, characterised by a state run, oversized hospital sector coupled with weak and underfunded primary care services. Despite this imbalance, this model had historically functioned with relative success, effectively covering the health needs of the population for several decades (1920s–1950s). However, with the advent of new technical developments and rapidly changing health needs of the population, the system buckled; burdened by a persistent lack of funds, highly centralised administration and an unmotivated workforce, improvements could not be incorporated and health care remained off the pace for several decades thereafter. The next opportunity for significant change followed the dissolution of the Soviet Union in the early 90s, when the newly independent states engaged in a continuous series of health sector reforms with the

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ultimate aim of universal health coverage (UHC) for its populations. The primary navigation point was to move away from overspecialised hospital care towards family medicine-based systems although different countries chose different reform approaches to achieve UHC.

59.1.1 Organisation Redesign

In terms of health system design, reforms have tried to address issues of finance, management and patient care pathways. As regards finance, the majority of countries opted to separate providers from purchasers of health services by creating national health insurance schemes funded through government taxes and salary contributions of the employed work force (e.g. Romania). Others chose nationally funded systems following the British NHS model (e.g. Kosovo). Managerially, the evolving family medicine systems ranged from free practice models as seen in Romania, to state- or community-run systems, as modelled in the Republic of Moldova. In most cases, some gatekeeping functions are allocated to family physicians who then regulate access to more specialised services and hospital care. Nevertheless, health services continue to be driven by professional interest rather than following people-centred approaches; many primary healthcare (PHC) systems still focus on providing acute care rather than managing complex lifelong chronic diseases (Non-communicable Diseases, NCDs) or producing health through a stronger engagement in preventive care. Reliable health and service data are frequently missing and, where available, are used for reporting and rarely analysed for decision-making or performance reviews. Inter-sectoral collaboration and the development of more integrated services are difficult due to a persistently sectoral orientation of services and fragmentation leading to working in silos. The same is valid for the sectorial orientation of funding streams or lines of information. Frequently, service providers rather than patients themselves own patient data, so that people-centred data management fails due to data protection regulations.

In recent years, many of these countries have recognised the PHC service gap to cover the most vulnerable population groups, particularly elderly people with multi-morbidities, patients with chronic disease, such as NCDs, and people living in remote rural areas. More integrated, multi-sectorial approaches involving community nursing, social work and local non-governmental organisations (NGO) and community-based organisations (CBO) have entered national strategies (Baxter et al. 2018) particularly following the WHO call for integrated people-centred health services (IPCHS) at the World Health Assembly 2016 (World Health Organization 2016a).

The following case studies from low- and middle-income countries (LMIC) in Eastern Europe and the Balkans illustrate various approaches and different entry points for the introduction of IPCHS. In Romania, integration of community health services is driven by an engagement of local authorities addressing the needs of its most vulnerable people at community level. The Republic of Moldova has developed a thriving social services system for child protection, which is now developing integrated case management strategies for elderly and multi-morbidity patients in rural communities. In the Republic of Kosovo, it is the family medicine centres, which drive the development of integrated people-centred health services (IPCHS) at municipality levels (World Health Organization, Regional Office for Europe 2016). For comparability and inspiration, the principles of service integration, decentralised decision-making, cross-sectorial information sharing and coordination are key elements in all three case studies, but the solutions identified by the lead organisations vary and depend on the predominant problems identified and priorities set. The presentation of the final outcomes is structured to reflect the quadruple aims in health (Sikka et al. 2015): patient benefits, service provider benefits; population benefits and cost effectiveness.

59.2 Local Authorities Driving Service Integration

59.2.1 The Romanian Experience

Romania adopted the Semashko style system in the 1940s in the wake of political changes and with a desire to address the low coverage offered under the preceding Bismarckian style social health insurance system that had been in place since the 1920s. In the early 1990s, following the end of the Ceausescu period, the country then reverted to its previous social insurance system but managed to retain the wider coverage achieved under the Semashko system. For primary healthcare delivery, family medicine quickly became the preferred model, with community nursing remaining only for regions with a high percentage of minority groups (Health Systems and in Transition (HIT) Report Romania 2016). With the privatisation of family medicine cabinets in the mid-1990s, community nursing was practically abandoned. The territorial organisation of primary health care by catchment area was changed in favour of listed patients, for whom family medicine functioned as gatekeeper to more specialised care.

Where it had been organised by catchment area now it changed in favour of listed patients, for whom family medicine functioned as gatekeeper to more specialised care. At the same time, payment through service contracts with the health insurance agency made family medicine cabinets more independent from public health planning and decision-making. And in turn, public health services within the community, home visits, elderly care and follow up for chronic disease patients at home were considerably reduced. As it stands, family medicine doctors have an upper limit of services they can provide per time period. Thus, even within the basic package of services guaranteed to insured patients, there is some limitation at the end of the billing period. Non-insured people benefit from a minimum package of services including emergency treatment, treatment for communicable diseases and some preventive services. Health and social services are delivered following sectorial policies, and there is little collaboration and coordination in-between.

Service decentralisation strengthened the involvement of Local Public Authorities (LPAs) in health since 2010 taking over the administration of public hospitals and picking up some regulatory functions related to health and the delivery of community services. Social services for example were decentralised to the community level under the mayor's office. Their general function was mainly the allocation of social benefits and to a lesser extent, addressing the social needs of the population. However, community nursing remained a centrally funded service with a weak foothold in community and district administration.

Today, considerable inequities in access to healthcare persist along geographic lines and between socio-economic groups, leading to visible differences in health outcomes. Amongst the many unbalanced developments within the Romanian health sector, the Ministry of Health acknowledges the lack of integrated community services to deliver comprehensive and equitable services to the most vulnerable parts of its population. This triggers reflections about a possible renaissance of community nursing in certain communities and districts.

Despite their public mandate, local authorities generally do not consider themselves as having a strong role in coordinating services related to health and well-being of their communities (Minca and Furtunescu 2010). Structural barriers also play a part, with the vertical organisation of health and social services and the difference in funding mechanism making it difficult for local administration to find their role. Auxiliary services, including local NGOS and self-help initiatives, are generally not part of the health/care network. Further, there is weak understanding of community health priorities due to a lack of comprehensive analysis and exchange of data and information between sectors. Joint health assessments or community health profiles to determine service priorities are missing, and joint inter-sectorial action is limited. Population perceptions depend on mobility, health insurance status and user needs and while ninety per cent of the rural population are covered by health insurance, for the rural poor, even the opportunity costs related to visiting health facilities are frequently too high.

Looking forward, the Romanian Government has recognised this gap and formulated a new vision (Farmanova et al. 2019) with the National Strategy for Health 2014–2020 for Romania (www.ms.ro/strategia-nationala-de-sanatate-2014-2020/), which includes the development of sustainable integrated socio-medical organisational structures. As part of this strategy, Community Care Centres covering health and social services in rural communities are regarded as an important step forward towards the development of integrated people centred health services (ICPHS) in Romania.

59.2.2 The Intervention

Funded by the Romanian government and local authority contributions and supported through Swiss Government contributions, seven Romanian communities within the Tulcea, Botosani and Salaj districts, with a total population of 17,000 inhabitants, organised a multi-sectorial community approach to elderly care and care of people with NCDs. In each of the communities, the mayors' offices took the lead using a "one-stop-shop" approach, which includes hosting critical services under one roof in community centres. Based on local needs assessments, existing services were improved and interlinked and new complementary services introduced. Although all communities centralised their interventions around community centres, different interventions were prioritised based on their specific context and the particular needs of their populations. Typical interventions were:

- Capacity development for local public authorities (LPA) to identify target groups, map needs for medico-social services, set priorities and manage change;
- Strengthening collaboration with LPA, family medicine cabinets (FMC) and social services;
- Reinforcement and capacity building of existing services around community nursing (Onofrei 2014) and social services, introducing new services in rural communities such as home-care workers employed by the local authorities where appropriate, and building partnerships with non-governmental organisations (NGOs);
- Infrastructure rehabilitation and upgrading equipment where necessary;
- Local health education and promotion campaigns.

Community projects were continuously accompanied by coaching activities from the Romanian Public Health Association. Project results were assessed at different levels using baseline and follow-up studies, as well as a mixed-methods survey to assess stakeholder and beneficiary satisfaction. At the household level, 700 individuals were interviewed on their service needs in terms of availability, access and perception of service quality as well as their perceived role in disease prevention and management. Similar questions were asked to service providers using focus group discussions. Key-informant interviews were used to clarify the understanding of local authorities at community levels. Financial data was collected on service costs and estimated cost savings by avoiding unnecessary service use during the intervention year.

59.2.3 General Findings

Individual and community needs varied by location, and there is no "one-size-fits-all" solution. However, a practical set of change management tools including assessment instruments, participatory approaches, small-to-medium size investment plus external management support and some coaching helped to better understand community issues and to identify local solutions. Community centres coordinated different service providers and provided better or more adapted services for people in need. Means of transport and empowerment of community workers were needed to serve remote places. As most communities launched complementary services (e.g. Luncavita), set up community centres and hired additional home-care workers, the sustainability of the intervention depended on the stability of community funding. Accreditation of social services with the Ministry of Labour and Social Protection (MLSP), which is necessary for the operation of these centres, was difficult because of the high standards and conditions it required, which were difficult to meet in small communities. A further obstacle was, and continues to be, the lack of common IT platforms for information exchange between service providers, which would help to create a care continuum and support integrated case management. LPA-led ICPHS created a variety of incentives for the different stakeholders involved in service provision, which are discussed below. However, it failed in many instances to make involvement in integrated care approaches more attractive to family doctors, due to their organisational structure and payment mechanisms.

Considering the resource limitations on the service provider side as well as the lack of capacity for service users to cover opportunity costs for service utilisation, there is an urgent need for improving the complementarity of available services, their coordination and outreach services to better focus on people's needs. Community health assessment and priority setting, involving population representatives or self-help groups, are essential to better define and coordinate services to fit to individual needs.

59.2.4 User Benefits/Satisfaction

Community health teams provided home-care services for elderly people with multi-morbidity conditions, patient activation sessions and health education and health promotion, as well as encouraging physical activities, organising group sessions for elderly people and running day care for young children, thus extending health and social services to otherwise marginalised population groups.

Service users of community medico-social centres highly appreciated the complementary services to existing family medicine practices in several ways: the joint needs assessment by a mixed team significantly improved communication between beneficiaries, caretakers and service providers, which in turn facilitated the development of more complex care plans. Perceptions on quality of life increased significantly within the year of intervention, as did the satisfaction with available services. Figure 59.1 compares user satisfaction with community nursing (AMC) services before (2016) and after the intervention (2019). Satisfaction has significantly improved regarding the frequency of home visits, the quality of services and the provision of medicines. Whereas 29% of interviewees were dissatisfied with the quality of services provided by AMCs, this reduced to 18% after the intervention. Access to care improved as shown by an increased number of service users, who were previously not registered with the national health insurance system. Anecdotal evidence shows that people, who previously felt excluded, perceived themselves and their needs as being better addressed by "the system", leading to better quality of life. In some communities, LPAs reported that the number of emergency calls had been reduced compared to the period prior to the intervention.

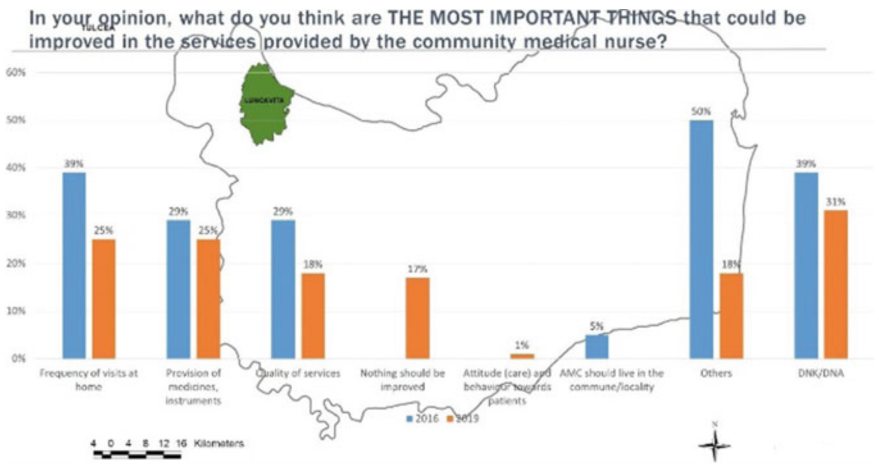

Fig. 59.1 Access to and quality of services pre- and post-intervention: Luncavita community

59.2.5 Service Provider Benefits

Local Authorities Management at LPA level significantly developed their capacity to assess community needs and the methodology to react to these needs by adjusting current services and shaping new interventions. Application of participatory methods increased the involvement of community members, which in turn improved the trust of LPAs in their own management and the population's faith in the LPA's reputation. Multi-stakeholder meetings for needs assessment and design of solutions managed to mobilise diverse participants including local entrepreneurs, the church, schools and individual citizens, which often multiplied the financial resources initially provided by the project. The interaction of various community members intensified a sense of "social cohesion" and many participants perceived local administration as positively engaging in community development (Dyakova et al. 2017). The joint assessment exercise made stakeholders aware of community issues, which were previously unknown, and frequently took citizens out of isolation, particularly in remote areas. Mobilising solidarity at community level frequently improved the reputation of LPAs and public institutions, which in turn increased people's willingness to contribute.

Community Services A variety of community stakeholders engaged in the development of integrated health services and its coordination. Collectively engaging in improving service access to marginalised people improved the satisfaction of many direct actors. As a social worker from Maliuc said: "*I have to tell you that the community nurse is helping me, because she does more fieldwork than me and he finds out about new cases. We have weekly meetings, even two, three times a week when the need arises and we also go in community*".

Some community nurses for instance combined work in community centres with home visits to individuals and families in need. Doing all visits inside the community by walking from one household to another made them, and their services, more publicly visible, which significantly increased their personal recognition and reputation in the community. In many cases, improved working places and having access to additional support, such as social services, increased their job satisfaction.

The picture was more mixed with family medicine practices. Coordination with other services is extra work, for which family physicians were not paid. Although some perceived people-centred integrated services as a benefit, particularly for their patients, others were less interested to participate. The arrangements are such that many of the additional services are provided by home-care workers, funded by the LPA themselves. However, the contribution of specialised services, such as family doctors is needed to guarantee the necessary quality of services. Thus, further incentives for this professional group need to be identified.

59.2.6 Population Benefit

The actual intervention was relatively short and population based data is not generally available to assess population health. At this stage, an improved health outcome at the population level facilitated by these projects cannot be shown.

59.2.7 Cost Benefit

Care provided closer to home reduces the need for emergency interventions, unnecessary hospitalisation and improves self-care abilities, which may reduce costs. Different budget categories, however, prevent potential savings to be accounted for against costs accrued, so saving costs is not necessarily an incentive to establish IPCHS in Romania. Incentive structures need to be developed to motivate key actors, particularly family medicine cabinets. The intervention uses mainly existing resources and improves their coordination and planning. Running costs are considered low but still need to be hosted within the small community budgets, which is difficult for some.

A costing study conducted in 2019 looked at all the seven pilot projects and compared service costs for home-based services for elderly people between commercial offers and the community centres in the seven communities. Eligible costs were labour costs, fuel, transport means, equipment (medical, non-medical), furniture, materials, training costs, communication, food, maintenance and spare parts, laboratory analysis, administrative costs and depreciation of goods and buildings.

Figure 59.2 presents the unit cost of one hour, under the assumptions that effective care is of 6 h per day and depreciation costs are considered. The red bars represent the average costs in Romanian currency for one working hour being reimbursed by the health insurance. The yellow dots show the number of clients consulted daily. Whereas the seven left bars represent the participating

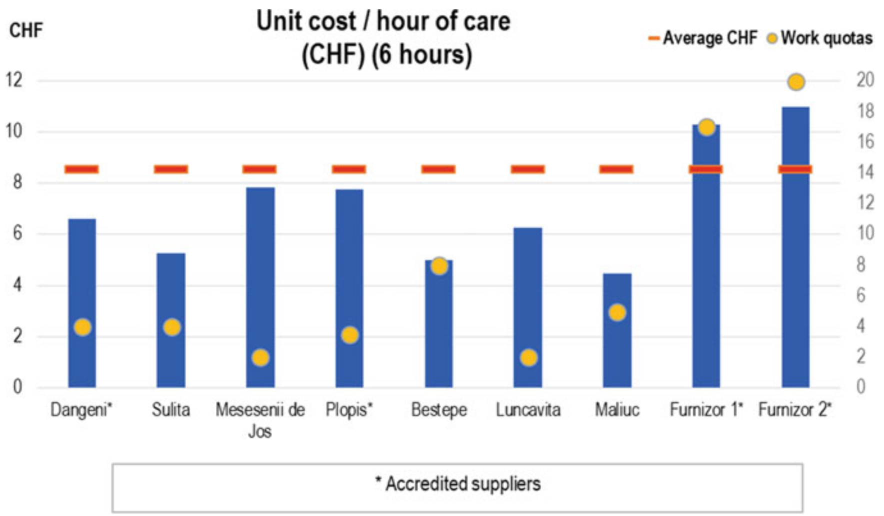

Fig. 59.2 Comparison of unit costs of community integrated services per hour (based on six working hours per day) in CHF

communities, the two bars at the right are costs from two different private providers. The study considered the weighted average cost for an hour of home care for elderly in 2018. Taking increases in structural and staff costs into account, this cost will increase by 67.5%—from 38.3RON to 64.2RON—in year 2022.

Consistent differences can be seen in unit costs, between the individual suppliers of the seven pilot projects and in comparison with the two private suppliers that serve as a reference. Main contributing factors for these differences are the different staff structure (community nurse, social worker, home-care giver) and the salary variations. Moreover, the projects faced legislative changes during the period of implementation regarding wages, which significantly affected the labour costs in both the public sector and the private and non-governmental sector. These types of changes will continue in the coming years and need to be considered accordingly.

Nevertheless, while the hourly costs of community-run services are considerably lower than commercial ones, the number of clients for community run services is also considerably lower. The number of clients for community services is determined by geographical location (e.g. their remoteness, which increases travel time), whereas most private services select their clients freely and more based on professional and organisational needs. As regards funding, community services generally have a variety of funding sources, such as the Health Insurance House, Ministry of Social Affairs, Ministry of Health, Local Councils and others without necessarily having any correlation or coordination between them. This increases the administrative burden and makes consistent budgeting more difficult, particularly when considering the instability of local budgets.

To redress issues related to making IPCHS sustainable in the Romanian context (Lewis et al. 2018), a range of actions need to be taken to establish favourable conditions:

- Decentralise decision-making for conceptualising, planning and implementing IPCHS at district and community levels;
- Provision of initial investments by external investments for setting up new services including training, continuous professional development (CPD) infrastructure, and others. These costs cannot be covered within the budget of LPAs;
- Reduce administrative barriers to facilitate accreditation processes for new services;
- Ensure sustainable long-term financing for IPCHS at community level by matching national strategies and new regulations with appropriate funding. Develop a funding system that considers multi-year budget projections with mixed financial allocations: fixed (per capita) and performance based. Consider territorial approaches to health rather than individual disease driven service planning and financial allocation. Allocate district and community budgets based on evidence and needs of the respective populations;
- Develop incentive structures for service providers, populations and patients to facilitate change;
- Develop data-driven methods to assess effectiveness and efficiency of measures taken and avoid ineffective procedures. Consider territorial approaches to health planning;
- Enable inter-sectorial sharing of patient data to reduce unnecessary duplication of services and service gaps;
- Intensify primary, secondary and tertiary prevention and activate people, patients and caregivers towards more self-management of NCDs to reduce the need for specialist consultations and hospital stays.

59.3 Social Services Developing Integrated Case Management Strategies for Elderly and Multi-Morbidity Patients in Rural Communities

59.3.1 The Moldova Experience

The Republic of Moldova chose a more evolutionary path towards health sector reform. Structural and organisational change of services started in 1991 as part of the movement away from the previous Semashko system. Primary healthcare (PHC) sector reform started in 1997 with the institutionalisation of a decentralised family medicine model. This has gradually shifted financial resources from tertiary to primary health care (World Health Organisation (WHO) 2015). Today, 35% of the public health budget is spent on family medicine. Since 2008, the PHC institutions operate autonomously from the hospital sector (Organizaţia Mondială a Sănătăţii 2012). However, regulatory functions, such as licencing, are still concentrated in the Ministry of Health, Labour and Social Protection (MHLSP) and not with independent bodies.

For individuals, real reform of healthcare financing started with the introduction of mandatory health insurance in 2004 (https://www.euro.who.int/_data/assets/pdf_file/0006/178053/HiT-Moldova.pdf?ua=1). However, this is no guarantee of access to all necessary health services. For example, the National Health Insurance Company (NHIC) coverage includes primary health care, but out of pocket (OOP) payments remain high, particularly for drugs (44,6% OOP according to WHO 2016 (https://www.euro.who.int/_data/assets/pdf_file/0007/177586/E96717-v2.pdf?ua=1) and exceed the European Union average by almost 4 times (World Health Organisation 2016b). Further, only insured individuals (approximately 74%) are covered for inpatient hospital services and specialised outpatient services (Vian et al. 2015).

Despite the many reforms, a lack of clear definitions around roles and responsibilities and the limited financial attributions has left initiatives without the resources they need to coordinate the necessary activities, and the systems have remained more centralised than envisaged. Today's family medicine centres are generally group practices of several family medicine teams, which include physicians and medical assistants under a joint directorate (https://ansp.md/wp-content/uploads/2014/07/STRATEGIA-HD-1032ENG.pdf). Community medical assistance exists as part of the family medicine team, but is not very well developed. The lack of training, unclear professional profiles and few full-time positions make them a rather weak contributor to community services. Recent discussions about a free practice model of family medicine services within single or group practices were stalled and did not lead to a next round of primary health care reform.

In addition to the classical family medicine services, there is a set of complementary services, such as adolescent health and mental health, which are also part of PHC. Whereas adolescent and mental health link up with district level institutions as their reference points, home-based care and palliative care is provided through complementary structures and funded through the National Health Insurance Company (NHIC). Services are not available countrywide.

59.3.1.1 Health Information Systems

The Moldova health information system (HIS) is still very centralised. Collected data are mostly used for reporting, rather than any in depth analysis to link determinants of health with interventions, activities and outcomes. The scarcity of data generated, limits system capacity to establish causality links, monitor impact and measure performance, without which decision-makers are left with minimal evidence to inform their decisions. A good example of this issue is that health status is not presented in terms of attributable risks, but only in terms of diseases frequency, which does not allow for the prioritisation of public health policy. External influences like legislation related to protection of personal data further exacerbates health information issues as they make it difficult to share patient information across sectors within an integrated community care setting. In terms of improvement efforts, here too there is a lack of evidence-based assessments and planning processes for health interventions, with little or no follow up on outcomes.

59.3.1.2 Sectoral Divide Between Medical and Social Services

The Moldovan Government is committed to reducing the burden of non-communicable diseases (NCD) by strengthening family medicine-based community services (https://lex.justice.md/viewdoc.php?action=view&view=doc&id=343682&lan). In its recent primary healthcare (PHC) reform, it created two new bodies: the Ministry of Health, Labour and Social Protection to improve inter-sectoral collaboration at a central level and the National Agency of Public Health as the central body to coordinate the public health agenda. At a regional level, public health activities are coordinated through the Raion (district) Public Health Councils (RPHC), involving local authorities and a variety of sectors including health and social services relevant for NCD control (https://lex.justice.md/md/331169/). At the local level, addressing the needs of vulnerable population groups in rural Moldova creates increasing pressure on local public authorities. The primary reasons for this are that medical and social services are organised in a sectoral manner and do not sufficiently reach remote populations. Long distance to services, professionals working in sectorial silos with little collaboration and little awareness of the value of preventive services, both for service providers and beneficiaries alike, increase the burden of NCDs and the likelihood of premature mortality.

On the social services side Moldova has developed a tight network over the last 20 years (https://www.legis.md/cautare/getResults?doc_id=27520&lang=ro), particularly focussing on child protection, the fight against human trafficking and domestic violence (Policy Brief 2019). Social workers are directly aligned to LPAs with the Directorate of Social Assistance and Child Protection as a reference structure at the raion (district) level. A case management system was developed where social workers are supported by other sectors (such as health, education, police and others) to assess individual needs and prepare case management plans for each individual child. In recent years, the impact of NCDs on people's vulnerability has been recognised and social sector managers have worked on the extension of these case management structures to cover elderly people as well as patients with chronic diseases and their caregivers. However, the lack of health sector participation in multi-disciplinary collaboration and case management at that level has limited the extension of integrated services to this vulnerable group.

Officially, one community medical assistance (CMA) position is foreseen for every 2000 population. In reality, however, CMA is just a small additional function to medical assistants in family doctor cabinets. Only 19.3% of community nurses registered in Moldova are employed full-time and nearly half of them (46.2%) are of retirement age (Volcov 2017). Those medical assistants, who partly have CMA functions did not receive any training and clear guidance enabling them to do their job. The prevailing sectoral top-down approach of most services at community level limits the potential benefits of team approaches based on patients' needs.

Hierarchical differences between family physicians and social workers make inter-sectoral collaboration at that level difficult. Community Medical Assistants (CMA) can be a welcome extension of family medicine services for elderly people living with NCDs.

59.3.1.3 Leadership and Priorities

Raion Public Health Councils (RPHCs) are the forum to coordinate public health matters at raion levels. Mostly, the medical sector (PHC, hospital, emergency, pharmacy levels), the education sector, and Local Authorities (LPA) of the district are represented. The social sector is not a compulsory part of this Council following an MoH decree from 2016. However, raions that recognised the value of involving the social sector in health matters included managers of the social assistance department in this structure. These councils have advisory functions to the local government, generally in terms of epidemiologic control, environmental protection, health promotion, food security and the management of public health issues. Although well-regulated in principle, their leadership skills, level of participation and functionality differs widely between raions in practice. RPHC members often have little awareness on public health matters and their potential coordination role at the raion level. Although the council includes most key stakeholders required for the design and implementation of integrated people-centred health services (IPCHS) and for developing population-based health promotion and behaviour change activities, it rather operates along sectorial lines than as an inter-sectoral team (School of Public Health Management 2019). Community health promotion is currently not a priority for most RPHCs, except for those where current or previous development projects have provided some impulses.

59.3.2 The Intervention

Since 2016, the Moldovan Government supported by the Swiss Development Cooperation (SDC) has been testing new integrated community service approaches in the three Moldovan districts (raion) Ungheni, Falesti and Orhei to identify and address people's health and social needs. Interventions supported RPHCs with data collection for fact-based decision-making and organised capacity building measures for project development, management and evaluation. Main professional authorities ensured capacity building of key relevant actors. National actors, such as the National Agency for Public Health (NAPH), were supported with capacity building on modern health promotion concepts including community health promotion and behaviour change communication. They subsequently developed training materials and delivered Training of Trainer (ToT) sessions for the raion and community levels. In parallel, the national policy context was further developed in favour of IPCHS and a strengthened role of CMAs. The Ministry of Health, Labour and Social Protection (MHSLP) clarified roles and working procedures of social as well as medical care at the community level. Additionally, CMAs and social workers as core members of the 48 community teams, together with representatives from the local public authority, home-care workers, police, specialised social services and volunteers were supported with capacity building measures on IPCHS.

Participating raions defined inter-sectoral teams to do stakeholder analysis, conduct needs assessments (Becker 2015) and develop targeted interventions for people with limited access to health and social services in an integrated manner. Most district projects focussed on patients with arterial hypertension, diabetes and cardio-vascular diseases. IPCHS interventions were based on particular vulnerability profiles and their priorities identified. The teams prepared integrated care action plans based on locally available data and additional assessments to identify health and social vulnerability amongst patients with NCDs. Although action plans varied between districts, all interventions included awareness raising sessions, messages for primary and secondary prevention, reducing risk factors and adjusting lifestyle factors. General well-being indicators and people's concerns were monitored, high risk patients identified and interventions for those with complex needs initiated. A common monitoring and data collection instrument was developed for all three districts. The implementation of the integrated care action plans was monitored and analysed quarterly by the RPHCs.

59.3.3 General Findings

Most elderly NCD patients (>60 years) in rural Moldova live in families and are taken care of by family members when needed. The majority of patients live independently without additional support (Chronic Disease Self-Management Program 2019). Of those 25% who benefit from additional support, approximately half of them receive social services. Less than half the elderly rural population (43%) would consult a family doctor in case of need. This is largely due to the absence of a family physician in their community and the lack of resources to seek treatment elsewhere. Those who access medical services receive treatment as well as counselling services and recommendations for behaviour change. There are significant differences in health-seeking behaviours and disease prevention between elderly men and women. Compared to women, men are less likely to engage in preventive activities such as behaviour change with risk reduction and self-management activities.

There is a general interest in engaging in inter-sectoral collaboration, and some communities show positive experiences with earlier project-driven interventions (End line Study Report, Healthy Life Project 2020). However, the traditional top down approach has created an environment where sector-specific concepts and working routines are not easily understood by others. Different organisational setups—community social services under the Local Public Authorities (LPA) and family medicine services under a more centrally driven structure—make collaboration difficult. The incomplete implementation of the community medical assistance (CMA) concept leaves the more people-oriented social services without a valid counterpart for IPCHS.

Limited capacity of data-driven planning, decision-making and performance evaluation, due to lack of management information and the sectoral organisation of data streams, reduces the coordination capacity of district bodies such as the RPHC. Moving from an individual care perspective to a more territorial approach to health and well-being with a stronger perspective on prevention, self-management of chronic conditions and increasing community and family resilience is difficult. Additionally, sector-specific databases and concerns about protection of patient/client data as well as technical limitations of the databases hamper the development of IPCHS.

Integrated community services with a core team of health and social workers supported by local authorities and interfacing with relevant professionals, formal and informal caregivers and volunteers have the potential to close the significant service gap in rural Moldova. The role of prevention, early detection and management of NCDs needs much more attention.

59.3.4 User Benefits/Satisfaction

People-centred interventions in the pilot districts included targeting people with medico-social vulnerabilities identified using health and social records, patient needs assessments through questionnaires and home visits of joint medico-social teams. Initial assessments showed a service gap of up to 25% of cases compared to current identification practices. Nearly half of those cases required the development of case management plans due to their complex conditions.

By end of the first quarter 2020, more than 4700 people were reached through these interventions (Fig. 59.3). Of those, more than 3000 received a health and well-being assessment. Almost 1200 people needed some further assessment or follow up by different services. The vast majority of beneficiaries perceived the integrated medico-social needs assessment at home as beneficial to their well-being status. The benefit for patients with complex needs, who were previously not identified, was even more pronounced. Some patients and their caregivers indicated that their need and utilisation of emergency services was reduced due to better case management and follow up home visits.

59.3.5 Service Provider Benefits

Local Authorities RPHCs benefited largely from joint analysis of the legal framework of their operations and the provided management training, which helped to clarify their roles within a wider concept of health as defined by WHO. A territorial approach focussing particularly on disease prevention, well-being and increasing resilience strengthened their engagement in inter-sectoral thinking. The project-driven data input in terms of studies and assessments, in particular the joint development of district health profiles, helped to identify needs and service gaps,

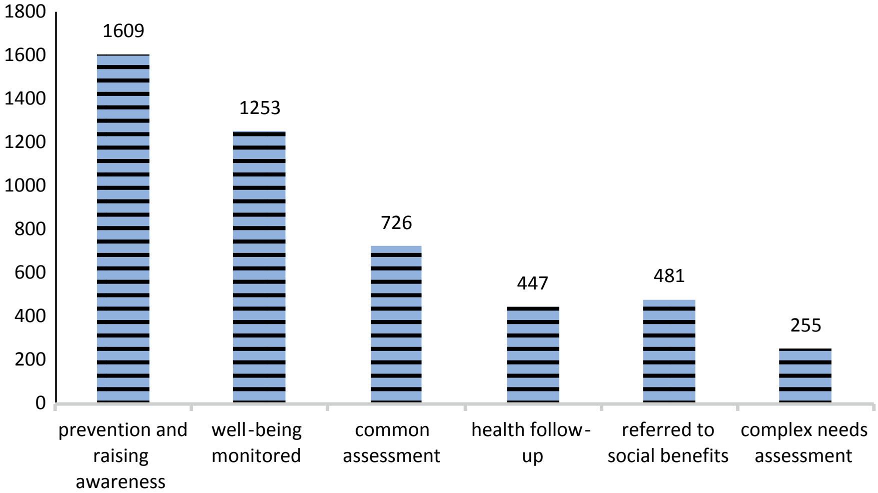

Fig. 59.3 People with NCD—Beneficiaries of integrated interventions

which in turn facilitated fact based planning, the development of concepts for small IPCHS projects and their implementation. Projects started with joint health and social service engagement, while other sectors such as school-based services and occupational health could follow. The assessment of people's health literacy and people-centred needs for NCD care (e.g. geriatric assessments, joint health and social service assessments of the elderly) could potentially be used as an entry door for planning future inter-sectoral interventions.

Community Services Capacity building for CMAs in terms of community nursing including social service principles in Moldova helped to improve mutual understanding between sectors. Capacity building in the area of integrated care approaches for the management of NCDs, patient self-management, the role of complementary services, such as social services and patient education, improved the ability of family medicine centres to care for complex cases. However, access to care for remotely living patients remains an issue and will probably be solved only with a stronger activation of patients and an additional layer of services, such as community centres for integrated community care.

Family medicine centres perceived integrated care services as a welcome complement. As a CMA in Redui put it: "*The very* fruitful *cooperation with the social work makes my work much easier. Together, we are able to better support people. Often in the villages, people neglect their health state. We go and find them, we go to their houses and we identify the health issue at the beginning*".

The question remained on how these services can be best aligned with existing sectorial structures. However, NGOs driving home-based care services, perceived a more integrated management of people-centred services rather as a competition to their offer. The Romanian context presented above may show that community-driven integrated care services could provide a cheaper service offer. However, it also indicated that private services tend to cater for a separate clientele leaving people living in the most remote places behind.

59.3.6 Population Benefit

Although people's knowledge about NCDs and the need for an active role in prevention and self-management has increased, it is too early to make assumptions on people's direct health benefits of these types of interventions. It is encouraging to see that district authorities recognise their role in population health and the current COVID-19 epidemic pushes even harder for integrated and well-coordinated approaches. The lack of data, particularly the lack of an in depth analysis of existing data, however will continue to make these assessments difficult in the future.

59.3.7 Cost Benefit

There is little evidence at this stage that the organisation of ICPHS at district and community levels have a positive cost impact. However, anecdotal evidence indicates that there might be lower utilisation of emergency services in remote areas due to better access to complex services. Opportunity costs for patients and possibly also out of pocket payments (OOPs) may be reduced. Taking up the social dimension of NCDs and elderly care, as well as bringing complex services to otherwise underserved populations, may reduce disease aggravation.

59.4 Family Medicine Centres Drive the Development of Integrated People-Centred Health Services (IPCHS) at Municipality Levels

59.4.1 The Kosovo Experience

Life expectancy in Kosovo is 72 years of age (The World Bank 2016) compared to the European average of 80.9 years. (Jerliu et al. 2013) showed that among people above 65 years the most common self-reported conditions were cardiovascular diseases (63%) followed by stomach and liver diseases (21%) and diabetes (18%). Despite the considerable contribution to overall morbidity and mortality by the elderly population, their complex needs are often neglected in the Kosovo health system (https://www.euro.who.int/_data/assets/pdf_file/0013/402250/KOS-PHC-Report-WEB-090519.pdf?ua=1). Overall, health literacy scores are lower among older people who report a poorer health status or at least one chronic condition compared with individuals who perceived their health status as good or had no chronic conditions (Toci et al. 2015).

Primary Health Care (PHC) in the Republic of Kosovo is administrated at the municipality level and organised in three service levels: One main family medicine centre (MFMC), several family medicine centres (FMC) and a series of so-called ambulantas. It follows the PHC strategy set out by the Ministry of Health, which is currently under amendment. Although directly controlled by the municipal Directorate for Health and Social Welfare, there is little tradition for multi-sectoral collaboration. Social services are relatively weak and focus on the payment of social benefits rather than on social work. Services are generally understaffed and often provided based on what services each sector wants to provide rather than what services the population actually needs.

Political instability with frequent changes in the Ministry of Health limits continuity and strategic thinking. Investment in health has favoured secondary and tertiary care over primary health care for many years. Secondary and tertiary health services are funded through the Ministry of Health and include over 72% of the budget allocated for health (https://www.kryeministri-ks.net/repository/docs/Strategjia_sektoriale_e_shendetesise_final-nentor_2016_ENG.pdf). Additionally, the reputation of family medicine centres is relatively low due to their poor infrastructure and endowment and even lower at the level of “ambulantas”. Whoever can afford it, goes directly to specialised care preferably in private practice. Home visiting for patients is tasked to family medicine centres, but in practice this rarely happens. A stronger “gate keeping” role for family medicine was planned for some time and is in the process of implementation.

Main family medicine centres host several family doctors, nursing staff, dentist and sometimes even specialised care and offer own laboratory services. Healthcare financing is tax-based. Patient co-payments are based on services and are due for each visit. Sometimes, they may have to be paid several times for one visit, depending on the number of services used. There is a large private market for specialised care and hospital services, the preferred option for those who can afford it. Plans to introduce a national health insurance system date back at least ten years are yet to be implemented.

Lack of reliable data is a serious challenge for health service management in Kosovo. The lack of data on, human resource allocation for urban and rural areas, and drugs and medical supplies, makes it difficult to take informed and strategic decisions. According to the Kosovo National Audit Office, the process for the management and implementation of the health information system is not functioning properly and characterised by irregularities (Ahmeti et al. 2017). The availability of patient records at the level of family medicine centres is inconsistent, which makes well-coordinated care for patients with NCDs difficult. Although decentralised in many ways, most service data are not shared and general performance assessment of services is difficult or not possible at all. Thus, typical instruments for strategic planning are not available at the municipal level and patient or population feedback mechanisms are generally missing, which critically undermines the development of integrated people-centred care systems.

In the last years, the Kosovo Government responded to these weaknesses with a series of improvement projects reviewing current healthcare financing mechanisms towards the development of a health insurance system and a national health information system. Supported by the Swiss Government, it also piloted a quality improvement programme for primary healthcare services including an integrated people-centred approach for elderly patients with hypertension and diabetes.

Through this investment, a number of different feedback mechanisms were implemented, enabling communities to influence management decisions towards the development of needs- and rights-based PHC services. These include the development of community score cards (CSC) and community needs assessments (CNA), focus group discussions (FGDs), round table meetings, community involvement in the evaluation of health education and health promotion (HE/HP) campaigns, and also by ensuring community representation in steering committees (SC). There has been a significant shift in service provider attitudes towards engaging with communities: they started to think about communities as key stakeholders and are showing an increased willingness to engage with them, both directly and indirectly.

59.4.2 The Intervention

The Municipality of Fushë Kosova developed an integrated people-centred care model that aims to improve the quality of health and social services provided for patients over the age of 65 years, diagnosed with Type 2 Diabetes. Driven by the Main Family Medicine Centre (MFMC), an inter-sectoral working group (WG), including representatives from PHC, the social welfare and education sectors, as well as patient and community representatives, local non-government organisations (NGOs), the Patients' Rights Association (PRAK), and the Association of Retirees, developed a person-centred, rather than service-led, multi-sectorial approach. Based on a rapid review of the scientific literature, international experience and a series of four workshops with the working group, a care process was developed and an integrate type 2 Diabetes care programme introduced. It established a core team comprising a nurse, GP and social worker, forming an integrated care team to develop individual care plans for, and with, the patients (Bytyci et al. 2019). The result was an integrated care pathway, which reflected the current availability of services and capability of the local system to implement the service improvements.

The development of a geriatric assessment tool (Mahoney and Barthel 1965) and joint assessment in the patient's home led to the creation of individualised patient care plans. Geriatric assessment is a standardised examination of older people with the aim to identify the medical, psychological, and social problems and resources of older persons, and to use it as a basis to develop a comprehensive individual care and re-enablement plan. The tools of the geriatric assessment are used not only as a screening tool for older people, but also play a crucial role in the continuous monitoring and evaluation of the care plan. Indications for the geriatric assessment include higher age, medical co-morbidities like heart failure or diabetes mellitus, psycho-social disorders like depression or isolation, specific geriatric conditions like dementia, falls (Wenger et al. 2009), or functional disability, previous or predicted healthcare utilisation, and consideration of a change in living situation like moving to a nursing home. Major components of the geriatric assessment include the following dimensions: functional capacity, risk of falling, cognition, mood, poly-pharmacy, social support, financial concerns, goals of care and advance care preferences.

Based on the results of the geriatric assessment, an individual care plan included the defined problems of the patient; specific, measurable, achievable, relevant, and time bound (SMART) goals for each of the patients' problems; and a set of activities to achieve these goals. A responsible professional was assigned to each activity to ascertain that the task was carried out in time. Some of the health and social services being delivered to these patients included: self-management support; patient education on diabetes management and risk factors; family/caregiver support; and management of clinical outcomes. Where needed, additional services were designed, for example, the delivery of individual- and group-based physical activity sessions to reduce frailty among elderly patients, and increase muscular strength and balance to prevent falls. To formalise this, PHC experts developed a training programme for nurses to increase their competency level on delivering this service. The training programme enabled the nurses to provide advice and simple individual exercises for older patients with type 2 diabetes based on their identified needs and physical activity level.

This intervention in the Fushë Kosova municipality was accompanied by a variety of measures. Management capacity was strengthened boosting quality management at the municipality level as well as leadership capabilities at the level of MFMCs. Quality of care was improved through the development and implementation of clinical practice guidelines and packages for NCDs services, particularly for hypertension and diabetes, based on WHO PEN (https://www.who.int/activities/integrated-management-of-ncds). Further, the development of patient and population feedback mechanisms increased the dialogue between communities and health service providers and health education, health promotion and behaviour change communication activities were conducted at the national as well as at community levels.

59.4.3 General Findings

Provision of health and social services in Kosovo is provider-driven like in all other country case studies described previously. Turning around the perspective and planning of health interventions based on individual needs and adapting the way services are delivered to patient and caregiver preferences was therefore a challenge. All participating organisations went through a steep individual and share learning curve: healthcare providers had to adapt to a holistic view of a patient situation rather than in a symptom-driven way; social services needed to go beyond assessing the legitimacy of social benefits and consider the specific social need of each individual person; the patient rights organisation had to move from the administrative task of registering complaints towards developing concrete alternative solutions to patient's problems. Together, the different partners had to understand sector-specific mechanisms and languages of their new collaborating partners. As one of the participating nurses said: "*We have completely changed our way of thinking and our approach to this category of patients*".

Behaviour change at the professional level is complex. Driven by vertical organisational structures, an outdated PHC strategy and little coordination between the different sectors, the transformation of PHC into a patient- and community-centred service is difficult. In Kosovo, PHC and social services are officially decentralised under one directorate at the municipality level. However, more financial resources are needed to operate and to invest in the services needed. At the same time, there is a lack of strategic and management capacity and little incentive to change. Any efficiency gains, which might result from quality improvement or services reform, would end in a reduced allocation of funds rather than freeing funds for further investment. Project supported interventions may bridge that gap for a while, but it needs real decentralisation with budget autonomy to reorganise and continuously improve services towards more integration and patient centeredness.

The lack of data and the weakness of patient information systems, particularly across sectors, limit case management and performance assessment of integrated services. This case study was based on separate data collection methods, which was an additional effort and not effective for the organisation of routine services. Although activating patients and their caregivers, increasing secondary and tertiary prevention and organising services around patient needs may have a positive impact on their well-being and potentially reduce hospitalisation, there is little chance to prove this without more appropriate data.

59.4.4 User Benefits/Satisfaction

By the end of 2019, a total of 84 geriatric assessments were conducted to assess both the health and social needs of the patient and their families/carers and 84 individual patient care plans (Ontario Medical Association 2014) developed. The team assessment, the patient-centred development of the care plans and the activation of patients and strengthening their self-management capacity was a novelty in Kosovo. Benefits of delivering integrated services for people with multiple needs are huge. The joint needs assessment resulting in a single care plan unifying different service providers around people's needs permitted the realisation of a "one-stop-shop" strategy: all relevant services for the care plans could be provided in one place. Targeting specific patient groups also permitted a more effective provision of services. Physical activity sessions for risk groups—more than 50% of people with care plans were in a pre-frail or frail stage—helped to activate patients towards more autonomy and a higher well-being status. (Romero-Ortuno 2013).

Based on patient feedback, the delivery of individual and group physical activity sessions has been very successful. One patient said: "*They've helped me a lot in these physical exercises, I'm feeling more energy and more relaxed*". Patients also acknowledged the social aspect of group sessions. Creating new social relationships with other participants helped to take participants out of isolation and allowed for the exchanging of experiences and sharing of coping strategies for their condition.

59.4.5 Service Provider Benefits

Local Authorities This intervention was driven by the family medicine sector, initially with relatively little engagement of local authorities. A key success factor has been the establishment of a municipality-level, multi-sectoral working group (WG), bringing key stakeholders, such as representatives from health sector, social services, patient representatives and local NGOs, together. Social services are weak with little focus on actual social work. Thus, engaging in mixed teams for geriatric assessment in people's homes and care plans was a welcome novelty, which resulted in demands for strengthening the sector at municipal level.

Community Services The joint planning process facilitated by external expertise and moderation created a decentralised initiative based on facts. Many of the interventions were nurse led, empowering the nursing profession in the management of chronic diseases. The intervention service package for diabetes patients recalibrated the available services, with some being newly developed and others given less importance than before. Health education became a central element in care management. Patient activation in terms of physical activity, but also in terms of playing an active role in their treatment as a partner rather than a recipient of services, was a new concept. Household visits of assessment teams and considering living contexts of patients as part of designing care plans was also new and may further help to strengthen nursing roles. Local NGOs played an important role in providing health information sessions to the community on this new intervention and its importance for improving chronic disease management.

59.4.6 Population Benefit

Little can be said about population health benefits at this stage. More robust data are required including better morbidity data, data on treatment costs, patient pathways and others. Longitudinal or time series studies on the impact of behaviour change communication might be helpful. The process of engaging diverse stakeholders to improve service quality carries knock-on effects for other beneficiary groups. For example, communication/health promotion activities in Fushë Kosova, and at the national level, may contribute to broader population benefits.

59.4.7 Cost Benefit

So far, there has been no assessment on the cost benefit of this intervention. This was not possible due to a lack of data, the small size of the intervention, and current in-transparent healthcare financing mechanisms.

59.5 Conclusions and Lessons Learnt

Since the 1990s, countries in Eastern Europe and the Balkans followed different pathways in an effort to advance from the previous centralised hospital-based services towards family medicine-oriented primary care systems. Decentralisation of various degrees happened in several reform steps. In most countries, the movement from acute care to the management of long-term conditions in PHC is still on-going. Unfortunately, most family medicine systems failed to reach the expectations of establishing access to high quality care for all. In particular, patients with NCDs and multi-morbidity conditions living in rural environments need additional assistance. The aforementioned examples show different ways of putting a complementary layer of people-centred integrated services in place, which have the potential to cover “the last mile” between service providers and the most vulnerable and are able to respond to the complex needs of NCD patients. Drawing from these experiences, there are a few essential success factors, which may help to drive the development of these systems:

- Decentralised services with decision-making and funding mechanism at district or community levels are important to organise IPCHS. To achieve this, communities and districts need technical guidance and a supportive legislative framework to develop a bottom-up approach with the necessary flexibility to answer each community´s needs and particularities;
- Integrated community care teams, with community nursing and social assistance as a backbone, can offer home visits, social support, health education and health promotion for the most vulnerable groups, which family physicians may not be able to provide in their daily routines. To achieve this, close collaboration, exchange of information and a clear sharing of tasks is needed between these layers of services;
- Service-based financing may have disadvantages compared to budget funding. Whereas budget funding is more flexible to develop adapted and integrated services across sectoral barriers, service-based funding might be better suited for performance control and improving cost effectiveness;
- Appropriate incentive systems are needed to improve multi-sectoral cooperation at district and community levels. Better coordination of services is a key building block towards the development of integrated community care;
- Prevention, health education, patient activation, increased self-management and recognising people and patients as partners in the conceptualisation and

implementation of integrated services is essential. In most cases, these elements are not included in routine sectoral health service concepts and activities. Thus, incentive systems need to be developed to facilitate and maintain the change process;

- Further development of community nursing in combination with decentralised social services could be the cornerstone of integrated community services and has a potential to improve access to care for the most vulnerable groups.
- Collection and utilisation of data needs reviewing to be suitable for integrated community services. Sectoral data needs re-compilation in a person-centred way. Additional data collection should follow classical quality management cycles (plan-do-check-act, PDCA): community needs assessments and community health profiles to identify needs and set priorities; performance monitoring to identify best practices and effective interventions leading to improvement in health outcomes: and feedback mechanism to influence managerial decision-making and priority setting;
- The evaluation of disease-specific parameters to guide interventions does not frequently improve people’s quality of life. Decentralised people-centred services for elderly people and those living with multi-morbidities need a different set of indicators oriented towards well-being, physical autonomy, functional status, depression and frailty to manage their conditions;
- An exchange of patient-centred data across providers needs to be developed to avoid duplication of services and reduce unnecessary services, in particular hospital stays, to make integrated services an effective tool.

The three case studies presented show typical entry points and a toolbox for the introduction of IPCHS at district and community levels, which can be used by other LMIC countries. It needs to be kept in mind, however, that there is no “one-size-fits-all” for these types of services. The same tools may be used in different settings, but tool selection must be guided by the local needs as well as priorities and resources, which may differ considerably between communities. On a final note, and in the light of the quadruple aim in health care, integrated community services are a living instrument, which can and should develop alongside people's changing needs, building new tools and people-centred services, considering the proven possibility of creating positive change despite the various challenges.

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Developing Integrated Care in Portugal Through Local Health Units

60

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60.1 Introduction

Portugal's healthcare system is influenced by a Beveridge model of a universal, tax-financed system. The National Health System (NHS), established in 1979, and composed by a public network healthcare structure within the scope of primary, secondary and tertiary healthcare, is the main provider of healthcare for the about 10 million citizens.

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In addition to the NHS, the Portuguese health system has two other co-existing systems, which are the health subsystems and private health insurance (Simões et al. 2017).

Public expenditure on the NHS accounts for 66% of total health expenditures and around 35% of this value corresponds to private financing (Simões et al. 2017).

The development of health policies, financing and regulation of the NHS, as well as the regulation and inspection of private health providers are the Ministry of Health's responsibility; the management of healthcare provision takes place at the regional level through the regional health offices (Santana et al. 2014; Simões et al. 2017).

The Portuguese healthcare system is organized into five regional health administrations that are responsible for the regional implementation of national health policies objectives and the coordination of all aspects of healthcare provision (Santana et al. 2014), including healthcare integration.

Over the past years, a set of reforms have been implemented to improve management efficiency, access, quality and integration of care. One of the main reforms with an impact on the integration of health care was the creation of Local Health Units (LHU). The LHU model focuses on vertical integration of healthcare by joining one or several hospitals with a determined set of primary health centers, into a single provider entity, within a geographic area (Santana et al. 2014). The LHU of Matosinhos was the first to be implemented in 1999, by Decree-Law nº 207/99.

Currently, there are eight LHU in Portugal: Matosinhos, Alto Minho and Nordeste (North); Guarda and Castelo Branco (Centre); and Norte, Litoral e Baixo Alentejo (South) (Simões et al. 2017), that cover around 10% of the Portuguese population.

However, in Portugal, there is no consistent national policy for the development of healthcare integration, which is evidenced by the lack of a central government structure dedicated to this strategy. Therefore, integrated care in Portugal is driven by teams and local professionals and their attempts to respond to the practical problems they face concerning healthcare demands.

With this in mind, the objective of this chapter is to describe two experiences of healthcare integration that are being developed in two different Local Health Units.

60.2 Integrated Care—Case Management

The first case study illustrates the development of a case management project in a peripheral Portuguese hospital that serves a population of around 100,000. The hospital is located in a rural setting of Alentejo Litoral (South Portugal), where the distance between patients and the hospital can reach 100 km. It has a total of 125 beds, with the following medical specialties 24/7: internal medicine, general surgery, orthopedics and traumatology, radiology, clinical pathology, anesthesiology and intensive care.

Case management is defined as a collaborative process of assessment, planning, facilitation and advocacy for options and services to meet an individual's holistic needs through communication and available resources to promote quality cost-effective outcomes (Marfleet et al. 2013). This provides an opportunity to optimize patients' self-care and promote cost-effective use of limited resources.

According to the Organization for Economic Cooperation and Development (OECD), Portugal has more emergency department (ED) admissions than any other member country. Rates are 70.5 visits for each one hundred persons, with 31% of visits being avoidable or inappropriate (Berchet 2015). Also, in 2013, 12.3% of the hospitalizations registered in mainland Portugal were attributable to ambulatory care sensitive conditions (ACSCs), which corresponds to an important indicator of the quality of ambulatory care and efficiency of the health system (World Health Organization 2016). Therefore, the need for better integration was identified in Alentejo Litoral, where healthcare resources are particularly scarce and could be reorganized for more efficient use.

The program developed, called "Gestão de Caso", is a case management project that consists of a collaborative process that allows integrated caregiving for patients that have multimorbidity, by accessing available and relevant resources necessary for the patients to attain their previously identified goals.

The program was initiated in January 2017 and comprises a multidisciplinary team, consisting of internal medicine doctors and nurses at the hospital, and general practitioners (GP), nurses and social workers in the community, that work together to enable a holistic approach. The fact that the program is being developed in an already integrated administrative system, that is, a LHU (hospital and community primary care—Local Health Unit of Litoral Alentejano), facilitates the application of strategies, with everyone working as a team.

The main objectives of the program are to promote better continuity of care with clinical stabilization and social problems resolution, to keep the patient at home, and to reduce healthcare resources utilization.

The first stage of the process is to identify patients through a risk stratification system based on high use of the emergency department (four or more episodes per year), using a proactive identification method. For inclusion on the program, patients must be 18 years or older and have at least one of the following conditions: four or more ED episodes in the last year; three or more hospitalizations in the last year; two or more comorbidities; and six or more daily medications. The exclusion criteria consisted of: patients in palliative care or end of life care; patients in nursing home care; patients with no prevention capacity (such as bedridden patients); and patients that refuse to participate.

After identification of a "case," the patient's clinical, social and cultural evaluation is performed, as well as a family and caregiver evaluation. In the community setting, the nurse is the case manager for each patient and is responsible for helping them navigate the health system network. The case manager nurse follows up with the patients through frequent home visits, manages their medication, teaches them about the comorbidities and alert signs, supports their self-care and, last but not the least, manages their expectations. The nurse is also available to answer phone calls from the patients. Every patient has their individual care plan, according to their morbidities and goals, which is monitored by the nurse. For the success of the process, the nurse is in constant touch with the multidisciplinary team, with information sharing and easy communication through cell phones, e-mail and videoconference.

The graphic representation of multidisciplinary team communication flow, with the patient at the center of the program, is shown in Fig. 60.1.

Since the start of the program, more than 100 patients have been enrolled. For the present analysis were considered 89 chronic complex patients who have been in the program for more than six months.

As an indicator of burden of disease and mortality risk was used the Charlson Comorbidity Index and as an indicator of social risk was used the Gijon score.

The 89 chronic complex patients have a similar gender distribution (51% females; 49% males), a median age of 76 years (55–88), a median Charlson Comorbidity Index of 6.3 and a median Gijon score of 7.

The main results of the program were a decrease in hospitalization days by 66.9% (Fig. 60.2), reductions in the emergency department visits by 61.6%, and the reduction of hospitalization rates by 52.5%, when compared with what happened in the same period the year before. These results are comparable to other international programs described in the literature, such as Tortajada et al. (2017).

Figure 60.3 expresses the comparison of the number of contacts with the healthcare service before and after the admission on the program “Gestão de Caso”.

Even though the experience is still limited, the significant impact on these patients’ lives is notable, along with a very significant reduction of healthcare costs.

The implementation of this program involved a process of change that faced some initial challenges. One of the barriers identified was the resistance to change associated with the fact that the LHU integrates one hospital and five primary healthcare centers, with different inter- and intra-organizational cultures, whose

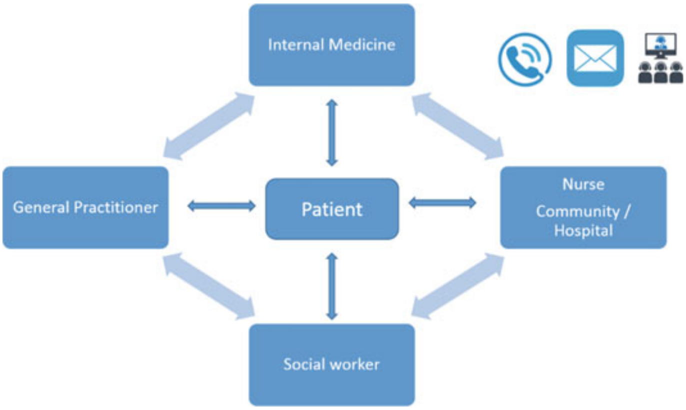

Fig. 60.1 Multidisciplinary team communication flow

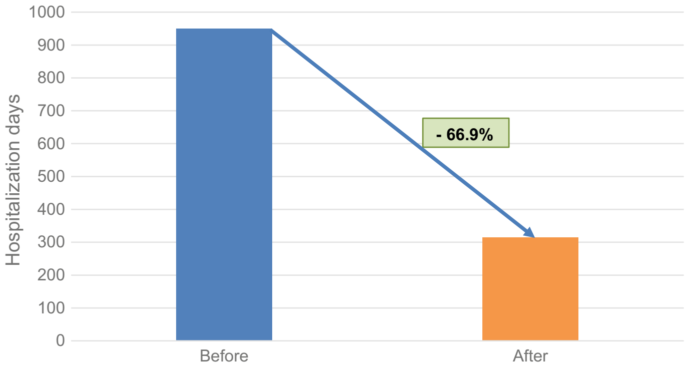

Fig. 60.2 Variation of hospitalization days before and after the admission on the program

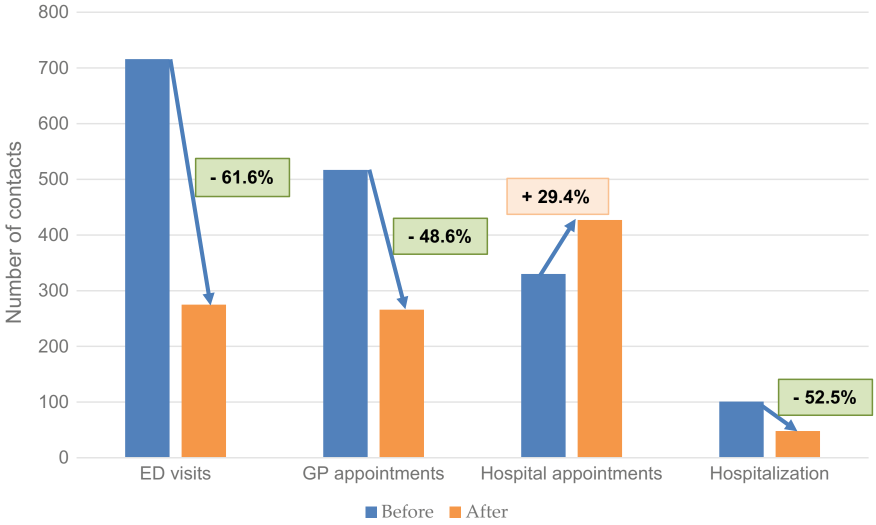

Fig. 60.3 Number of contacts with the healthcare service before and after the admission on the program

tradition is to work independently. Other limitations were the lack of human resources, namely doctors and nurses that would allow the creation of teams dedicated to the project; and the geographical dispersion between the patients' homes and the institutions, which translates into time-consuming trips. To mitigate this last limitation, partnerships were created with local institutions and relations between patients and the neighborhood were strengthened.

Despite these barriers, professionals increasingly adhered to the program, which was a crucial point for its successful implementation. Also, the adherence of patients and families was essential to encourage the professionals involved and it was an important determinant for the results obtained.

Patients and families were empowered by being able to self-control their conditions and identify warning signs of decompensation. They were also able to easily contact the case manager. These factors in combination with the multidisciplinary nature of the program have resulted in better monitoring of patients, reduction of emergency department visits and patient engagement and satisfaction, contributing to the reduction of healthcare resources utilization.

This program experience results in a more effective answer to the patients' needs, not only related to their physical health, but also their psychological well-being and their social and economic needs, resulting in a more people-centered health system.

60.3 Integrated Care in Mental Health

The second case presented is the integration of horizontal and vertical care in the area of mental health in the LHU of Matosinhos.

As mentioned previously, the LHU of Matosinhos was the first to be implemented in Portugal, and it is the only one inserted in an urban setting, in a large metropolitan area. According to the last census (2011), the municipality of Matosinhos has a population of 175,478 residents.

Mental disorders are one of the most significant public health challenges, being a leading cause of disability worldwide (World Health Organization, 2020). In this respect, the World Health Organization (WHO) has made several recommendations to promote an effective mental health system, such as a larger involvement of primary health care and more integrated care. Nevertheless, an evaluation of the Portuguese Mental Health Plan stated that Portugal is failing to achieve WHO recommendations (Perelman et al. 2018).

One example of the lack of integration of care in mental health was the case of Matosinhos, where, until April 2009, the provision of mental health care to the population was assured by two institutions, with no connection between them.

The LHU of Matosinhos psychology service, although directed toward health promotion, was registering increasing requests for intervention to mental illness, with a waiting list of eight months. In contrast, the Magalhães Lemos Hospital (a hospital specialized in psychiatric and mental health care), composed essentially of psychiatrists, was unable to absorb requests for psychological interventions. It was further observed that the general practitioners had little or no involvement in the therapeutic process of their patients getting psychiatric appointments at the hospital and also delegated the routine medical monitoring to the assistant psychiatrist. This reality made the collaboration for compliance promotion, therapeutic optimization and prevention of relapses difficult.

Given these disjointed circumstances and the objective of implementing the National Mental Health Plan, the Department of Mental Health (DMH) was created at LHU of Matosinhos in 2009.

The National Mental Health Plan issued guidelines to promote the decentralization of mental health services to allow the provision of community-based care services and to facilitate greater participation of communities, patients and their families. The plan has also issued guidelines to promote the integration of mental health care in the entire health system, at the levels of primary care, general hospitals and long-term care, to facilitate access and reduce hospitalizations.

Therefore, the DMH is configured as a decentralized unit with autonomy in terms of its competence and comprises the Psychiatry Service, Psychology Service and Functional Pedopsychiatry Unit. The unit is managed by the management council which consists of a director, an administrator and a technician.

It is DMH's mission to conduct short-, medium- and long-term strategic planning for the process of integrating mental health care into primary and hospital health care and incorporating the transition of adult mental health care from the Hospital to the LHU of Matosinhos, based on the National Mental Health Plan.

In order to integrate mental health care in primary health care, a new patient referral model was developed through a consultative process between the general practitioners and the psychiatrist/pedopsychiatrist. The psychiatrist develops, in primary health care, the psychiatric appointment of the common mental pathology, with the purpose to provide a short period of follow-up and stabilize the patient so that he/she can continue the process of care with the GP. This initiative contributes to greater collaboration between GP and psychiatrist/pedopsychiatrist, allowing for a closer follow-up of the patient and family.

During the process, the need for mental health training programs for GP was recognized. A course on the diagnosis and treatment of depression in primary health care was developed to progressively train GP in the management of depression. The aim was to reduce the referral of adults with common mental pathology, allowing the psychiatrist to focus appointments on more complex cases.

This initiative had positive results, with several improvements in psychiatric appointment referral, in the selected therapeutic approach and in the quality of the information reported.

Another initiative implemented in 2010 is the collaboration between the DMH and the GP internship coordination office to offer training of GP interns, through mental health internships. The mental health internships of GP interns are enriched by the elaboration of thematic academic works that are presented and discussed. These discussions resulted in a set of procedures in the area of mental health in primary health care, validated by the DMH.

Concerning the integration of mental health care in hospital care, since April 2009, the DMH has been training and sensitizing medical doctors of all hospital specialties to the pathologies that must be referred to the consultation–liaison psychiatry. This model aims to define a liaison psychiatrist for the different services, who connects regularly with the service professionals, contributes to the discussion of clinical cases and defines care integration protocols in a team.

Other clinical activities taking place in the hospital are the psychiatric appointment for severe mental illness, where the psychiatrist and the GP closely connect, particularly around the therapeutic adherence, and the creation in 2012 of a multidisciplinary team (consisting of a psychiatrist, a psychologist and a nurse) for clinical interventions for mental health patients in crisis.

Specifically, these interventions consist of a partial admission to the LHU of Matosinhos outpatient hospital for typically three weeks, with a psychopharmacological prescription in addition to daily psychotherapeutic intervention. Furthermore, an individualized post-discharge plan is developed to optimize the therapeutic intervention initiated in outpatient care. The main benefits of these interventions are the reduction of complete hospitalizations and, with the planning of therapeutic strategies, the therapeutic optimization and the prevention of relapses after discharge.

In 2015, an integrated care program for the recovery of the patients with severe mental illness was developed, structured according to the assumptions of the clinical case management model. This included the assignment of a therapist and a set of strategies, namely psychiatric and mental health nursing appointments, the definition of the individual care plan, participation in psychoeducation groups in mental health and the formulation of an individualized plan for the prevention of relapses and socio-professional integration.

Concerning the transfer of adult mental health care from the hospital to the LHU of Matosinhos, it should be noted that until the creation of the DMH in 2009, the mental health care for the adult population of Matosinhos was provided by Magalhães Lemos Hospital. Only after the creation of the department, the LHU of Matosinhos started to guarantee the outpatient response of all cases of psychiatric pathology of Matosinhos' adults, except for three specialized clinical areas, namely dementia with significant behavioral changes, disturbed eating behavior and clinical sexology.

Integrating mental health services contributes both to the promotion of mental health in the population of Matosinhos, as well as to the improvement of the quality of life of patients with mental illness. This is achieved by providing community-based care, timely diagnosis and an effective therapeutic approach, reducing the need for hospitalization.

60.4 Conclusion

Both case studies presented in this chapter show positive results, with benefits for patients, families and healthcare professionals and system, thereby emphasizing the importance of an integrated care system to address the real health necessities of patients, improving the quality of care and contributing to the system sustainability.

In both cases, a set of strategies was introduced, including case management and the coordination of different professionals to enable multidisciplinary teams to share individualized health decisions and plans for their patients. Implementation of strategies further included the provision of community-based care, leading to a greater follow-up of patients and a subsequent reduction of hospitalizations, which contributes not only to the patients' quality of life, but also to a more efficient use of resources.

Although vertical and horizontal integration faces tough challenges, especially resistance to new care models, it has been proving to be an efficient response to improve the care provided.

In Portugal, the Local Health Units, created to promote vertical integration of care especially between primary and secondary care, are proof that new models are needed.

However, Portugal does not have a systematic, structured policy for the integration of care, with a vision of what is intended for the future. The supply structure, the organization of healthcare services, financing, performance evaluation, and especially, a healthcare system that is not truly patient-centered, leads to political approaches carried out in silos (by level of care or by vertical programs, instead of integrated programs). Due to the absence of an integrative policy, the capacity for local implementation and replication of good practices in other contexts is limited because they depend entirely on healthcare professionals' initiative.

In order for our two presented cases to show more significant and consistent results, it is crucial to have concerted action to replicate good practices of healthcare integration. This will require a national strategy for the integration of care, through the creation of a central structure dedicated to its development.

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Primary Healthcare Integration Practices in Turkey

61

Sema Safir Sumer and Ahmet Levent Yener

61.1 Introduction

Turkish health system has gone through a number of major transformation processes between 2003 and 2013 where people were the exclusive focus and where the emphasis was primarily on improving and reshaping the primary healthcare structure through the introduction of the family medicine (FM) model. Universal health coverage has been established, and the Turkish Ministry of Health (MoH) initiated various programs to improve the healthcare service provision at all stages. Even though the overall transformation process includes many aspects of care integration, integration is a new concept for the Turkish health system and was introduced into MoH strategic planning in 2013 with a particular focus on non-communicable diseases (NCDs).

Four features of the transformation process within the Turkish health system are worthy of note concerning care integration: Firstly, FM model facilitated and encouraged access to and use of primary care through an enhanced network of family medicine centers (FMCs). Secondly, newly introduced Healthy Living Centres (HLCs) are enhancing the scope of primary and preventive care in Turkey as supportive structures to FM model. HLCs provide people centered/personalized services through lifestyle advice and supervision, screening and prevention on priority NCDs. Thirdly, MoH has introduced a cloud-based platform, called *e-Nabiz* (meaning e-pulse in English) which integrates all patient records electronically. E-Nabiz allows both patients and providers to access all patient data at all care levels based on patient consent. It also encourages active patient engagement to the

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healthcare processes. Lastly, MoH gave exclusive importance to the development and use of Health Information Systems (HIS) that would help facilitate operations, decision and policy making for care integration. Concerning how HIS contributes to care integration efforts and NCD management, recently developed disease management platform (HYP) and its modules for priority NCDs (diabetes (DM), hypertension (HT), cardiovascular disease (CVD) risk assessment and obesity) are expected to allow health providers to pursue a comprehensive prevention, diagnosis, treatment and follow-up process for an effective disease management.

The chapter is organized to first provide an overview of the background factors necessitating change, followed by the detailed description of the elements which shape care integration in Turkey. The following two sections describe the scaling up practices for care integration as well as the details of the implementation and its impact so far on the health system. The chapter concludes the discussion with lessons learned and next steps for care integration.

61.2 Problem Definition and Motivation

Various contextual drivers, including population-related dynamics as well as economic, institutional and health system internal factors have necessitated the change in the Turkish health system and the introduction of elements that would facilitate or lead the way for care integration.

61.2.1 Demographic Transition

Similar to global trends, population demographics change in Turkey, and there is a significant shift in toward increasing age. Between 1970 and 2018, the share of population aged 65 years and above within the total population has increased by 100%, while the increase in the share of population aged between 15 and 64 years was only 26%. In the same period, the share of population aged between 0 and 14 years decreased by 44% (TURKSTAT).[1] Increasing share of the elderly population imply increasing and changing health system pressures with the growing need to deal with NCDs and related multimorbidities and to introduce longer and continuous care modalities.

61.2.2 Rapid Urbanization and Changing/deteriorating Lifestyles

Before 1980, less than half of the Turkish population lived in urban areas, but the urbanization increased remarkably starting from mid-1980 and since then has

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[1] https://www.tuik.gov.tr/UstMenu.do?metod=temelist (accessed on 20.12.2019).

continued. Currently, more than 75% of the population lives in urban areas (World Development Indicators).[2] Need for better employment opportunities, need for access to better education and health services were among the main reasons of migration to urban areas. The rapid urbanization therefore created a challenge for cities to cope with a significant population inflow and put pressure on public services in urban areas.

Along with the urbanization, the lifestyle of the population has also changed adversely affecting overall health with deteriorating dietary habits and sedentary life. A recent survey in Turkey suggests high levels of unhealthy dietary habits among the population: Almost 90% of the respondents have inadequate daily fruit and vegetable intake, around 50% of the respondents have low levels of physical activity, and 64% are overweight and 29% obese. Around 30% of respondents have high blood pressure, and 11.5% have high glucose levels (STEPS 6). Such worsening lifestyle habits lead the way to increased exposure to NCD risk factors, thus to NCDs.

61.2.3 Changing Disease Patterns from Communicable to Noncommunicable Diseases

Similar to global trends, NCD burden increases in Turkey. The Burden of Disease study of 2004 conducted by the Turkish MoH suggested that 79% of the deaths were due to NCDs. According to the Turkish Statistical Institute (TURKSTAT) 2018 statistics, cardiovascular diseases (CVDs) and cancers are the top two causes of mortality for the entire population (CVD 38.4% and cancer 19.7% for the overall population).[3] Recent World Health Organization (WHO) estimates suggest that NCDs account for 89% of all deaths in Turkey, where CVDs account for 34%, cancers 23%, and diabetes 5%.[4]

Changing disease patterns have implications on the health system and particularly on health economy as economic losses incurring due to morbidity and mortality. NCDs require novel means to be introduced in the health service delivery since they are chronic and require long and continuous care. According to a 2018 joint study by MoH and the WHO on case for investment for NCDs, total direct and indirect costs of all NCDs in Turkey is 69.7 billion TL, which account for 3.6% of annual GDP (WHO 9). The study also reveals that an intervention package consisting of tobacco control, physical activity awareness, alcohol control, salt reduction, and CVD and DM clinical intervention will have an overall return on investment (ROI) of 3.3 in 5 years and 4.3 in 15 years. Salt reduction is the most efficient healthcare investment, offering the highest ROI; 51 for 5 years and 88 for 15 years, respectively.

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[2] https://data.worldbank.org/indicator/SP.URB.TOTL.IN.ZS (accessed on 20.01.2020).

[3] Ölüm Nedeni İstatistikleri, 2018 TUİK https://www.tuik.gov.tr/PreHaberBultenleri.do?id=30626 (accessed June 14 2019).

[4] https://www.who.int/nmh/countries/tur_en.pdf?ua=1 (accessed February 17 2020).

61.2.4 The Need to Change Care Delivery Structures

Similar to global trends and as explained above, diverging requirements of health care in Turkey necessitates change in existing healthcare delivery structures, which so far have been based on the diagnosis and treatment of acute conditions and the improvement of the system to cope with long-term health problems more effectively (WHO 8). Integrated care approach is perceived as a response to the challenges of changing demographics, increasing NCD burden, and the need to reduce costs on avoidable hospitalizations and care services (Lyngsø et al. 1). Turkish context also necessitates that changes in care delivery should facilitate the shift of the burden of work toward primary care, disease prevention, early detection, and control through care integration.

61.2.5 High Burden of Ambulatory Care in Hospitals

The WHO's STEPwise Approach to Adult Risk Factor Surveillance survey suggests that 81% of respondents' NCD care in hospitals was ambulatory (STEPS 6). Per capita number of visits to healthcare institutions as per the recent MoH data is 3.2 visits per family medicine physician (FMP) and 6.3 for secondary and tertiary care.[5] These figures suggest a hospital-centric utilization, and there is a need to shift ambulatory care to the primary care level to the extent possible.

MoH data also reveals that emergency room (ER) utilization for ambulatory care is very high where the majority of ER cases have a triage category yellow (having a share of 64% of total ER visits) or green (having a share of 22% of total ER visits). These figures imply that many of these cases can actually be addressed at the primary care level thus necessitating arrangements to reduce emergency care workloads.

61.3 Description of the Model

61.3.1 Integrated Care at High Policy Level

Care integration has been emphasized as a main focus area in higher policy documents in Turkey. The MoH of Turkey has shown commitment to address prevailing health system challenges and reflected it in its strategic plans. The Strategic Plan covering 2013–2017 (MoH 2012) highlights MoH's intention to improve the integration and continuity of care by strengthening the role of primary care, especially through strengthening the integration of other primary care services into the FM model and through strengthening the integration of the FM model into

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[5] https://dosyamerkez.saglik.gov.tr/Eklenti/33116,haber-bulteni—2018-30092019pdf.pdf?0 (accessed February 17 2020).

hospital care and laboratory services. The plan also suggests strengthening the infrastructure and technological capacity of FM laboratory services, developing a system that will enable family physicians to consult with relevant specialists, improving the hospital appointment system by integrating it into the FM system, and improving laboratory services by integrating them into the FM system.

Recent MoH Strategic Plan covering 2019–2023 (MoH 2019) highlights the necessity to manage NCDs effectively, and to improve health care delivery models to ensure continuity, proactive approaches, and close patient follow-up. The new Strategic Plan focuses on preventing population exposure to environmental risks and promoting healthy lifestyles through healthy nutrition and a physically active lifestyle and increasing health literacy. The new Strategic Plan also highlights MoH's intention to introduce multidisciplinary and integrated health care specifically through a strengthened FM structure, which is expected to prioritize NCD management and systematic population-based screenings for early detection by using well-defined and standardized processes, supported with technology. The processes will include case-based clinical treatment protocols, decision trees, service points, actors to assume the roles, and service delivery flow diagrams. An individual-based model is foreseen for the NCD management and follow up, which would incorporate information on different areas such as patient history, patient's other medical conditions, patient's communication preferences, and behavioural patterns (Sumer et al. 5).

61.3.2 Elements of the Care Integration in Turkey

Turkish health system transformation elements, together with the newly introduced features, constitute the building blocks of the recently evolving integrated care system.

Primary Healthcare Model: The FM model has been introduced as the main primary healthcare providing structure in 2005. The underlying idea to initiate FM model was twofold: to improve the physical access to and the quality of primary and preventive care services by shifting care provision from health posts (sağlık ocağı) to FMCs and to contribute to decrease the high ambulatory care workload of public hospitals. The new network of FMCs is also strengthened by the inclusion of mobile care services and addressing primary care issues at family medicine level in a less costly way.

Family medicine practices have been incentivized by bringing family physicians' salaries up to those of specialists and adding performance-based payments to salaries, promoting the use of clinical guidelines, enhancing and improving health information and decision support systems (DSS). Initially introduced as a pilot, the FM system has been scaled up nationwide in 2010. Primary care services are delivered in FMCs by FM practitioners (FMPs) and support staff. As of December

31, 2018, there are 26,252 FM units, and the population covered is 3,098 per active FM unit.[6]

Current FM model does not have a referral system for higher levels of care. In addition to FMCs, there are community health centers (CHCs) at the district level which deliver community and public health services, including environmental health (potable water analysis, closed space air quality analysis), health/hygiene at community areas such as schools and dormitories, logistics support to family medicine system such as the provision of consumables and vaccines, data collection, analysis, surveillance and reporting for communicable disease control and management and public health awareness activities.

HLCs have been introduced in 2017 to complement and strengthen the FM model in the efforts to increase access to care, protect individuals and the community from risk factors, encourage a healthy living style and decrease the hospital ambulatory care workload that could be addressed at primary care level. HLCs are designed to serve a maximum of 75,000 people within their catchment area and provide multidisciplinary services which include nutritional counseling, physical activity counseling, NCD management, healthy aging counseling, social work and support, smoking cessation, health literacy counseling, imaging and medical laboratory services and cancer early diagnosis, screening and education activities. They conduct patient follow-up activities when referred by FMCs and carry out population screening programs to identify and stratify the population for specific diseases, NCDs in particular. The underlying idea of introducing HLCS into the primary care is to introduce a proactive approach and thus plan ahead for NCD management.

FMPs and CHCs also provide mobile primary care services to rural areas where access to care is difficult/challenging. Mobile care services include medical examination, screening and follow-ups. Based on the needs of the rural population, patients are also referred to HLCs as necessary.

Health Information Systems (HIS): HIS in Turkey are well advanced, and they have substantial capabilities to collect and report data. Individual-level patient data are collected through different information systems operating under the MoH. Among them, family medicine Information System (AHBS) is used by FMPs; Public Health Information System[7] (HSYS) is used by primary care institutions; Hospital Management Information System (HBYS) is used by public hospitals and Medical Examination Information System (MBYS under HSYS) is used by healthcare institutions including FMCs, FMPs, CHCs, and other FM staff. MBYS records data on diagnosis, prescription, medical report, referral and medical interventions done as well as type of examination (emergency, follow-up, normal consultation, and so on).

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[6] Ministry of Health Public Health General Directorate, Department of Family Medicine.

[7] HLC modules operate under the HSYS. As of November 19, 2018, HLC sub-modules that are operational are school health, cancer, preventive dental health, and nutrition and physical activity. HLC sub-modules for which the software is ready and tested and which are ready to be operational are psychological support and social worker services. HLC sub-modules for which the software is to be developed are physiotherapy services and substance control.

MoH has recently introduced HYP, a web-based platform supporting healthcare providers (FMPs in particular) for screening and follow-up of NCDs.[8] HYP is planned to be integrated with AHBS through a web-link.

MoH intends to launch the priority NCD management modules of the HYP (namely HT, DM, obesity, and CVD risk assessment) by the end of 2020. These modules aim to integrate services among FMCs, HLCs, and secondary care. The process flow for each chronic disease has been designed end to end (across different levels of care) and the referral chain is intended to be operational under HYP in the future. The second group of NCD management modules will include the conditions of kidney failure, stroke, and coronary diseases, and the third group will include chronic obstructive pulmonary disease (COPD), asthma, and elderly care. MoH expects that the second and third groups will be operational by 2023.

HYP NCD modules are designed to allow family physicians to stratify and proactively manage their registered NCD patients and to monitor their own progress and performance. They can provide specific clinical data (such as list of patients whose HbA1c is greater than nine and whose blood pressure is greater than 140/90). The individual-level patient data can be aggregated on different levels such as FMC/district/provincial/regional and national levels. To complement HYP, other patient-specific historical information such as ICD-10 diagnosis code, date, and results of current and previous laboratory tests trended over time is also available through the cloud-based platform, e-Nabiz. This will help the family physicians to proactively manage NCD patients. To facilitate NCD patient follow-ups, HYP NCD modules also have reminders and pop-ups for physicians.

One significant feature of HYP NCD modules is that they do not only keep track of the patients but also the healthy population, ensuring to take the entire records of population health. This way, the modules guide the physician on the next actions/interventions for each registered individual.

NCD Care pathways: Patient pathways for the prioritized NCDs have been developed by MoH. These pathways are planned to be in use when HYP and its NCD modules become operational. MoH supports this effort by carrying out population awareness activities for priority NCDs and building capacity through health worker training. HYP features allow to track the compliance to screening and follow-up for both the patient and the provider and will keep data on clinical details of these interventions (e.g. concerning HT, data on blood pressure levels of the patient will be systematically collected.[9]

Sharing of electronic patient records: Individual-level patient data are collected through different information systems operating under the MoH HIS. Individual-level patient data from these information systems are kept on a cloud-based platform called *e-Nabiz* (e-pulse in English). While all public hospitals are integrated with e-Nabiz, university hospitals and private hospitals currently

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[8] https://dosyamerkez.saglik.gov.tr/Eklenti/31647,ahbs-hyp-entegrasyon-ek-dokuman-v2pdf.pdf?0 (accessed on 18.02.2020).

[9] Feedback from the Head of Chronic Diseases and Elderly Care Department, December 3, 2019.

provide data to e-Nabiz voluntarily. As a default, family physicians can access individual patient data through e-Nabiz. Other healthcare providers (including HLC care providers, secondary care providers and ER staff) can access individual patient data with the patient's consent. The patient can limit or extend access privileges to his/her data (for one time, for a period of time, or for always) to one, some, or all providers.[10] Patient data stored under e-Nabiz is comprehensive and include diagnosis, prescriptions, medical surgical history, imaging and reports, laboratory test results, medications used, and epicrisis[11] reports (if entered by the physician) (Sumer et al. 5).

DSS from an integrated care perspective. The main data source for individual-level health data, e-Nabiz, is updated near real time. Patient data are transferred through two Structured Query Language[12] (SQL) servers and are currently kept on three separate reporting platforms. As data processing and analysis are done at the data warehouse level (through Oracle, MSSQL, and big data), these functions do not impose any burden on e-Nabiz making the system flexible, agile, and efficient.

Concerning integrated care, DSS has several capabilities for risk stratification, population targeting, and disease prioritizing. It can populate the numbers of any new or prevailing NCD cases on different disaggregation levels (such as FMC, district, province, regional, or national level; by gender and age and by upper and lower diagnosis groups). DSS can also populate data on diagnoses based on International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD 10) codes, ambulatory care sensitive conditions (ACSCs) admissions and readmissions within 30 days to hospitals (by different disaggregation levels such as by hospital and length of stay) and ER visits (by hospital and by triage color). Although DSS can generate reports on a large number of queries, it currently generates reports centrally, based upon formal request from MoH units and does not allow the family physicians or other care providers to develop customized queries and generate reports. For reporting and analysis, the DSS also uses business intelligence (BI) tools and MoH plans to make the health data accessible to the local users through such BI tools in the future (Sumer et al. 5).

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[10] The exception is the mother and child health-related data as sharing this information across the levels of care is a requirement for primary care.

[11] A critical or analytical summing up especially of a medical case history (https://www.merriam-webster.com/medical/epicrisis).

[12] SQL is a standard computer language for relational database management and data manipulation. SQL is used to query, insert, update, and modify data. Most relational databases support SQL, which is an added benefit for database administrators (DBAs), as they are often required to support databases across several different platforms. (https://www.techopedia.com/definition/1245/structured-query-language-sql).

61.4 Dissemination and Replication

Family medicine pilot implementation law[13] has come into force in November 2004, and first pilot implementation of family medicine model has started in one province in September 2005. First six months of the pilot implementation has been assessed in terms of operational results, patient satisfaction, and utilization of primary care services and the findings shaped subsequent pilots in 2006 where six more pilot provinces have started implementing family medicine model. While identifying the provinces for each piloting stage, emphasis is given to rather smaller provinces at the beginning (with the idea that they would have fewer complex issues when compared with big/highly populated provinces.

By the time family medicine model was introduced, the number of physicians specialized on family medicine was quite low, and in order to support/improve the supply side (health human resources) of the family medicine model, MoH decided to deploy general practitioners in the model after letting them go through an orientation training on family medicine. A second supply side measure was to improve the financial conditions of the family medicine practices in order to shift physicians' preferences toward family medicine model. Both actions worked and physicians specialized on family medicine as well as general practitioners who wanted to make a transition to the family medicine took part in the new model.

Family medicine system rolled out throughout Turkey in phases. It started with seven provinces in 2005–2006, reached to 31 provinces in 2008, and had a nationwide coverage in 81 provinces in 2010, Figs. 61.1, 61.2, and 61.3.

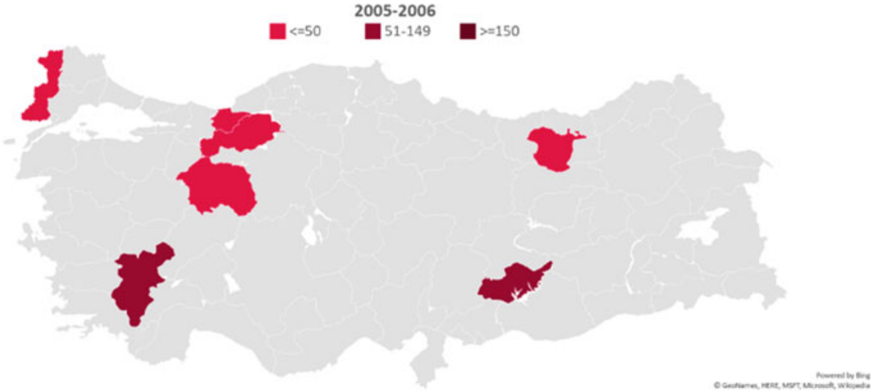

Fig. 61.1 Geographical coverage of FMCs 2005–2006

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[13] https://www.sb.gov.tr/EN/belge/1-7284/5258-sayili-aile-hekimligi-pilot-uygulamasi-hakkinda-ka-.html (accessed on 03.02.2020).

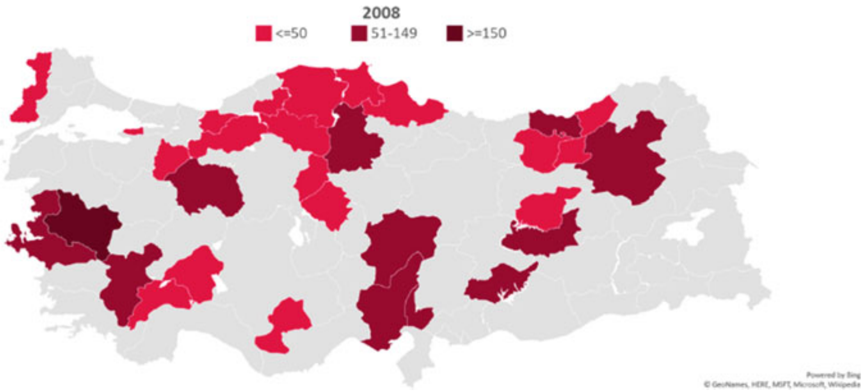

Fig. 61.2 Geographical coverage of FMCs 2008

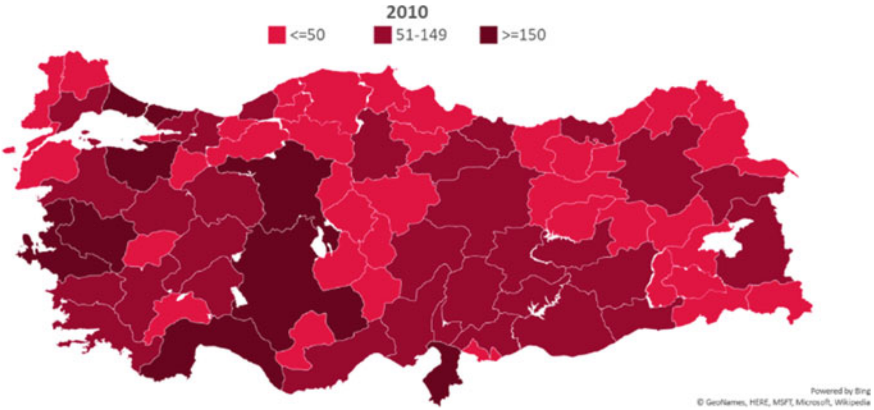

Fig. 61.3 Geographical coverage of FMCs 2010

HLCs have started operating in 2017 and continued to be rolled out nationwide. In 2017, there were 108 HLCs in 48 provinces. The number of HLCs reached to 193 in 2018. As of end 2019, there are 202 HLCs in 74 provinces, Figs. 61.4, 61.5 and 61.6.

The original plan of MoH was to establish around 1,000 HLCs throughout Turkey, each serving to 75,000 people in the catchment area. But, MoH revised the expansion projections for HLCs in the last Strategic Plan and now aims reaching 350 HLCs throughout Turkey by 2023.

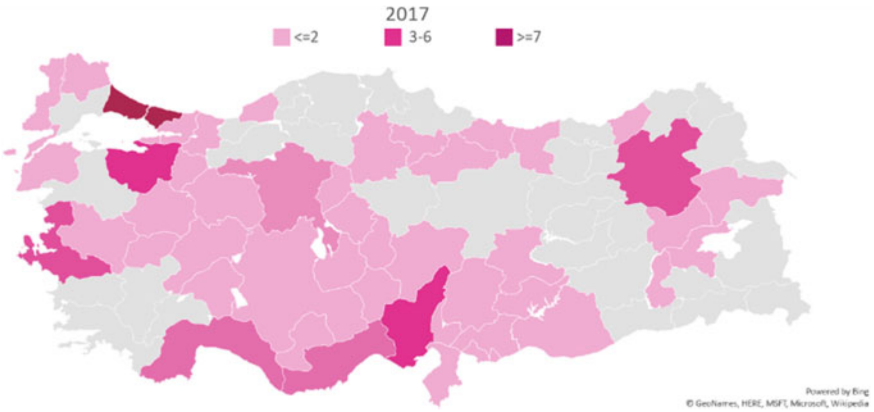

Fig. 61.4 Geographical coverage of HLCs 2017

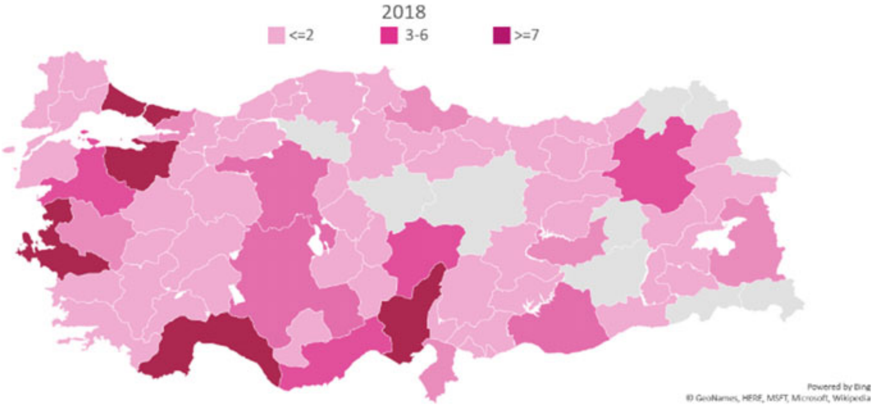

Fig. 61.5 Geographical coverage of HLCs 2018

61.5 Implementation and Impact

61.5.1 Implementation

Highlights on the implementation mostly concentrate on the integration practices at the primary care level, namely on multidisciplinary teamwork in HLCs, on local good practices for HLC-FMC coordination as well as HLC-hospital coordination for some specific cases and on awareness raising efforts for HLC services.

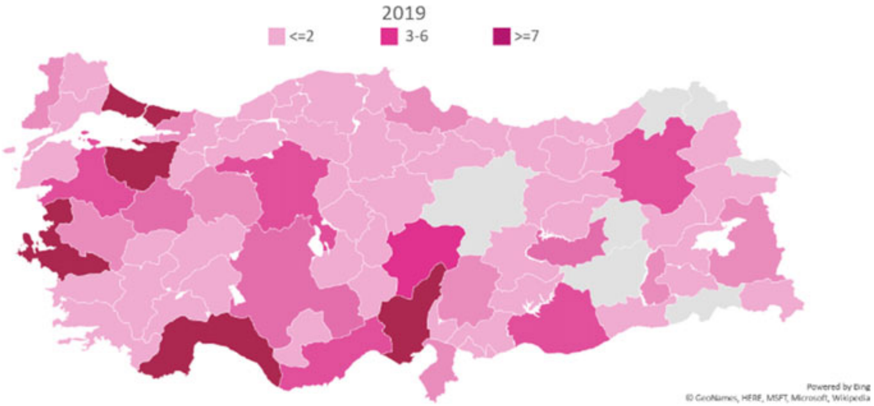

Fig. 61.6 Geographical coverage of HLCs 2019

Multidisciplinary teams: HLCs' multidisciplinary framework for service delivery is shaping up through actual implementation at the local level. There are some good examples which successfully adapt new staff to HLC multidisciplinary work. One orientation program carried out in one HLC mainly focuses on behavior development to contribute to multidisciplinary work, and on allowing new staff to closely observe and understand the HLC activities, process flow, and operational issues in real time. During orientation, HLC staff give feedback to the HLC management about the behavioral progress of the new staff toward multidisciplinary work. The HLC who developed the orientation program has also established a *case assessment board* to regularly convene the involved HLC staff for the patients in focus to discuss, make decisions, and report about the progress of these cases. FMPs for these patients are also invited to the board meetings if needed.

Care coordination: HLCs are managed by a responsible physician who is appointed by the MoH. The responsible physician allocates and reallocates staff into the HLC service units, ensures proper work conduct, and makes HLC's official correspondence with the MoH. A registration/information desk is formed at the HLC entrance where medical secretary and other appropriate personnel are responsible for entering patient data in the registration system and referring patients to the related HLC unit (Sumer et al. 5).

The HLC framework currently describes the role of the case coordinator as an administrative work rather than a medical one. This role is usually defined under the medical secretary as to carry out correspondence and communication for the continuity of care; manage appointments and patient registration; keep patient administrative and medical data and convert all medical data into medical documents; file, archive, and retrieve all patient data; carry out clinical coding; compile statistical data and prepare reports for the upper management; and manage patient discharge work and communications.[14]

While the current position of a case coordinator mostly assumes an administrative role, actual implementation practices necessitates an enhanced role for a more effective service delivery. To this end, the case coordinator should be able to make a holistic patient assessment including his/her need for a referral to higher levels of care, his/her overall health status, and should be able to take initiative, similar to a case manager. Concerning NCDs, this preliminary data/information collected by the case coordinator can then be analyzed and shared with the FMC for further coordination and patient care.

A good example for HLC coordination practices at the local level is cancer screening. In one of the HLCs in Bursa Province, people are called individually for cancer screening or they are contacted through their family physician. If their screening results are positive or suspicious, they are quickly referred to a secondary care institution. This referral is done manually with a paper given to the patient. With this 'referral paper,' the patient can get the same-day service at the secondary level. A second example is peculiar to Hatay Province. Because of the demographics and thalassemia being a hereditary disease, its prevalence and incidence is high in Hatay. All couples planning to be married are mandatorily tested for thalassemia. These tests are conducted in Hatay HLC, and those with positive and suspicious test results are immediately referred to secondary care. Another local pilot initiative for coordination between FMCs and HLCs is introduced by the General Directorate of Public Health in Kırklareli Province, where a brief paper-based referral form has been designed, and FMPs are asked to use this form to refer their patients to HLCs. Data from these forms are later shared with the Chronic Disease and Elderly Care Department.

Communications and awareness efforts for HLC services. As there are no mandatory referrals between and within the same levels of care,[15] creating patient and provider awareness for the use of primary care services is critical. There is a good understanding of this need at the local level and local health teams actively promote HLCs and their services. To illustrate, in Bursa, to inform FMPs and specialist physicians on HLC services, HLC staff call them and explain the HLC system and its necessity and complementarity for the FM model. As another example, in Hatay, the case coordinator, who is a medical secretary, makes scheduled visits to rural areas and villages by a vehicle and brings patients to the HLC for cancer screening and thalassemia. Once the patients are in the HLC, in addition to receiving screening services, they are also informed about other HLC services. Additionally, HLC services are promoted in schools and in FMCs in Hatay (Sumer et al. 5).

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[14] https://dosyaism.saglik.gov.tr/Eklenti/12541,20140522-29007-sag-meslek-mensuplari-ile-sag-hizde-cal-diger-meslek-mensuplarinin-is-ve-gorev-tanimlarina-dair-yonetmelikpdf.pdf?0.

[15] From a health system resources point of view, the head of GD Chronic Diseases indicates that mandatory referral between FMCs and HLCs can be possible when the number of HLCs reaches more than 1,000.

61.5.2 Initial Impact of Care Integration Efforts

As care integration efforts are rather new in the Turkish System, a number of preliminary results, namely HLC utilization/visits, usage of e-Nabiz, the cloud-based electronic patient records platform and patient satisfaction can give an indication on the short-term impact of the novel primary care structures and care integration practices.

Utilization of e-Nabiz platform: Since its introduction, there is an increasing interest in using e-Nabiz both by the citizens and providers. Number of active e-Nabiz users (citizens) have increased by 97.6%, from 8.5 million in November 2018 (Sumer et al. 5) to 16.8 million people in January 2020.[16]

MoH data suggest that the number of e-Nabiz visits at all levels of care increased threefold, from 3.2 million visits in November 2018 to 13.4 million visits in December 2019. The share of FMP visits within total number of provider visits was 92.3% in November 2018, implying FMPs' significantly high interest for e-Nabiz platform. High e-Nabiz utilization figures at the primary level suggest that on the one hand there is a trusting relationship between the primary care provider and the patient (patient acknowledges the primary health care) and on the other hand the e-Nabiz is getting acceptance from the primary care providers to access data (Sumer et al. 5).

While there have been 29,146 total providers who visited e-Nabiz in Nov 2018, this number increased to 59,093 by end December 2019. 2018 figures show that 68.8% of providers were FMPs while the rest were secondary and tertiary care providers. 2019 figures suggest a more balanced picture concerning the share of physicians using e-Nabiz among all levels of care, where the share of FMPs is 43.0%, secondary care physicians is 34.2%, and tertiary care physicians is 22.8%. These latest figures also show that there is growing interest in using e-Nabiz in higher levels of care.

MoH data suggest that e-Nabiz is mostly accessed by mobile phones (71.5%) followed by computers (27.4%).

HLC utilization: MoH data suggest an increasing use of HLC services in time. While the number of people who visited HLCs in the last four months of 2017 was 1.72 million, this number rose to 11.8 million in 2018 and 18.5 million in 2019, implying a 56.8% increase in a year.

Patient Satisfaction: To monitor an important health system outcome, patient satisfaction (WHO 7), MoHs has recently conducted a telephone survey on patient satisfaction for HLCs.[17] The survey was conducted in December 2019 and comprised 150 HLCs which actively use HSYS. A sample of 9604 citizens has been selected out of a universe of 109,410 citizens who have received service from these HLCs in the last 3 months. The sample size constitutes 8.8% of the universe.

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[16] Data provided by GD HIS of MoH as of 28 January 2020.

[17] MoH General Directorate of Health Promotion, Healthy Living Centers Satisfaction Survey, 2019.

A multistage stratified sampling method is used for the survey. The survey used a 10-item questionnaire elaborating satisfaction on different aspects of HLC services including patient help desk and patient orientation, waiting time for registration and time allocated to medical examination and counseling, protection of privacy, informing patient about his/her medical condition, time to obtain laboratory results, cleanliness of the facility and ease of access to the HLCs. Nine out of 10 items of the questionnaire used a 5-point Likert scale.

The findings of the survey suggest that the biggest share of population using HLCs are 35–44 of age (32.3%) and 45–54 of age (28.2%). Female population is significantly the biggest user group of HLCs by 87.8%. Top three mostly used HLC services are cancer screening (39.8%), nutritional counseling services (32.2%) and physiotherapy support (6.0%). Citizens learn about HLC services mostly through recommendations from their relatives and friends (47.5%) and from physicians (35.0%). The survey highlights an overall HLC patient satisfaction score as 84.1 out of 100.

In addition to the above survey on satisfaction, MoH intends to measure the impact of the interventions on four prioritized NCDs (DM HT, CVD risk assessment and obesity) in future. One of the indicators they plan to use is the quarterly prescription rate for the prioritized NCDs, which will give an indication of regular patient follow-up. This indicator is expected to be used by the end of 2020. A second indicator will measure the performance vis-à-vis ACSCs and will measure the number of people (out of total screened and followed up people for the prioritized NCDs) who made an ER visit for a specified time period. This indicator is also expected to be used by the end of 2020. Finally, MoH expects to keep track of mortality data on the prioritized NCDs by the second half of 2021.[18]

61.6 Lessons Learned and What's Ahead

61.6.1 Next Steps in Care Integration

Having started the integration efforts mostly at the primary level, Turkey's plans for integrated care include making these efforts more sustainable through FM performance payments and making HYP operational. Turkey will pursue a stepwise approach for integration at different levels of care by giving priority to most critical NCDs, and the efforts will start with the obesity.

Incentivizing NCD care: While pronounced and discussed for a long while, performance incentives for NCD care at FM level have not been materialized so far. However, MoH and Ministry of Treasury and Finance recently had a consensus for introducing NCD performance payments for the family physicians. NCD performance payment system is expected to be operational within 2020, possibly in the

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[18] Interview with Head of Chronic Diseases and Elderly Care Department, Ms. Banu Ekinci, 21 January 2020.

first half. Technical teams from both ministries currently work of the NCD performance payment formula. As an additional effort, MoH also works on incorporating DM and CVD risk assessment in the performance evaluation process of Provincial Health Directors of MoH.

Use of HYP: A pilot implementation for the use of HYP has been done in four provinces, where 12,000 people have been screened for the prioritized NCDs of DM, HT, CVD risk assessment and obesity. Through these pilots, the share of population with a new diagnosis has been found as 2.5% and basic screening data have been transferred to HYP. MoH plans to enter detailed data of the pilot implementation to HYP within the first half of 2020. Pilot implementation revealed that the average time required to use and enter data to HYP by the physicians is around 2 min. Concerning feasibility of using HYP, MoH perceives this duration as a reasonable time for HYP usage. This result also implies that the platform is user friendly and effective.[19]

Disease prioritization for integration with higher levels of care: For vertical integration, MoH pursues an approach focusing on highly prioritized diseases/ conditions in the Turkish context. Obesity care is an initial good example. MoH has recently developed a comprehensive care pathway for the obese patients to navigate through different levels of care for treatment. The pathway allows patient navigation in the health system based on an initial body mass index (BMI) assessment.

The journey for an obese patient starts at the primary care level, namely at the FMC. Patients with BMI less than 30 are given counseling for a healthy life and are kept in the FMC screening list for future monitoring. Patients with a BMI between 30 and 40 are referred to HLCs and are kept in the follow-up list for closer monitoring. These patients who are referred to HLCs are provided with counseling and care by the dietitians, psychologists, and physiotherapists for a defined period of time ranging from 1 to 6 months. Depending on the progress made at the end of this period, the patient is either referred to obesity treatment centers (entities established within hospitals exclusively focusing on obese patients care) for specialized treatment, or to HLCs for being followed up or to FMCs for periodic controls.

Through initial FMC assessment, patients who have a BMI more than 40, together with accompanying conditions such as coronary artery disease, are referred to obesity treatment centers and are kept in the follow-up list for closer supervision. These patients are then guided by the treatment center medical secretaries or care coordinators to the obesity treatment center's programs on physiotherapy, psychosocial support, diet, and physical activity systems for an in-depth assessment. Following the multidisciplinary assessment stage, the patient is then routed for a number of physician consultations including internal medicine, cardiology, physical

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[19] Interview with Head of Chronic Diseases and Elderly Care Department, Ms. Banu Ekinci, 21 January 2020.

medicine, and rehabilitation, general surgery and psychiatry. After these specialist consultations, the patient is closely monitored and followed up for a period ranging from 1 to 6 months by the obesity treatment center's dietitian, psychologist, and psychotherapist. Depending on the results obtained at the end of this period, the patient is either referred back to the FMC for regular controls or is being followed up at the obesity treatment center for an additional period of 3 months or referred to higher specialist care for surgery through making an official surgery registration to the e-Nabiz HYP platform. Patients who have gone through the surgery are then followed up by the dietitian, psychologist, and psychotherapist of the obesity treatment center.

Obesity care integration is supported with the disease management platform, HYP, which allows to enter and collect patient records at all levels for obesity treatment.

61.6.2 Lessons Learned

Integrating healthcare services is a new concept for Turkey, and the implementations are at the infant stage. Still, there are some lessons learned from the initial implementation efforts. The first one is the importance of effective communication between different MoH units. The comprehensive care pathway developed for the obese patients to navigate through different levels of care for treatment is a good example of collaboration based on improved communication between Public Health and Public Hospitals units. When the HLCs and obesity treatment centers were piloted at the beginning, the quality of communication between MoH units was not very high. MoH's upper management efforts to inform all MoH units on the MoH's strategic objectives and action plans helped different units working on different parts of the pathways to coordinate and work together.

The second lesson is about implementing a manageable expansion strategy for the HLCs. MoH upper management stepped back from the ambitious expansion plan of HLC throughout Turkey, by relying on the successful roll-out plan of the FMCs. Increasing the number of HLCs before integrating them to the care pathways could have had negative effects on the user/patient satisfaction and create a negative reputation for the integration efforts. The HLC satisfaction survey presents that the modest expansion strategy was welcome by the users of the HLCs, and there exists public support for further expansion.

A last but not the least lesson is about benefiting from good experiences of other countries as an effective way of improving the integration plans. To this end, MoH hosted or participated in international events on care integration to share its experiences and finding better ways of integrating care.

61.7 Conclusion

From the central policy making and the local implementation perspectives, Turkish health system has strong aspects including a robust and flexible IT system, local efforts on care coordination and multidisciplinary work. These aspects will help take the care integration efforts forward effectively.

Good and increasing coverage of primary care structures together with increasing utilization figures imply public awareness and acceptance for the primary level services. These initial results present a good indication of success in the efforts to shift ambulatory care load toward the primary care.

Concerning vertical care integration, the prioritized disease approach will give the Turkish health system the chance to take it as pilot and reflect the implementation lessons to upcoming steps.

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Israel: Structural and Functional Integration at the Israeli Healthcare System

62

Ran Balicer, Efrat Shadmi, Orly Manor, and Maya Leventer-Roberts

62.1 Integrated Care in Israel

The Israel healthcare system was transformed with the enactment of the National Health Insurance Law (NHIL) in 1995. The law states that health care in Israel shall be based on three values—justice, equity and solidarity (Gross et al. 1998). To assure these principles are upheld, the law enacted several important mechanisms, including a mandatory progressive health tax and universal coverage to all Israeli residents. Universal coverage is provided by one of the four non-profit health funds (also known as health plans, HPs), Clalit, Maccabi, Meuhedet and Leumit, of which any one of the 8.5 million (current) Israeli residents is free to choose from. HPs serve as insurers and providers of services, providing all outpatient care (primary, speciality, laboratory, imaging and pharmacy services) and some of the in-patient services (about a third of hospital beds, owned and operated by Clalit). All other

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in-patient services are provided by the Ministry of Health and a mix of non-profit and for-profit organisations. The NHIL determines a broad unified benefits package (also called the "health basket") that each of the HPs is required to provide to its members and which is reviewed and updated annually by a budgeted governmental committee in a thorough and transparent process (Chinitz et al. 2009).

Health spending in Israel is relatively low. In 2013, it was 7.56% of GDP compared to 8.7% for the EU average (2012) and 8.9% for the OECD average. This low level is generally attributable to several factors. First, HPs are financed through a capitated formula that is adjusted for age, sex and area of residency (periphery versus central Israel). Israeli residents can freely switch between HPs, but yearly movement between HPs is very low, at <1% among those aged 30 years and over. Thus, capitation creates a strong incentive for HPs to provide efficient, effective, preventive and integrated care to keep their member population healthy and reduce costs. Additionally, HPs work as managed care organisations with gatekeeping and some cost sharing through out-of-pocket payments for visits to specialists and for medications. Finally, in-patient service supply is highly regulated with constraints on costs and bed availability (Van de Ven et al. 2013).

The system is financed mainly through a combination of a progressive payroll-based health tax and general taxation. Yet, despite equitable principles asserted by the NHIL, a growing percentage of financing is private, reaching up to 39% in 2012 (Bin-Nun 2013), with a surge in the breadth and scope of services provided by HPs as voluntary health insurance (VHI) benefits and by independent private health insurance companies (Brammli-Greenberg et al. 2014). Thus, while Israeli residents value their freedom to receive care outside the HP scheme, the growing privatisation of healthcare services erodes its equitable nature. Another negative by-product of the surge in private services is fragmentation, as information on the type and content of services privately consumed is unavailable to the HPs, which as insurers and integrative providers are ultimately accountable for the health of their member population.

In recent years, two major reforms that took place in the Israeli healthcare system have significantly contributed to integration. Beginning in 2010, dental services for children are included in the basket of services. This is the first time any type of dental care services (with the exception of limited services for trauma and oncology patients) was added to the health basket. The benefits initially included preventive and preservative dental care for children up to age 8, and this was recently expanded to cover children up to age 14. In 2015, mental health services, which despite numerous efforts since the enactment of the NHIL, were until then provided by the Ministry of Health, were added to the basket of services to be provided by the HPs. This major reform shifted responsibility for in-patient and ambulatory mental health services to the HPs, aiming to provide better access to ambulatory mental health services, reduce psychiatric hospitalisation rates and integrate mental health with all other healthcare services (Aviram and Azary-Veisel 2015).

Overall, the structure of the Israeli healthcare system can be described as one that is extensively integrated. Nonetheless, fragmentation still exists, in particular as it relates to long-term care and social services, which are provided directly by government social security and welfare services. This structural fragmentation leads to significant challenges in providing integrated care for those with health and social care needs, and while work to reform the infrastructure has been ongoing for some two decades (Asiskovitch 2013), it has yet to materialise.

62.1.1 A National Perspective: How Integration in Practice Can Improve Quality of Outpatient Care

- The National Programme for Quality Indicators in Community Healthcare (QICH) was initiated in 2000 as a research project founded by the Israel National Institute for Health Policy Research. The QICH programme maintains and updates comprehensive and integrative measures of the quality of primary care provided by the health plans, including selected services in the fields of prevention, diagnosis and treatment. There are 50 indicators in eight domains: health promotion, cancer screening, child and adolescent health, health in older adults, respiratory diseases, cardiovascular health, diabetes and antibiotic usage.
- Data are continuously collected for the entire population of Israel from the integrated electronic health records of the four health plans using multiple sources such as physicians' and nurses' records, pharmacy claims, laboratory results, hospital procedures and reimbursement claims from private suppliers.
- The indicators are implemented in a cascade-type manner to integrative multiple fields into a single measure. For example, in order to evaluate monitoring of diabetic co-morbidities, an initial filter identifies patients with diabetes, followed by monitoring of renal function and diagnosis of diabetic nephropathy, and only then, compliance with appropriate treatment of Angiotensin-Converting Enzyme Inhibitors or Angiotensin Receptor Blockers is evaluated.
- The impact of this strategy can be exemplified as follows:
  - The rate of BMI documentation, which increased from less than 6% in 2003 to almost 88% in 2014.
  - The rate of individuals who underwent colorectal cancer screening increased from 11.5% in 2003 to 58.9% in 2014. This level advances Israel to the top position among OECD countries.

62.2 Integrated Care in Practice: Clalit Health Services

Clalit Health Services (Clalit) is the largest health plan in Israel, covering about 4.3 million Israelis, about 52% of the Israeli population. Due to historical reasons, Clalit, relative to the other three HPs, has an overrepresentation of members with lower socioeconomic status, ethnic minorities, elderly and those with chronic conditions. Clalit insures over 70% of all Israelis aged 85 and over, and about 80% of the non-Jewish minority populations (Social Security report 2015). Clalit owns and operates 30% of the acute hospital beds, over 1500 primary care clinics and specialist clinics, and a complete set of ancillary services (imaging, pharmacy, laboratory). Clalit members mostly receive primary care from salaried physicians at clinics owned and operated by Clalit. Patients are free to choose their general practitioner or primary care physician (PCP) and can switch as often as they wish. Primary care is also delivered by independent physicians operating their own facilities, mostly in solo but also some in group practices. Clinics' size varies, with some small, rural clinics serving several hundred patients, up to large clinics covering up to about 10,000 members. Specialist services are either provided at speciality care centres located throughout the country or in multidisciplinary clinics that provide both primary and speciality care services (Rosen et al. 2015).

At Clalit, most PCPs are payed a monthly salary, based on the size of their roster, or patient list, plus a capitation fee, which reflects the age composition and morbidity levels of their patient population (Rosen et al. 2015) and is determined according to the case-mix system score of the Adjusted Clinical Groups® system (Shadmi et al. 2011). This payment scheme creates a form of an accountable care system, in which PCPs and primary care clinics are accountable for the health and healthcare service use of their member population. The scheme does not involve penalties or financial incentives; instead, it builds on the performance of the clinics, the health status of the populations and the resources used and costs accrued which are monitored by the respective managerial units at the sub-regional and regional levels and ultimately at the managerial headquarters. That way, the scheme avoids otherwise commonly occurring perverse incentives to seek volume over value and provides a drive for investing in effective preventive services.

All GPs and specialists use a single electronic health record (EHR) software, and all clinical data, administrative and claims data are unified into a single data warehouse centre. The data are both ID-tagged and geo-coded. Additionally, to achieve interoperability between its primary, speciality and in-patient care services, a health information exchange (HIE) system, which connects EHR systems across various clinics and hospitals, has been implemented in Clalit since 2005 (Flaks-Manov et al. 2016). This HIE system (OFEK) links patient health records and allows providers to access critical clinical data at the point of care.

While all HPs in Israel are similar in that they serve as insurers and providers of all services covered by the health basket, Clalit is the only HP structured mostly as an integrated delivery system. It owns and operates most services, including a third of all hospital beds, as mentioned earlier, and it is also the only HP in which patients are registered to receive services with a particular PCP, who is accountable for their care and health. Also, in Clalit, the PCP plays a gatekeeper role in which access to all speciality services is contingent upon referral (Tabenkin and Gross 2000), expect for five areas, ear, nose and throat, dermatology, orthopaedics, ophthalmology and gynaecology. The second-largest HP, Maccabi, covers about 25% of the population, and it is structured mostly as a preferred provider organisation, in which PCPs work as independent contractors, mostly in solo practices, and although most patients receive the bulk of their care from one PCP, there is no mandatory registration. In the two other HPs, Leumit and Meuhedet, the majority of

PCPs work as independent physicians, and similar to Maccabi, there is no mandatory registration with one PCP, and PCPs do not serve as gatekeepers of speciality services (Rosen et al. 2015). With the exception of one private hospital chain owned by Maccabi, none of the other HPs own and operate their own hospital system.

It is this structural integration of Clalit, in which ambulatory and a large share of in-patient services are provided by the same organisation, and in which the organisation of management is fully integrated, with the community care division and hospital care division working in close collaboration, in conjunction with the aligned incentives, which creates an important foundation for care integration.

62.2.1 Problem Definition: Unplanned Readmissions

Readmission reduction is a primary focus of healthcare systems worldwide in efforts to improve quality of care and efficiency across care settings (Jencks et al. 2009; Nolte et al. 2012). In Clalit, approximately one out of five older adults who are hospitalised in internal medicine wards return to the hospital for an unplanned readmission within 30 days. Readmission reduction is one of the few strategies that can serve as a prime example for care integration between primary, secondary and tertiary care (Leppin et al. 2014). To maximise clinical relevance and efficiency, interventions should vary according to patients' readmission risk. Patient surveys and computerised risk prediction models are increasingly used for such high-risk patient targeting purposes (Amarasingham et al. 2015).

In 2011, Clalit implemented a comprehensive three-level approach to achieve early identification and readmission prevention in targeted high-risk patients.

62.2.1.1 The Strategy: Vertical Integration

The organisation-wide integrated programme includes three components:

(I) Development and implementation of a predictive modelling tool for high risk of readmission, which is provided to healthcare providers (primary care physicians and nurses) at the patients' primary care clinic and upon admission to the hospital;
(II) A transitional care intervention in which community care nurses are positioned within the hospital to facilitate complex care transitions; and
(III) Integrated quality monitoring of key objectives (readmission rates and early post-discharge primary care visit indicators) and patient-reported indicators (quality of the transitional process). Each component is detailed below.

62.2.1.2 Predictive Modelling

To guide the strategy and to identify patients who are most likely to benefit from an intensive readmission reduction intervention, a prediction algorithm was developed. This algorithm is based on medical history from EHR and administrative data, the

Preadmission Readmission Detection Model (PREADM), and it uses a preprocessing variable selection with decision trees and neural network algorithms in order to identify patients at high risk for an unplanned subsequent hospitalisation, upon admission to any internal medicine unit at any hospital. The aim was to achieve a generalisable model that contains data that could potentially be used in any health system with EHRs. Model construction also emphasised the importance of applicability and weighed the likelihood of data availability at the time of admission. Ultimately, the PREADM included variables such as chronic conditions, prior health services use, body mass index and geographical location variables to determine each older adults' risk score. This algorithm was introduced into all of Clalit's hospitals and primary care clinics' EHR system to yield a readmission risk score for all patients on admission to an internal medicine department at any hospital in Israel (Shadmi et al. 2015).

62.2.1.3 Transitional Care Interventions

The PREADM risk score is used to target patients for specific interventions in hospitals and primary care clinics. In all general hospitals in Israel, a transitional care nurse (TCN) uses the PREADM score to target high-risk older people aged 65 and above. The TCN role was developed by Clalit's community care division for this programme and implemented country-wide for all Clalit members. The nurse provides in-hospital coordination, discharge planning and coordination with primary care clinic services for post-discharge follow-up and monitoring. Moreover, primary care nurses from each patients' primary care clinic receive notices that their patients are hospitalised, complete with their PREADM score, enabling them to prioritise reaching out efforts to high-risk patients immediately after discharge. Nurses use a specially tailored EHR embedded screening and action tool to assess patients' needs and plan their post-discharge care (e.g. need for a home visit and/or medication reconciliation) and provide or refer them to needed services.

62.2.1.4 Quality Monitoring

Quality monitoring is performed using both objective and patient-reported measures. Hospital managers as well as primary care clinics' regional managerial teams receive quarterly reports on the readmission rates and post-discharge follow-up (within 3 and 7 days) in their respective areas and compared to other regions. Additionally, patient-reported data from the post-discharge nursing assessments are collected via surveys to evaluate the quality of their post-discharge care.

62.2.2 Impact

The vertical integration strategy has produced multiple levels of results. First, the Preadmission Readmission Detection Model (PREADM) has been shown to comparatively accurately identify patients at high risk for readmission (Shadmi et al. 2015). Second, the TCNs role was implemented in all 27 general hospitals across Israel, including the eight Clalit hospitals, in which approximately 40% of

Clalit's member population is hospitalised, and the 19 government owned and operated hospitals. The TCNs helped to tailor the care of individual high-risk patients and to establish mechanisms that improve care transitions in multiple settings, for example, improved transitions to rehabilitation services. Finally, quality monitoring identified several areas for improvement: (1) rates of follow-up post-discharge, defined as a visit or a phone call with a primary care physicians or nurses within 7 days of discharge, have risen substantially, from an already relatively high rate of 68% in 2012 to a rate of 86% in 2015; (2) most primary care clinics are using patients' assessments of their own post-discharge needs to guide personalised follow-up interventions; and (3) within the patient population hospitalised in Clalit's hospitals, a significant reduction in readmission rates was observed in high-risk older patients, from 34.3% in 2012 to 32.4% in 2015, which translates into approximately 9100 averted hospitalisation days.

62.2.3 Dissemination and Replication

The observed results of the vertical integration strategy implemented by Clalit to effectively address readmission rates point to the potential outcomes of a strategy which establishes links between healthcare providers and services at different levels, uses the same tools to guide their intervention and incorporates advanced EHR-based predictive algorithms and quality monitoring measures. The favourable results observed for the Clalit health system illustrate the importance of structural integration, which can fully capitalise on the benefits of an integrated delivery system design. The Clalit experience also provides several principles that can be widely disseminated. For example, with the wide-spread adoption of EHRs, there is increasing opportunity for their "meaningful use" by targeting highest-risk patients for interventions and creating feedback mechanism that contribute to a transparent reporting system in which various managerial units (in Clalit, both at the hospital and community division levels) can act upon.

62.2.4 Lessons Learned and Outlook

As improving continuity of care remains a national priority and given the integrative structure and availability of interoperable electronic HIEs, several trends will likely impact the further implementation of care integration in Israel in the coming years.

With the 2015 mental health reform, an ongoing process of integrating mental health care into the outpatient setting and GP practices is taking place, which is expected to lead to a considerable improvement in the quality of care for mentally ill patients. There is dire need to implement a similar reform to integrate the social and healthcare aspects of care for older people in particular, which is currently disjointed and so reduces the efficiency, effectiveness and patient centredness of care for older people in Israel.

Israel has put a considerable emphasis on embracing digital health on the national level, with a national initiative called "Digital Israel" now funding innovation in digital health that may increase care effectiveness and patient engagement. With its long tradition as the "start-up nation", it is likely that the coming years will show new and innovative technologies that can enhance care integration such as through smartphones and immersive technologies (see Chap. 30 Vol. 1 HBIC) These technologies may allow better flow of real-time data between providers, patient guidance within the healthcare system components according to the illness at hand, and predictive/ prescriptive provider and patient decision support based on advanced analytics. The digital infrastructure is there, and it is the scaled implementation that will be the upcoming challenge in harnessing these promising technologies to improve care integration and patient-centred care outcomes.

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Integrated Care Concerning Mass Casualty Incidents/Disasters: Lessons Learned from Implementation in Israel

63

Bruria Adini and Kobi Peleg

63.1 Introduction

Mass casualty incidents (MCIs) of all types tax the immediately available resources of the healthcare system and impact on the capacity to provide optimal treatment to all casualties and patients needing medical services (Schenk et al. 2014). At times, especially during and following natural or manmade MCIs and/or large-scale disasters, the medical providers themselves may be impacted by the event, and their resources become even more dwindled (Ardagh et al. 2012). Provision of integrated care and business continuity, that are crucial in such events, necessitate pre-planning and implementation of actions targeted to assure stability and continuous operation of vital, life-saving services (Wen et al. 2014).

The aim of this sub-chapter is to describe the methodology adopted in Israel to assure an integrated care approach before, during and following mass casualty incidents and disasters.

63.2 Basic Assumptions

- Actions well versed in routine will work efficiently during MCIs and disasters.
- As MCIs are frequently characterized by chaos, confusion, contradictory or unclear information, an automatic response should be in place.

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- The emergency response system and the personnel need to be acquainted, educated and trained concerning what is expected of them in advance.
- A prepared healthcare system-based national doctrine, replenishment, order of operations, method, trust and training are the key for an effective response to MCIs.
- Clear and structured modes of authority and responsibility are needed in order to assure a coordinated response.

63.3 Main Components of Integrated Care

63.3.1 The Preparatory Phase

Why is it important that the healthcare systems be prepared to MCIs and disasters? The answer can be found in the statistics of damages inflicted by these events. Despite the fact that in the year 2014, the annual average of disaster frequency (324) was lower than that observed in the former decade (384 average frequency of events between 2004 and 2013); natural disasters still killed 7823 people and victimized 140.8 million people worldwide (Guha-Sapir et al. 2014).

The responsibility of the national authority charged with assuring emergency preparedness consists of three main functions, including the establishment of national policies, creation of standards and criteria for the implementation of the policies, and control as well as monitoring the actual application of the policies and standards. Accordingly, ensuring efficient preparedness to provide integrated care is based on five main preparatory measures: (1) development of national multi-sectorial, multi-organizational guidelines and institutional standard operating procedures (SOPs) for emergency response (Peleg and Rozenfeld 2015); (2) instigating training programmes to assure knowledge and competencies of personnel (Leow et al. 2012); (3) implementing ongoing monitoring systems to assure effectiveness and validity of the readiness of each institution (Adini et al. 2012); (4) operating information systems to collect and distribute crucial data in all phases of emergency management (Bar-El et al. 2013); and (5) procuring and installing vital equipment and infrastructure (Duncan et al. 2014).

63.3.1.1 Development of Integrated Guidelines and SOPs

The Israeli Ministry of Health (MOH) has the overall responsibility to assure an effective emergency preparedness and response of the healthcare system to all types and scopes of MCIs and disasters (Adini and Peleg 2013). The responsibility and authority of the MOH concerning emergency management encompass all health institutions regardless of their ownership, thus including all governmental, public and private hospitals. Aligned with this responsibility, the MOH adopted an integrated centralized approach; thus, all activities are directed and monitored by the national level. Accordingly, risk assessment procedures are in place and implemented continuously in order to identify the emergency scenarios that may occur in the region (Adini and Peleg 2013). Based on the results of the risk assessment, national guidelines for emergency response are developed, encompassing the expected mechanisms and modes of operation that must be adopted by different stakeholders, including the emergency medical services (EMS), hospitals, health district officials and health maintenance organizations (HMOs). Though the guidelines are prepared by the national level, representatives from different stakeholders and various professional sectors are involved in the development process, consisting of the most senior experts from each entity/ profession. Resulting from this process, the guidelines are characterized by cross-sectoral and multi-professional coordination, taking into consideration various needs and challenges. Following the approval of the guidelines by the Supreme Health Authority (the highest authority in the healthcare system, headed by the director-general of the MOH), they are disseminated to all entities, as obligatory policies. Each medical organization is then committed to preparing an institutional SOP, based on the building blocks that are delineated in the guidelines, modified according to the organizational infrastructure and available resources. The SOPs are reviewed by the MOH and the Home Front Command (HFC) to ensure their applicability to the national doctrines and policy. Accordingly, as all SOPs are based on the same policy and guidelines, there is great similarity between them, and during emergency response, coordination of actions and intra-organizational collaborations are easily attained.

63.3.1.2 Training and Exercise Programmes

Cross-sector multi-disciplinary joint training programmes are implemented in order to achieve the development and ongoing use of a common “disaster language”. The training materials are centrally developed by the MOH which also conducts training programmes for “nucleus knowledge teams” from different entities, designated to provide them with the capacity to further implement the materials in their respective organizations. Using a “snowballing technique”, the trainings are then implemented in different entities, encompassing various sectors, emergency sites/wards and levels of responsibility. The effectiveness of the training programmes and the knowledge and competencies of the personnel is reviewed in a series of exercises, commencing in institutional local drills and completed by national exercises that are initiated and conducted by the MOH and the HFC. Each entity participates in at least one exercise annually, designated to assure a continuous maintenance of competencies (Adini et al. 2010a).

63.3.1.3 Ongoing Monitoring Systems

Similar to the development of guidelines and initiation of training and exercise programmes, the continuous monitoring system is also enacted centrally and nationally by the MOH (Adini et al. 2012). The monitoring is designated to assure an ongoing continuous level of emergency preparedness of all entities involved in the response to MCIs and disasters. It is based on objective evaluation measures that were developed and disseminated to all entities, serving as benchmarks that must be implemented in each organization to maintain a continuous high level of emergency preparedness to all scenarios that were identified in the risk assessment process as potential in the region. Once every two years, an extensive evaluation is conducted in each institution, based on expert evaluators from the MOH and the HFC, in which all aspects of emergency preparedness including the SOPs, the equipment and infrastructure, knowledge and competencies of personnel, implementation of policies, etc., are reviewed. Upon the completion of the evaluation, the organization, as well as the senior managers of the MOH, receives a comprehensive report delineating strengths and gaps and an overall summation of the level of emergency preparedness. The specific organization is compelled to submit a plan to correct gaps in a short period of time, and the implementation of such steps is monitored by the MOH.

63.3.1.4 Information Systems

Accurate and timely situation awareness is crucial to apply an efficient response to MCIs and disasters. In order to achieve availability of and accessibility to needed data at times of emergency, the information needs to be collected and disseminated routinely; otherwise, at the time of need, it will not be attainable. The optimal mechanism to access data is through online continuous stream of information from the source entities, such as from the hospitals, to the agencies responsible for the evacuation of casualties (the EMS) and for defining the policies of emergency response (the MOH). In order to assure the availability of the needed information, two types of data are continuously transferred by all acute-care hospitals to the MOH: admissions to the emergency departments and admissions to different hospitals' wards. The data is streamed online from the computerized information systems of each hospital to the MOH and is thus available at any point of time, displaying the relative load that characterizes each entity, including crucial sites/departments such as intensive care units, upon the occurrence of an MCI (Adini and Peleg 2013). Nonetheless, additional information is needed concerning the load in the respective organizations, such as in the operating rooms, availability of vital equipment such as ventilation machines, presence of personnel, for example, surgeons, anaesthesiologists, etc. In order to access such data in the needed time frames, a web-based computerized programme was developed. During routine, the hospitals report to this system once daily, in order to accustom them to utilize the system. During a MCI, the frequency of reporting may be accelerated, according to the specific needs.

63.3.1.5 Equipment and Infrastructure

Assuring an effective response to MCIs and disasters necessitates the utilization of designated infrastructure (such as decontamination sites) and expanded inventories of vital equipment (such as ventilation machines, monitors or unique drugs). Significant resources are needed in order to procure these equipment and infrastructure over time and maintain their validity over time (Duncan et al. 2014). This is achieved in Israel through a joint effort of the MOH and the respective institutions. The initial procurement of equipment is performed by the MOH which then distributes part of the inventories to each respective institution. Each institution is then required to implement the needed maintenance steps designated to assure the ongoing validity and readiness of the equipment for immediate use during MCIs. Similarly, vital infrastructure such as helipads, decontamination sites and generators; are installed in various entities by the MOH, and the administrations of all respective organizations are then required to assure their proper state at any given point of time.

63.3.2 The Response Phase

The implementation of integrated care during the response phase is constituted on five major components: (1) an automatic response; (2) central control and coordination; (3) collaboration and connectivity between all the emergency and the response agencies (4) collaboration between military and civilian entities; and (5) coordinated risk communication.

63.3.2.1 Implementation of an Automatic Response

The SOPs for MCIs of all emergency responders, including the emergency medical services and the acute-care hospitals, constitute an automatic response that is initiated upon such an occurrence, aimed to ensure an effective and coordinated response, decrease confusion, stress and inefficiency. The Israeli EMS is a national service operated by Magen David Adom (MDA), divided into 11 main districts. Upon a notification that an MCI occurred or is suspected, an automatic response is initiated, according to which the adjacent MDA regions dispatch two basic life support and one advanced life support ambulances to the scene, to reinforce the resources dispatched by the local operation centre. The hospitals in the vicinity of the event are all prepared to admit casualties in the scope of 20% of their routine bed capacity (Peleg and Rozenfeld 2015). As most hospitals are characterized by nearly 100% occupancy levels, they implement the SOPs which delineate which sites can be immediately deployed to expand surge capacity. Equipment that is stored in the immediate vicinity of the emergency department is rolled in, and the staff that is on alert reports to the admitting sites. Direct communication is immediately formed between the MDA operation centre and the control rooms of various hospitals in the region in order to share information concerning the event and the capacities of each entity. Nonetheless, based on lessons learnt from former MCIs, liaison officers from the MDA are immediately sent to the emergency departments of each admitting hospital, in order to facilitate a face-to-face connectivity. These officers relay information to the MDA operation centre concerning the capacity of the hospital to admit and treat casualties and report to the hospitals the scope and type of casualties that are being evacuated from the scene and their destinations.

63.3.2.2 Central Control and Coordination

The scene of an MCI is frequently characterized by the presence of massive emergency resources, operated by both formal and informal entities, as well as well-meaning bystanders. Lack of coordination between these different entities may increase the chaos that is characteristic of such events. In order to mitigate confusion and uncoordinated operations, the lines of authority were very clearly defined and integrated in the laws and regulations. The police force has the overall responsibility to direct all on-site operations, and as such is authorized to control and command the operations of all entities, including the MDA (Peleg and Rozenfeld 2015). Under the jurisdiction of the overall responsibility of the police, and in coordination with the MOH, the national MDA was authorized to direct all medical on-site operations (Adini and Peleg 2013). Accordingly, the senior, experienced MDA officer is appointed as the on-site commander of medical operations. All ambulance services that are present at the scene act under and according to the directives of this commander and abide to his orders. The local MDA operation centre maintains direct communication with this commander, provides him with crucial information concerning the capacities of the admitting hospitals and relays his directives concerning evacuation destinations to the relevant medical facilities. In order to ascertain effective coordination and sharing of information throughout the response phase of the event, several operation centres are activated: an on-site front command unit is deployed, which consists of representatives from different first responders that are active on the scene of the MCI; operation centres are also immediately activated by the MOH, the HFC and various admitting hospitals. The information concerning the event as well as the admitting capacities of all entities is shared by these operation centres, through the computerized information systems as well as through direct communication. Overall coordination is thus maintained throughout the event and facilitates sharing of information and effective communication and coordination with all relevant stakeholders (Peleg and Rozenfeld 2015). If needed, teams from one entity can easily assist other entities, as the work is based on similar guidelines and milestones.

Central control and coordination are also maintained concerning the hospitals' resources. The MOH, through the operation of the Supreme Health Authority, directs all activities aimed to maximize the surge capacity including limiting internal beds while expanding trauma capabilities, expanding surge capacities of geriatric and psychiatric hospitals so that patients may be transferred from acute-care facilities to these institutions, thus vacating additional beds to treat trauma casualties. As abovementioned, the MOH directs the operation of all hospitals, both public and private, and thus, maximum optimization of crucial resources may be achieved.

63.3.2.3 Connectivity Between Response Agencies

Connectivity between various first responders and additional emergency authorities is achieved through the implementation of three major elements. The first is the sharing of information, which is crucial in the emergency response (Bar-El et al. 2013). Direct communication lines are installed between the MDA and the emergency departments of all acute-care hospitals. These systems are utilized to transmit information concerning the occurrence of a MCI, the extent of incurred casualties, evacuation destinations and any other relevant information, throughout the event. Direct communication lines are also operated between various first responders, such as the police force, the fire and rescue commission, and the MDA. The operation centres of these organizations maintain an open line during the event, to ensure joint sharing of information and ongoing updates. The HFC can access the civilian computerized information systems, which facilitates the coordination between the two systems. The second step to assure connectivity is the allocation of liaison officers. For example, upon the activation of an operation centre in the MOH, a liaison officer from the HFC is appointed to that centre, in order to facilitate a coordinated response, concerning both policy and decision-making as well as to monitor the implementation of all directives in the field. The third step is initiation and ongoing maintenance of direct dialogues between all stakeholders. Considering the importance of maintaining close communication with the response agencies, in prolonged scenarios (continuing for over a day, such as following major natural disasters or during periods of conflicts), forums for daily consultations and coordination are implemented, based on tele-conference lines. These daily discussions are used to share information concerning the events, debate over potential solutions to various challenges, consult concerning different needs and achieve consensus regarding modes of operation. All hospitals, MDA and other involved stakeholders participate in these coordination meetings (Adini et al. 2010a).

63.3.2.4 Collaboration Between Military and Civilian Entities

A very close collaboration is maintained between the military and civilian entities, in all phases of the emergency preparedness and response. The Surgeon-General of the Israeli Defence Forces' Medical Corps is a member of the Supreme Health Authority, thus is part of the highest mechanism that is responsible for both policy and decision-making concerning emergency management. The chief medical officer of the HFC participates in all physical and virtual meetings of this Authority and thus is also involved in all facets of emergency management of all events. The military medical resources can be immediately deployed to assist the civilian forces in all emergency events. The aerial medical evacuation resources, including helicopters and planes, are frequently deployed to provide reinforcement to the civilian limited means. Thus, the military and civilian personnel are well versed in working together during MCIs, and their joint work is characterized by extensive acquaintance of their respective capacities, competencies and abilities (Adini et al. 2010a).

63.3.2.5 Coordinated Risk Communication

Similar to routine operations, during emergencies, all the first responders and emergency authorities have their respective spokespersons, responsible for dissemination of information to the public. Nonetheless, considering the impact of each message to the population, during emergencies, coordination of messaging is employed. Through close collaboration of both the managers and the spokespersons of all major stakeholders, the coordination is implemented, and coordination mechanisms are at place targeted to jointly decide upon and disseminate accurate and applicable information. The great challenge in the last few years is the rapid dissemination of information, both accurate and false rumours, through the social media (Simon et al. 2015). As there is no control over the information that is published by any person through Facebook, Twitter, WhatsApp or other channels of the new media, the emergency responders must very quickly relay accurate and reliable information to the public. The public's trust in the formal entities can be significantly damaged if this is not done. This need of urgency proves to be very challenging to all formal responders, and thus, steps are at present being implemented with the aim of strengthening the capacity to effectively provide risk communication to the population during MCIs and large-scale disasters. During prolonged emergencies, such as during conflict situations, central spokespersons are allocated by the HFC to all major TV channels. These representatives relay information to the public and answer questions, several times daily; thus, a two-directional communication is being attained, and crucial, rapid information is accessible to the public. More so, a central information centre is operated by the HFC, which is accessible 24/7 to the population.

Another facet of crucial information that the public searches for during MCIs is the location of a relative that may have been involved in the event. In order to provide this data, the MOH developed a designated computerized system (called "ADAM") which interconnects the admission systems of all acute-care hospitals with each other, as well as with the MOH and the HFC (Adini et al. 2010b). This information is immediately available to the public upon the onset of a MCI, by approaching (by phone or physically) any information centre that is operated (all hospitals, police and local municipalities operate such operation centres in all MCIs). Due to personal data protection, the only information that is provided upon approach is where the person that is being searched for is located (i.e. in which hospital).

63.3.3 The Post-response Phase (Return to Normalcy)

Learning lessons from each training programme and real MCI is crucial in order to assure continuous improvement of the capacity to provide integrated care during any type of emergency scenario (Wen et al. 2014). Aligned with this need, following each training session and/or MCI, a structured After Action Review (AAR) is implemented. This is a multi-disciplinary, multi-organizational process, based on a series of debriefing meetings that are conducted, initially at the site/sector level, through an institutional AAR, and up to a regional AAR, organized and directed by the MOH. Each of these meetings is designated to identify strengths and weaknesses, elements that should be maintained or improved, and potential mechanisms to achieve a better preparedness and response modes of operation (Tami et al. 2013).

The AAR meetings are conducted in a non-judgmental atmosphere, aimed at identifying elements for improvement without laying blame to any of the participants. This medico-legal balance must be very carefully maintained; otherwise, various involved parties will be reluctant to share actual experiences that may not represent best practices. It should be stressed that lack of fear from being liable or prosecuted for any potential (non-negligent) wrong-doing is crucial not only in the AAR phase, but also during the response phase; thus, complete insurance and coverage for any liability, for both employees and volunteers, are integral in the emergency response system.

It should be stressed that in large-scale disasters, the recovery phase may take many years and necessitate the investment of significant resources. An effective response should consider the implementation of an early recovery stage, in parallel to the response phase. Thus, care for ongoing humanitarian needs such as food, shelter, routine medical and public health care (including immunization programmes) should be instituted at the same time as the emergency response actions.

63.4 Conclusions

The challenge in attaining delivery of integrated care during MCIs or large-scale disasters is achieving optimal coordination and collaboration among various stakeholders. This crucial element is implemented in Israel routinely, and thus, it is more easily attained also during emergency scenarios. Different involved medical entities, including the EMS, hospitals, other health providers, as well as the additional first responders such as the police, interact continuously in developing plans and guidelines and conducting integrated training programmes. These joint collaborations facilitate an efficient coordinated response during MCIs. More so, adopting automatic responses to MCIs enable to overcome the initial chaos and confusion that characterize emergency scenarios. When each entity and every member of the responding entities are well acquainted with what is expected of them, they can more easily and efficiently react to the situation and collaborate more smoothly with all involved parties. Accordingly, the needs and expectations of the public can be met, and optimal care can be provided. The Israeli emergency management system has established a clear and structured mode of authority and responsibility, which facilitates the provision of an effective and coordinated response to the needs of the affected population, while maintaining flexibility to modify the response to the specific characteristics of each event.

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Canada: Application of a Coordinated-Type Integration Model for Vulnerable Older People in Québec: The PRISMA Project

64

Réjean Hébert

64.1 Integrated Care in Québec and Canada

Canada is a confederation of ten provinces and three territories. In the province of Québec, the population is mostly French speaking. The healthcare system in Canada was developed in the sixties, based on a Beveridgian model of universal, public, tax-funded coverage of hospital and physician services. Under the Canadian constitution, health care is the responsibility of the provinces and territories. However, in 1966, the federal government set out four principles for implementing a national healthcare system: public administration, comprehensiveness (all "medically necessary" services), universality, and portability (between provinces). The Canada Health Act (1984) consolidated the four original principles and added a fifth: accessibility (without any financial barriers). Although not responsible for delivery of health care, the federal government used its spending power to introduce the public healthcare system and committed to partially fund provinces that complied with those principles. Originally, the federal share was 50%; now, it is around 25%. The healthcare system in Canada covers hospital and physician services ("medically necessary"). Dental care, professional services (other than from physicians) provided outside hospitals, and drugs are not included, except in the province of Québec which introduced a universal mixed pharma care program in 1997. Hospital services are delivered through public or not-for-profit organizations. Physicians work mostly in private clinics and are paid directly by the government without overbilling.

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The province of Québec set up its system in 1971 (Act Respecting Health and Social Services) with full integration of health and social services at the local, regional, and provincial levels. There was a Ministry of Health and Social Services, regional authorities for health and social services, and local institutions that integrate those services. Québec is still the only province in Canada to integrate health and social services. The Ministry sets policy, pays for physician services, and allocates budgets to the 18 regional authorities. Regional authorities were responsible for adapting services to their particular population and allocating budgets to the local institutions. Locally, services are provided via hospitals, rehabilitation centers, youth centers, and nursing homes. In addition, local community services centers (center locaux de services communautaires, CLSC) were designed to be the primary care portal for health and social services in the community.

Private for-profit operations are virtually non-existent in the Québec healthcare system, except for residential facilities for older people. Voluntary agencies are well developed, particularly for home services. Social economy agencies (not-for-profit) are also very active in providing support for domestic tasks and personal care.

64.2 Integrated Care in Practice

64.2.1 Problem Definition

The population of Canada and Québec is aging quickly. In 2014, 17% of the population in Québec (1.4 million people) was over 65 years old. Since the baby boom in the fifties, particularly in the French-speaking Québec population, it is expected that older people will make up over 25% of the population by 2031 (Azeredo and Payeur 2015). Despite the integration of health and social services, delivering services to a growing vulnerable older population was a challenge. Prior to 2003, many public organizations (hospitals, nursing homes, rehabilitation centers, CLSCs), together with social economy and voluntary agencies, delivered care, without coordination. Multiple assessments, delays, redundant services, gaps in services, and multiple providers created inefficiencies, compromised service quality, and increased costs probably unduly. There was a pressing need to integrate those services (Hébert 2010).

To address these challenges, two large experiments were carried out simultaneously from 1997 to 2001. First, the SIPA (Integrated Services for Older People: Services intégrés pour les personnes âgées) project in Montréal was an attempt to test a fully integrated model in the Québec context. Experimental implementation took place from 1999 to 2001 across two sites in Montréal. The SIPA team of professionals (case managers, nurses, physicians, physiotherapists, social workers) was responsible for the care of frail older people at home, with some services outsourced to the usual healthcare organizations. An evaluation of SIPA using a prospective randomized controlled trial demonstrated its efficacy in improving the use of home services instead of institutions (Béland et al. 2006). However, the capitation funding that was part of the model was never implemented in the experiment. Since the SIPA organization operated in parallel with the usual healthcare system, generalization of such a model was deemed difficult within the universal healthcare system in Québec. The SIPA model was abandoned after the experiment.

Program of Research to Integrate Services for the Maintenance of Autonomy (PRISMA) was the second large project designed to better fit the healthcare system in developing a coordinated-type integration model. PRISMA was developed by a steering committee including policymakers at the provincial and regional levels, healthcare managers, clinicians, and researchers. The coordination level of integration was originally suggested by Leutz (1999) as one of the three types of integration (in addition to liaison and full integration), but at that time, there was no model developed to operationalize it. Unlike fully integrated systems such as SIPA, this model includes all public, private and voluntary health and social service organizations involved in caring for older people in a given area. Each organization keeps its own structure but agrees to participate under an umbrella system and to adapt its operations and resources to the agreed requirements and processes. At this level, the integrated service delivery system is not just nested in the health care and social services system (like fully integrated models); it is embedded within it.

64.2.2 Description of the PRISMA Model

The PRISMA model comprises six components: (1) coordination between decision-makers and managers at the regional and local levels, (2) single entry point, (3) case management, (4) individualized service plans, (5) single assessment instrument coupled with a case mix management system, and (6) computerized clinical chart. Coordination between institutions is at the core of the PRISMA model. Coordination must be established at every level of the organizations. First, at the strategic level (governance), a Joint Governing Board (JGB) is created involving all health care and social services organizations and community agencies (public, private and voluntary), and the decision-makers agree on policies and orientations and what resources to allocate to the integrated system. Second, at the tactical level (management), a service coordination committee, mandated by the JGB and comprising public and community service representatives together with older people, monitors the service coordination mechanism and facilitates adaptation of the service continuum. Finally, at the operational level (clinical), a multidisciplinary team of practitioners surrounding the case manager evaluates patients' needs and delivers the required care and services.

The single entry point is the mechanism for accessing the services of all healthcare institutions and community organizations in the area for a frail senior with complex needs. It serves as a unique portal that older people, family caregivers, and professionals can access by phone or written referral. A link is established with the Health Information Line available 24/7 to the general public in Québec. Callers are screened using a brief 7-item questionnaire (PRISMA-7)

(Raîche et al. 2008) that has shown good levels of sensitivity and specificity in identifying older people with significant disabilities. PRISMA-7 is also used by health professionals in physicians' offices, emergency rooms, and flu shut clinics to screen older people. A detailed assessment of disabilities is then undertaken for those screened positive; individuals deemed eligible for the integrated service delivery are referred to a case manager. The eligibility criteria are to be over 65 years old and present significant disabilities as defined by a SMAF score over 15 or an Iso-SMAF profile over 4 (see Box 1).

Box 1 Functional Autonomy Measurement System: SMAF (Système de mesure de l'autonomie fonctionnelle).

The SMAF (Hébert et al. 1988, 2001; McDowell 2006) measures functional ability in five areas:

- Activities of daily living (ADL) (seven items);
- Mobility (six items);
- Communication (three items);
- Mental functions (five items);
- Instrumental activities of daily living (IADL) (eight items).

For each item, the disability is scored on a 5-point scale:

- 0: independent;
- −0.5: with difficulty;
- −1: needs supervision;
- −2: needs help;
- −3: dependent.

The resources available to compensate for the disability are evaluated, and a handicap score is calculated. The stability of the resources is also assessed. A disability score (out of 87) can be calculated, together with sub-scores for each dimension.

A case mix classification system based on the SMAF has been developed (Dubuc et al. 2006). Fourteen Iso-SMAF profiles were generated using cluster analysis techniques in order to define groups that are homogeneous with regard to their profile.

- Profiles 1–3: slight disabilities in instrumental activities of daily living only;
- Profiles 4, 6, and 9: moderate disabilities predominantly in motor functions;
- Profiles 5, 7, 8, and 10: moderate disabilities predominantly in mental functions;
- Profiles 11–14: severe disabilities (those people are usually cared for in nursing homes).

The Iso-SMAF profiles are used to establish eligibility criteria for different services and to calculate the organizations' required budget, based on the disabilities of their patient groups (Tousignant et al. 2003, 2007).

The case manager (CM) model included in PRISMA draws directly from those described as a Clinical CM (Scharlach et al. 2001), Neighborhood Team (Eggert et al. 1990), or Basic CM (Phillips et al. 1988). The case manager is responsible for conducting a thorough assessment of the patient's needs, planning the required services, arranging patient access to these services, organizing and coordinating support, directing the multidisciplinary team of practitioners involved in the case, advocating for, monitoring, and reassessing the patient. The CM is legitimate by the JGB for working in all institutions and services. The CM can be a nurse, social worker, or other health professional and should be specifically trained. An ideal caseload is around 40 patients per CM. Figure 64.1 summarizes the flow of patients through the coordinated PRISMA model.

The individualized service plan (ISP) results from the patient's overall assessment and summarizes the prescribed services and target objectives (Somme et al. 2009). The ISP is led by the CM and established at a meeting of the multidisciplinary team including all the main practitioners involved in caring for the older person. The ISP should be confirmed with the patient and informal caregivers so that they are empowered in the decision-making process.

The single assessment instrument is used to evaluate the needs of clients in all organizations and by all professionals working in home care organizations or in hospitals and institutions. The instrument implemented in the PRISMA model is the SMAF (French acronym for Functional Autonomy Measurement System), a 29-item scale developed according to the WHO classification of disabilities (see Box 30.1) (Hébert et al. 1988, 2001).

Finally, the PRISMA model includes a computerized clinical chart (CCC) to facilitate communication between organizations and professionals. This shareable clinical chart specific to the care of elderly people uses the Québec Ministry of Health and Social Services Internet network and is interconnected to other clinical electronic records (hospitals, physicians' offices).

64.3 Experimental Implementation and Impact

After being pretested in the Bois-Francs area with promising results (Tourigny et al. 2004), the PRISMA model was implemented in July 2001 in three regions of the Eastern Townships in the province of Québec: (1) the city of Sherbrooke, an urban area (population: 144,000 of which 18,500 were over 65 years of age) with many institutions (university regional hospital, university geriatric institute, regional rehabilitation institution, and many nursing homes); (2) the rural Coaticook region (population: 16,500 of which 2300 were over 65) with no local hospital; and (3) the Granit region a rural area (population: 22,000 of which 3300 were over 65) with a local hospital.

The PRISMA model was subject to rigorous evaluation, including an implementation study that sought to monitor the degree and the process of implementation, and an outcome study, using a population-based quasi-experimental design.

The implementation evaluation study was carried out using an embedded multiple case method (Yin 1994), with each region being a case. Mixed methods, quantitative and qualitative, were applied using multiple sources of evidence (policymakers, managers, clinicians, patients, caregivers, and administrative data). Multiple data collection methods were used: documentation analysis (minutes, charts, CCC data), individual interviews (policymakers, managers, clients, caregivers), focus groups (CM, clinicians), postal questionnaires (physicians), and standardized questionnaires. Detailed results from these studies can be found elsewhere (Hébert et al. 2005, 2008a, b). Postal questionnaires were used to measure the opinion of family physicians regarding the integrated service delivery network and CMs. The response was very positive, with CMs being perceived as very useful by family physicians (Milette et al. 2005).

A method was developed for monitoring the degree of implementation, based on specific indicators for each of the six elements of the PRISMA model (Hébert and Veil 2004). The indicators were weighted according to their importance, and different elements of the model were also weighted to obtain a score out of 100. Overall, the degree of implementation reached 70% after 2 years. This was the a priori threshold set for defining a significant degree of implementation. After 4 years of implementation, the rate reached 85% in Sherbrooke, 78% in Granit, and 69% in Coaticook (Hébert et al. 2008a).

To evaluate the impact of the PRISMA model on health, satisfaction, empowerment, and services utilization of frail older people, a population-based, quasi-experimental study was conducted with the three experimental and three comparison areas. From a random selection of people 75 years and over, 1501 persons identified as at risk for functional decline were recruited (728 experimental, 773 comparison). Over 4 years, participants were measured for disabilities (SMAF), unmet needs, satisfaction with services, and empowerment. Information on utilization of health and social services was collected via bi-monthly telephone questionnaires (Hébert et al. 2010).

Over the last 2 years (when the implementation rate was over 70%), there was a 6% reduction of functional decline (62 fewer cases per 1000 individuals) in the experimental group ($p < 0.05$). In the fourth year of the study, the annual incidence of functional decline dropped by 14% in the experimental group (137 cases per 1000; $p < 0.001$), while the prevalence of unmet needs in the comparison region was nearly double the prevalence observed in the experimental region ($p < 0.001$).

Satisfaction and empowerment were significantly higher in the experimental group ($p < 0.001$). For health services utilization, fewer visits to emergency rooms ($p < 0.001$) and hospitalizations (p 0.11) than expected were observed in the experimental cohort (Hébert et al. 2010). Using growth curve analysis, Dubuc et al. (2011) showed that the needs of elders living in the area where PRISMA was implemented were better met over time. An economic analysis comparing the cost of care in the experimental group, including the cost of the PRISMA component, to the comparison group showed that the costs were similar. This means that the PRISMA model was more efficient than the usual care.[1]

64.3.1 Dissemination and Replication

During the study in 2003, the Québec Minister of Health was convinced that the model would be successful (even before the results were formally published) and decided to undertake the major healthcare reform merging different public organizations involved in caring for older people within a local area (hospitals, nursing homes and CLSCs) in the CSSSs (health and social services centers) (Levine 2007). This structural integration was seen by the Minister as providing strong support for improving the coordination of services. However, as demonstrated in other contexts, structural integration does not necessarily foster functional integration (Demers 2013). The reverse was actually observed in Québec over the first 4 years of the reform. According to the Québec Ministry of Health, the implementation rate of the PRISMA model, based on the same indicators developed in the experiment, was only on average 38% in 2008, although wider roll-out of the PRISMA model was included in the Ministry's 2005–2010 action plan (Gouvernement du Québec 2005). It was noted that the newly created CSSSs (health and social service centers) struggled to implement the strategic planning process and the reorganization of services. The roll-out of the PRISMA model was slowed considerably and even stopped momentarily in many regions because, first, the CSSSs' different programs continued to work in silos and, second, this new big organization in the system (the CSSS) no longer prioritized coordination committees and collaboration with the voluntary agencies, social economy enterprises, and private providers also involved in delivering services for frail older people (INSPQ 2014).

This natural experiment showed that it is not always desirable or necessary to structurally integrate different providers into a common organization in order to implement a functional integration model like PRISMA. Nevertheless, after 10 years, implementation of the PRISMA model reached 70% across the province in 2014 (Fig. 64.2). Implementation of the computerized clinical chart, the sixth element of the PRISMA model, was delayed because the Ministry wanted to develop new, more powerful Web-based software. This allowed for the utilization of the management tool (Iso-SMAF profiles) and completed the implementation of the fifth element of the PRISMA model. In 2014, a module to support the

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[1] All the publications on the PRISMA model and experiments, in both French and English, are available on the following Web site: https://www.prisma-qc.ca/cgi-cs/cs.waframe.index%3Flang%BC2.

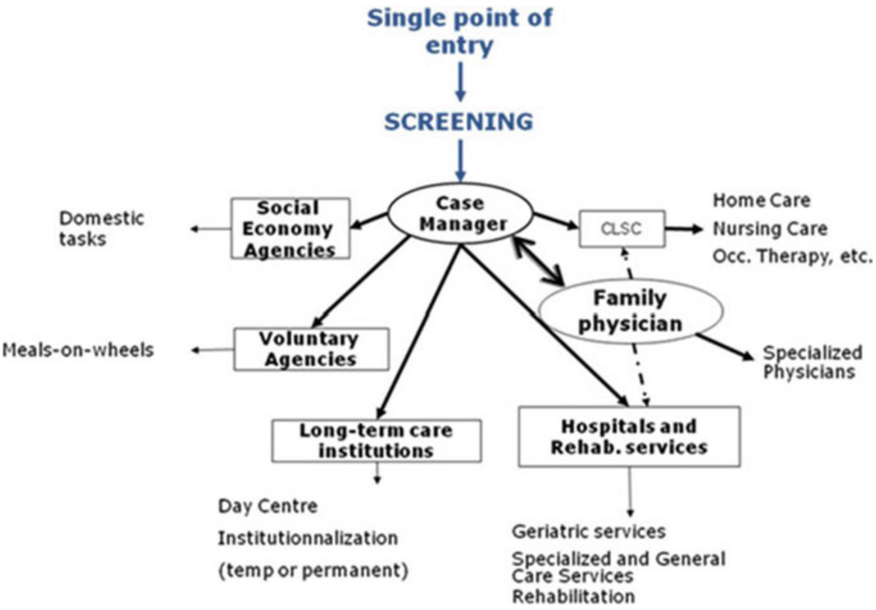

Fig. 64.1 Flow of patients through the coordinated PRISMA model. Reproduced with permission from the Journal of Integrated Care—Emerald Group

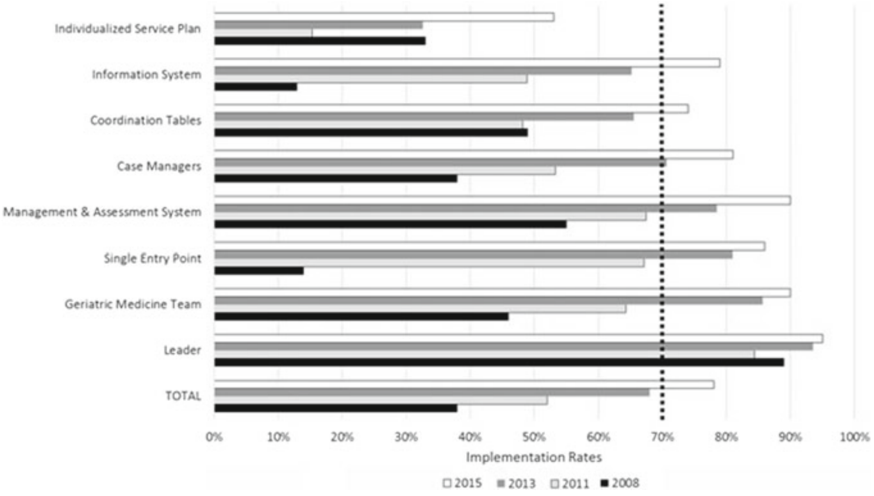

Fig. 64.2 Implementation rates of the PRISMA model in Québec, Canada, from 2008 to 2015

elaboration of the individualized service plan and the allocation of services was added to the software, boosting the implementation of this element.

In 2015, a new structural reform was implemented in Québec, merging all the public institutions in a region, including rehabilitation and youth centers this time. These new integrated health and social services centers (CISSSs) replaced also the regional authorities. From a three-tiered system (provincial, regional, local), Québec moved toward a two-tiered system by abolishing the regional level. In each region, only one public institution provides all the health care and social services to the population. Although improving integrated services was one of the reasons for the reform, this new structural integration will likely have negative impacts on functional integration as it was the case in the 2003 reform.

The experience of the PRISMA model influenced integrated care models beyond Québec. For example, in France, where the comparatively high number of actors involved in funding and delivering care to older people was seen to be a challenge for coordination, the PRISMA model was adapted in three experimental implementations (Somme et al. 2008). Following this experiment, the model was applied to people with dementia in the so-called MAIA model of care (Maison pour l'autonomie et l'intégration des malades d'Alzheimer) as part of the 2008–2012 Alzheimer Plan (République française 2008). In 2013, the MAIA model was extended to cover all frail older people, and over 350 MAIA homes were set up across France. The acronym MAIA was then used for Méthode d'Action pour l'Intégration des services d'aide et de soin dans le champ de l'Autonomie. The PRISMA model is also being implemented in several areas in Spain.

64.3.2 Lessons Learned and What is Ahead

The PRISMA model can be seen to be a good illustration of an effective transfer of scientific knowledge to public policy. The continuous presence, right from the beginning, of representatives from the Ministry of Health and Social Services and regional authorities on the PRISMA steering committee was one of the factors that led to this success.

However, wider dissemination of the model following the experimental phase was not optimal. Implementation has been very slow, due to mainly the structural reforms, delays in designing the new computerized clinical chart, and budget restrictions that slowed the recruitment of case managers. Additional financial resources to hire case managers were spread over a long period of time. One of the Leutz's laws (1999) was confirmed: "Integration costs before it benefits." Despite the experiment showing that PRISMA was cost-efficient, implementation requires investments upfront to generate the expected benefits.

The role description and training requirements for case managers were not precise enough; in many areas, case managers received only minimal training. This was not sufficient to induce a real role change away from that taught by the previous professional education. In some areas, there are still waiting lists to get access to case managers, and the waiting time can be very long, with inevitable consequences for frail older people. The Joint Governing Boards are no longer active in many areas, not only because of the recent structural reform but also because this mechanism is not considered critical by new managers coming on board. Contrary to the experimental setup, administrative collection of data to generate indicators is not verified independently. There is also evidence that, when completing the instrument measuring implementation, some areas reported false results. In one area, we observed that the official rate was more than 10% over the actual one.

Institutionalization of an innovation is a challenge, and there is a real risk of the system returning to its previous state without sustainable change. Although the PRISMA model is not very prescriptive and elements of the model can be adapted to the local context, it should be acknowledged that it is being implemented within complex organizations and networks in which self-regulation mechanisms can prevent any significant change (Begun 2003).

In PRISMA, a necessary seventh component was not included in the model, namely financing which is usually one component of integrated models (Kodner 2006). This was not possible since the Québec healthcare system is a universal, publicly funded, Beveridge-type system. Long-term care is included in the overall funding of health and social services. This arrangement makes it impossible to prioritize long-term care and home care, especially during a period of budget restrictions since, with global funding, hospital care drives most of the budget. In the new CSSSs (and more so in the CISSSs), most of the funding is directed to hospitals and nursing homes, which leaves home care programs with insufficient funds to really make a difference in the way care is provided to frail older people with multiple care needs. Improving the efficacy of the PRISMA model and case managers' actions would require a specific funding scheme for long-term care modeled on the public long-time care insurance programs which are in place in many European and Asian countries (DaRoit and LeBihan 2010; Ikegami 2007). Following the needs assessment by the case manager, an allowance corresponding to the disability level of the frail older person could then be managed in order to outsource the appropriate services to the client. Such a financial incentive could give the case manager real power to obtain the necessary services from providers. Québec and Canada will have to move toward this type of funding scheme, coupled with the integration of services, in order to cope with the rapid aging of the population (Hébert 2011). An attempt to implement an autonomy insurance plan in Québec was unfortunately stopped for political reasons in 2014 (Hébert 2016).

PRISMA-type integration needs the funding model to be adapted in a Beveridgian context for long-term care by borrowing characteristics of social insurance systems. This type of integration can be facilitated in Bismarkian systems, where such funding is already in place. This was the case in France.

The PRISMA model has been adapted to other populations. In Québec, it is used for young patients with mental and physical disabilities. It could be used to meet the needs of patients with mental health problems.

Integrating services for a given population (e.g. frail older people) may conflict with disease-oriented integration (e.g. diabetes, cancer). According to another Leutz law (1999), "Your integration is my fragmentation." An older patient with diabetes, cardiovascular disease and cancer may have three different disease-oriented case managers and another from the frail older network. In such cases meta-integration mechanisms are necessary. With an elderly population with comorbidities, only the case manager from the frail older people network should get in touch with the patient and communicate with the other case managers, who would not deal directly with the patient.

The PRISMA model shows that it is feasible and efficacious to improve integration functionally without—or in spite of—structural integration and merging of organizations. Implementation of the innovation should be closely monitored, and adequate resources should be allocated to support the implementation and training for professionals and managers. Funding is a key issue in integration, and budget incentives and mechanisms should be adapted to the integration model. The most difficult challenge is to institutionalize the innovation, given the complexity of healthcare systems.

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New Zealand: Canterbury Tales Integrated Care in New Zealand

65

Brian Dolan, Carolyn Gullery, Greg Hamilton, David Meates, and Richard Hamilton

65.1 Integrated Care in New Zealand

New Zealand's health and disability system is mainly funded from general taxation. It has a public and private healthcare system, which both offer high standards of care. In the public system, essential healthcare services are provided free or subsidised for some community services (including general practice) for all New Zealanders, people from countries with reciprocal healthcare provision and people in New Zealand on a work permit valid for 2 years or longer. Emergency hospital care is free as are specialist services and non-urgent surgery although access is prioritised on the basis of clinical need. Alongside the public system, private health care offers access to private hospitals for the treatment of non-urgent and some

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non-deferrable conditions. The network of private hospitals and clinics provides a range of services that include recuperative care, elective procedures and a range of general surgical procedures. There are also private radiology clinics, private oncology and testing laboratories.

The government-funded public health system works on a community-oriented model, with three key sectors. Twenty District Health Boards (DHBs), established in 2001, plan, fund and deliver local services. Primary health care covers a broad range of out-of-hospital services, including the first-level services such as subsidised general practice, pharmacy services and diagnostics, home-based support services, free mobile nursing and community health and dental services which are only free for people under 18 years Thirty-two primary health organisations (PHOs) are the local structures for coordinating primary healthcare services which are largely delivered by a network of small private businesses. They are funded by the DHBs. PHOs bring together doctors, nurses and other health professionals, in the community to serve the needs of their enrolled patients. There is a co-payment model for general practice, with children under 14 free, and fees for other ages subsidised based on income with additional funding for people with long-term conditions.

Approximately one-quarter of New Zealanders purchase private health insurance in order to receive care in private hospitals and to avoid waiting lists for the treatment of non-urgent medical/surgical conditions. People with private health insurance are still eligible for free public health benefits.

This chapter focuses on Canterbury District Health Board (CDHB), which serves a population of over 578,000 people in a country of some 5.0 million and has a budget of NZD $1.8 billion, or approximately 11% of total state health funding allocated to DHBs. It has a workforce of 10,500, supplemented by a further 9000 personnel who are funded in primary health organisations (PHOs), non-governmental organisations (NGOs), for profit providers, aged residential care providers, mental health providers, health-related charitable bodies and others.

65.2 Integrated Care in Practice

65.2.1 Problem Definition.

The Canterbury health system is widely considered to be a well-integrated health system (Timmins and Ham 2013; Charles 2017). Like many other health systems in New Zealand and globally, Canterbury had to address growing waiting lists, delays in investigations and treatments and a disengaged and dissatisfied workforce, along with overcrowding in the emergency department, cancelled operations, staff-threatening industrial action, a disconnect between general practice and hospital clinicians, rising locum medical costs and nursing shortages. A substantial shortfall of NZ$20 million in 2005, and the inability to meet performance targets for elective services, a priority area, in any of the preceding four financial years, along with safety concerns around surgery highlighted the significant and complex challenges the system was facing and the need for systemic and systematic change.

At the same time, the primary care system was considered to be highly organised, involving a well-connected network of general practices that were linked by joint education processes, a successful experience of budget holding for pharmaceuticals and pathology services in the 1990, and an innovative hospital admission avoidance programme that had been in place since 2000. This had been achieved almost in isolation from the secondary care system. Yet despite the relative successful primary care system, it was estimated that if admissions kept growing at their then-current rate, by 2020, Canterbury would have needed a second 450-bed Christchurch Hospital, another 20% more general practitioners (GPs) and 2000 aged care residential beds.

Overall, the Canterbury health system was considered to be highly fragmented, against a backdrop of an ageing population and a scarce and ageing workforce. The transformation of the health system towards an integrated solution was eventually initiated with the appointments of a new Executive Director of Nursing and Chief Medical Officer who created a new focus on patient experience and led to the.

introduction of the ‘Improving the Patient Journey’ programme in 2004–2005. This programme sought to re-engineer hospital activities using a ‘lean’ approach and focusing on identifying and reducing needless waste. The challenge was to change both mindsets and the system as a whole.

Key strategies to achieve this were a series of *Vision 2020* workshops in 2007 and 2008 (Fig. 65.1). These workshops brought together 80 clinical, managerial and patient representative system leaders, and they sought to encourage ‘disruptive

Fig. 65.1 Canterbury health system vision

thinking' and prompt new ways of refocusing the system on home and community delivered care. This led to the emergence of a strategic vision of a connected system that is centred around people and that aims not to waste their time.

This visionary approach was further strengthened with the appointment of a new General Manager of Planning and Funding in 2007, who introduced a 'one system, one budget' strategy which sought to reconnect the primary and secondary health systems. The interface between general practices and hospital services was recognised as a major area requiring redesign and key to the development of an integrated health system. With the assistance of senior health system managers, community clinicians, funders and a facilitator, a plan was prepared that proposed changes in pre-referral and post-referral patient management. Following acceptance and implementation of the plan, this process became known as the *Canterbury Initiative,* and it is one the examples in Canterbury of using a network of influencers to empower clinically led change rather than a formal project process or a hierarchical response.

One example of this approach is the process by which GPs and other clinicians (and, more recently, consumers) were brought together to develop what became *HealthPathways*, such as a clinical pathway for the management of chronic obstructive pulmonary disease (McGeoch et al. 2015a, b). By 2020, there were almost 1200 such pathways that provide locally relevant, evidence informed, iteratively and clinically co-created concise information required for a patient consultation and to overcome the difficulty general practices which may experience when organising multiple sources of information. A *HealthPathways* website provides information on investigations, differential diagnosis, acute and conservative management, patient education and links to electronic referral to services across the health system, including public and private specialists, in a standardised format (Kenealy et al. 2015). Important information on possible severe adverse events is highlighted by a 'red flag'. The pathway may include links to resources on background clinical information, aetiology, supporting international guidelines or the details of the extensive array of educational sessions funded by the DHB for community-based clinicians. The *HealthPathways* Community has now expanded to 46 regions in New Zealand, Australia and the UK to guide the care of over 30 million people.

The majority of pathways include a link to *HealthInfo*, a sister website that provides health information for patients, consistent with that described in the clinical pathways (https://www.healthinfo.org.nz/). Consensus, transparency and equity were key values used during this process with the main focus on what is considered best for patients. The pathways reflect evidence-based best practice while incorporating local expert usual practice and provide a flexible guide outlining 'how we do things around here'. This HealthPathways 'family' now also includes *Hospital HealthPathways*, *Allied Healthways* (guidance for community allied health professionals) and *Leading Lights* (providing teachers and education professionals with guidance and request/referral to general practice).

The Canterbury Clinical Network (CCN), founded in 2009, is a formal collective alliance of healthcare leaders, professionals and providers, from across the

Canterbury health system, with an Independent Chair all working with the DHB in its planning and funding (commissioning) role. (Canterbury Clinical Network 2016). It provides leadership to the transformation of the Canterbury health system in collaboration with system partners and on behalf of the people of Canterbury. The CCN has developed new service delivery models, funding and contracting mechanisms that are based on principles of high trust, low bureaucracy, openness and transparency. It makes recommendations for developing new models of care and service delivery across Canterbury based on a sophisticated and efficient co-design process. The planning and funding function of the DHB implements the decisions of CCN and ensures that procurement processes are managed to the standard expected in a public system and to minimise the conflicts of interest that are inherent in a clinically led system.

65.2.2 People Involvement/Service User Perspectives

One of the key elements in the success of the Canterbury health system has been the input of patients, carers and their families. Where new service developments are planned, these are often co-designed in conjunction with the Canterbury District Health Board (CDHB) Consumer Council. This was set up in 2008 to provide consumers with a strong voice in planning, designing and delivering services in the Canterbury health system (Canterbury District Health Board 2016a; b).

The council is made up of a diverse range of people with ethnic backgrounds and areas of interest that include Māori, Pacific Islanders, people with mental health problems, long-term conditions, or physical, intellectual and sensory disabilities, older people, young people, men, women, rural communities, people with visual and hearing impairment and people with alcohol and other drug addictions. The Consumer Council's slogan is 'Nothing about us, without us', stipulating that health care should always be planned with consumer involvement, right from the beginning (Canterbury District Health Board 2013).

Listening to the voice of the consumer includes a website, surveys, focus groups and suggestion boxes that invite suggestions, compliments or complaints and family meetings. Minutes of the Consumer Council's monthly meetings are also published on the Internet, so the wider public can have wider access to the discussions and decision-making.

Consumers also sit on all of the Canterbury Clinical Network's Service Level Alliances, including the overarching group, the Alliance Leadership Team (Canterbury Clinical Network 2016). These Service Level Alliances are made up of groups of people with expertise from across the health system to provide leadership for service development and improvements in the way services are provided. This enables consumers to work in partnership with clinicians and health managers at a senior level and so influence the transformational change of the health system.

65.2.3 Impact

65.2.3.1 Building a Social Movement

HealthPathways can be seen to be one example of new ways of thinking and enabling people to develop new ways of working. This approach was reinforced upon appointment of a new chief executive in 2009, who ensured visible political support and commitment through media liaison, regular presence at events and activities, a weekly newsletter to the whole system, and holding forums and away days to keep clinicians and other senior staff informed, led by key messages such as 'We need the whole system to be working for the whole system to work'.

Investment in a learning culture had already begun in 2007 with the launch of *Xcelr8*, an 8-day training programme aimed initially at middle managers and quickly adding senior medical, nursing and allied health leaders from both within and external to the DHB's employed workforce. The programme aims to provide staff with 'the tools and techniques for managing processes and resources more effectively' and to equip them with 'on-the-job knowledge, skills and tools' to empower them and prepare them for future challenges (Canterbury District Health Board 2016b). Participants were provided with a signed card with the CEO's 'permission to make change to our health system', which can be seen to be a powerful tool for support to implement change.

Xcelr8 was followed by *Collabor8,* a 2-day programme aimed initially at nurses and allied health personnel and then broadened to all staff across the health system and aimed at creating '1000 stories of change'. *Particip8*, a 14-h programme sought to enable staff to pitch their ideas and give them the tools to make change happen. Each of these '8 s' programmes reinforced the same key system messages so that staff at all levels were encouraged and equipped to apply the principles of lean thinking, improvement science and culture change to their workplaces.

The *Vision 2020* workshops mentioned earlier enabled the concept of 'Canterbury health system' to emerge, as a system based on trust, of 'one system, one budget', being about people, creating a shared purpose (Box 1). These were systematically followed up with Showcases to ensure scaling up the spread of new ideas and highlighting what had already been achieved as in *Showcase 09*. Undertaken in an old warehouse that was fitted out to provide a series of interactive spaces to promote dialogue and discussion, alumni of the *Vision 2020,* by now 80 people, were asked to bring along 10 people to visit *Showcase*. There were to be no official e-mail invites, no social media encouragement and no letters, and invitation was by word of mouth only.

Box 1 Creating a shared purpose

- Clinicians are trusted
- Care pathways are re-designed
- Funding is arranged to support best practice

- The patient is in the middle of the process
- The systemresponds well to external shocks
- Adaptive leadership in action.

Each group of 10 participants at *Showcase* could experience future scenarios, for instance, sitting at the bedside during a specialist consultation via Skype and observe innovative procedures. Each group ended their visit with a debrief asking what they personally would like to change about the health system and how they could make that change happen.

A graphic facilitator translated their views into images, creating a poster summary that participants could take home. Often the posters instantly reappeared in workplaces, prompting more discussion and encouraging more people to see *Showcase*. The season extended into 2010, because by word of mouth the hoped—for 800 participants became over 2000 who eventually had the *Showcase* experience. This experience can be seen to be an example of fostering an engaged social movement that wanted to contribute to change. It can also be seen to be an endorsement of the new Canterbury health system's three strategic goals:

The development of support people/whanau (Māori for family) to stay well and take increased responsibility for their own health and wellbeing;

The development of primary care and community services to support people/whanau in a community-based setting and provide a point of ongoing continuity, which for most people will be general practice;

The freeing-up of hospital-based specialist resources to be responsive to episodic events and the provision of complex care and support and specialist advice to primary care.

By 2011, a transformed health system had successively been put in place, which was however ultimately put to test by the 2010–2011 earthquakes (Gullery and Hamilton 2015).

65.2.4 The 2010–2011 Earthquakes

Two major earthquakes, in September 2010 and in particular in February 2011, had a significant impact causing widespread damage in Christchurch, the second-largest city in New Zealand and the seat of Canterbury region, killing 185 people and injuring at least 6600 with some 10,000 families permanently displaced due to the damage to their homes; about 25% of health service staff had damaged homes (Ardagh et al. 2012). The health system lost 106 acute inpatients beds (17% of its acute capacity), along with some 635 aged residential care beds. Two hundred CDHB-owned buildings were damaged, and 44 were subsequently demolished. Many non-government organisations were displaced from the central city that was cordoned off for 12 months.

The February 2011 earthquakes posed significant challenges for the Canterbury health system, while at the same time, the system was seen to have demonstrated remarkable resilience, being organised and connected across Canterbury, and delivering free care to people in their communities within a short period of time, a success that was attributed, in large part, to the integrated way of working, which the Canterbury health system had built up over time (Gullery and Hamilton 2015).

65.2.5 Vision 2020 Becomes Vision 2011

Following the February quakes, one general practice was destroyed with staff and patients killed, while many others were damaged and displaced, 12 pharmacies were also lost and the Canterbury earthquakes highlighted the risks in holding electronic information in unconnected systems or relying on paper records. At a critical time following the earthquakes, access to some patient information was lost —in some cases permanently (Ardagh & Deeley 2018).

This accelerated the introduction of an electronic shared health record in the form of *HealthOne* (then electronic Shared Care Record Viewer—eSCRV), launched by mid-2012 (healthone.org.nz). It stores and updates at least hourly key information such as conditions, allergies, medical history, prescribed.

Medications and test results and enables faster, more informed treatment of patients. In addition to general practice, pharmacy and the hospital services, ambulance services, district nursing and increasingly private sector providers have signed up to *HealthOne,* and it is being delivered outside Canterbury to cover a population of one million people across the whole South Island.

Also following from the earthquakes was the Community Rehabilitation and Enablement Support Team (CREST) that began as a community-based supported discharge team facilitating earlier discharge from hospital to appropriate home-based rehabilitation services. Introduced just 3 weeks after the February 2011 quakes as a Service Level Alliance, it has since been extended to accept referrals directly from general practice, providing older people referred to it with care and support to be rehabilitated in their own homes, so as to avoid hospital admission altogether. As such, CREST constitutes a further component of the suite of programmes that influence acute demand, and shift care and rehabilitation to community settings.

In parallel, the acute demand management service (ADMS) aims to provide the most appropriate urgent care options for patients, and it was expanded from around 14,000 referrals before the 2010/2011 earthquakes to 34,000 by 2020 to ease pressure on the hospital. General practice and acute community nursing deliver packages of care allow people who would otherwise need an emergency department visit and possible hospital admission to be treated in their own homes or community. Services include: practice support; mobile nursing service; home IV therapy; logistical support; extended care management; urgent tests/investigations, doctor visits; community observation; and home support (McGeoch et al, 2019). A proxy measure of demand management can also be found in the number of people who have an advance care plan (ACP), and currently, only 26% of people over 75 who die in Canterbury do so in hospital. While this reflects a growing trend elsewhere, in Canterbury, it has been accelerated and embedded into care.

These examples illustrate that the earthquakes served to accelerate thinking and initiatives that were already in development. However, the earthquakes also challenged financial stability, because the national population-based funding formula model did not take into account natural disasters and the rapid fluctuations in population and demand that were consequences of the earthquakes. That noted the disaster became an opportunity to accelerate the introduction of concepts then in development, notably finding ways to treat more people in the community and making greater use of information shared electronically to connect the whole health system.

In 2014, the Office of the Auditor General (NZ) rated Canterbury District Health Board's service performance and management controls in the top 4% of all public entities. The New Zealand State Services Commission (2013) further highlighted the innovative nature of the system (Box 2). The Canterbury health system has further been recognised by New Zealand's Productivity Commission for its integrated approach to achieving outcomes and in 2015 was awarded with four prizes by the Institute of Public Administration New Zealand including the Prime Minister's supreme award.

Box 2 Keys to innovation (State services commission 2013)

- Organisations that enable innovation:
- Are customer focused and solicit idea from and engage with diverse internal and external sources
- Have leadership that is clear about what it's trying to achieve (outcomes/goals) but flexible about how to reach those goals
- Have capability, skills and experience in innovation disciplines and methods supported by resources (funding, time, space)
- Encourage experimentation and bounded and informed risk-taking.

65.2.6 Dissemination and Replication

If the 2010–2011 quakes shifted the 2020 vision to a 2011 vision, it also accelerated the need for data to be made available to frontline staff to provide information to plan, predict and improve, such as through the Canterbury DHB's online health dashboards. The dashboards are also displayed in a Real-Time Operation Centre and in locations around the hospital network and onwards. They are reviewed with both operational and patient journey issues addressed as part of broader 'real-time' hospital flow and resource management. The operation centre also enables clinicians to work through initiatives to further improve care using predictive data to inform changes and determine the effect of their interventions.

Organisations such as Lightfoot Solutions were commissioned to assist with the development of predictive modelling of data from different healthcare providers in an integrated approach. It enables the measurement of patient outcomes across the whole pathway, linking all of the services in each patient's journey. Using statistical process control, Lightfoot's *Signals from Noise* has provided insights into the behaviours of real-world processes and pathways and contributes to evidence-based strategic and operational decision-making. Furthermore, it has provided trusted data sought by clinicians and engaged them with opportunities to improve the services they provide.

65.2.7 Lessons Learned and Outlook.

Showcase 2012 was borne of the need for new facilities and also further engaging the workforce to redesign its future. From mid-December 2012, visitors to the second iteration of *Showcase,* also set up in a warehouse, which became known as the Design Lab, could walk through the new hospital ward designs, sit on a bed and 'see the view' from the proposed new hospital and leave notes and comments. By the end of the *Showcase 2* season, the moveable walls were festooned with notes and posters on which visitors had written suggestions about everything from the design of bed trays to the cleaning of sliding doors, as well as ideas such as a designated 'end-of-life' area for each floor.

The second *Showcase* was also designed to bring people up to date with progress and achievements, despite the earthquake, and remind them of future challenges. Like its predecessor, *Showcase* 2 was interactive, but offered different experiences, with a new focus on international demographic and environmental issues likely to impact on health. *Showcase 2* was again a huge success, attended by over 3500 visitors and had to be extended well into 2013. The Design Lab, where Showcase 2 was held, continues to be a space for teaching, events, collaboration with other social services and life-sized mock-ups of facilities such as wards, CT rooms and integrated family health (extended general practice) centres with visitors from all over the world coming to see what is being done in this and the Canterbury health system space. At 3000 square metres, it is believed to be the largest of its kind in the world.

In 2013, Canterbury DHB developed an outcome framework to measure collective impact of the system on population outcomes (Fig. 65.28.2). It starts with the high-level outcome of people being well and healthy in their own homes and communities. From there, it identifies key strategies and nine system-level outcomes:

- Improved environment supports health and wellbeing;
- Delayed/avoided burden of long-term conditions'

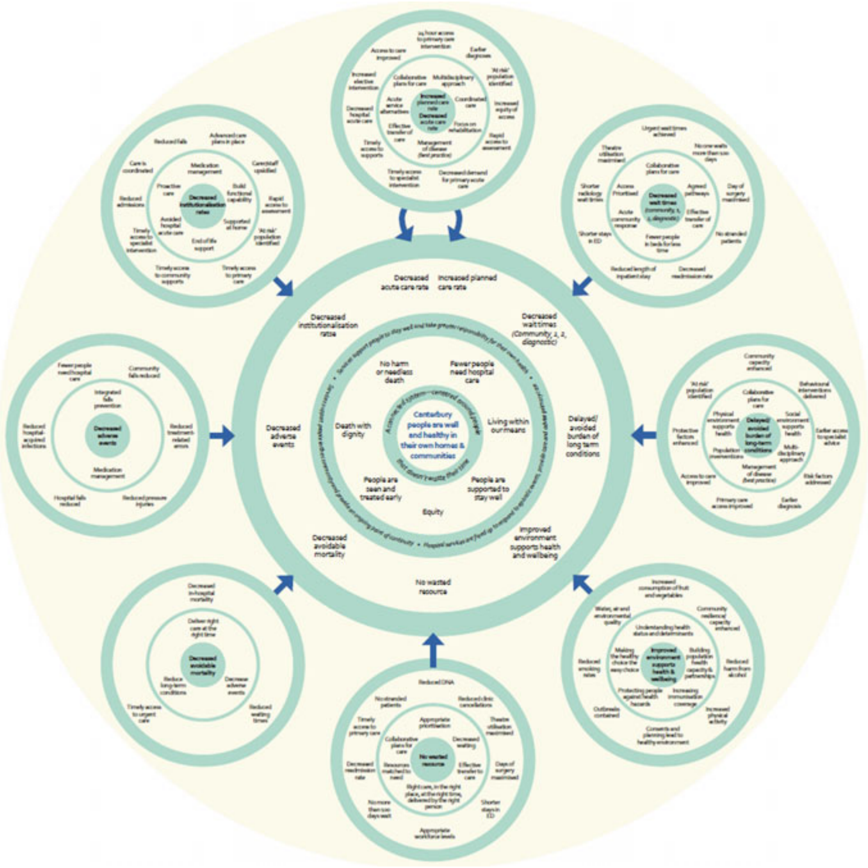

Fig. 65.2 Canterbury health system outcome framework

- Decreased wait times;
- Increased planned care;
- Decreased acute care;
- Decreased institutionalisation;
- Decreased adverse events;
- Decreased avoidable mortality;
- No wasted resource.

Within each of these second-tier outcomes lie further levels of detail, which provide a set of coherent outcomes that allow all providers in the system to identify their various operational contributions towards higher-level outcomes. The outcome framework is a continuation and codification of some of the principles and visions identified in the *Vision2020* process and early health service planning exercise.

The overarching aim of this approach is to support the population to stay well and self-manage in their own homes and communities. There have been measurable impacts of this strategy, with, for example, the number of beds required by people over 75 years with long stays (14 days or longer) decreasing by 28 beds (14%) with in the space of 12 months between 2013 and 2014 (Gullery and Hamilton 2015). In addition, people over 75 years of age living in care homes having fallen from approximately 16% in 2006 to just above 12% in 2013/2014, equating to over 400 fewer people in such beds despite a growing older population (Box 3).

A further example of keeping people in their own homes and/or be managed in community settings, while reducing acute hospital bed demands, can be found in the work of Epton et al (2018). They note that by international standards, patients with chronic obstructive pulmonary disease (COPD) had a high rate of admission.

What became clear in understanding admissions with COPD to Christchurch Hospital was that the behaviour of the patient, in the context of exacerbations, and the subsequent response of the system to the patient, led to admission being the default option, in spite of low severity of the exacerbation itself. By altering systems' responses to exacerbations, with a linked care process between ambulances, community care and hospitals, we were able to safely reduce admissions for COPD, with a sustained overall reduction in bed-day occupancy for COPD of ~48%.

Box 3 Benefits of supporting people to stay well in the community in Canterbury Health System

- Achieved the lowest ED attendance rate in Australasia (178 per 1000 in 2017/18).
- The proportion of people over 65 who are attending ED has remained between 17 and 19% over the last 12 years.
- 27% fewer acute medical admissions in 2018/19 compared to the New Zealand average.
- In 2018/19, if Canterbury health system admitted at the same rate as the rest of the country, there would be 14,700 more people in hospital.
- In 2018/19, over 34,000 people who would previously have been treated in ED or acutely admitted to hospital received their treatment and care in the community.
- Integrated falls prevention strategies are contributing to a reduction in harm from falls in the elderly population. Over the 7 years from the introduction of a community falls prevention programme in February 2012 (compared with outcomes expected based on the previous trends for over 75 s), there were;

– 3291 fewer people with falls presented to ED.

– 981 fewer than expected admissions for hip fractures, saving about 30 hospital beds each year.

  - 327 fewer deaths at 180 days post-discharge after treatment for a fractured neck of femur (hip).
  - The reduction in hospital beds is approximately one ward reduction each year resulting in reduced expenditure of over NZD$45 M over 5 years for an annual investment of around NZD$0.75 M.

- Supporting people in their own homes means the number of people in residential aged has increased by 0.4% since 2006, despite an 18% increase in the over 65 population.
- Increased access to elective surgery by 31% since 2007.
- The number of hospital beds has remained stable, despite a population increase of 98,980 since 2006 which means the beds per capita have declined.
- Despite significant increases in demand for mental health services after the 2010/11 earthquakes, services, including general practice teams have stepped up and met the demand, with an increased range of flexible, responsive mental health services across community and specialist care.

Love (2015) noted that within the Canterbury health system, there is a widely held view that the next level of challenge will be to integrate health and social services such as education and welfare, and to develop the next level of shared information systems, both to support clinical activity and to generate business improvement.

The goals of valuing patient and staff time have become the focus across the system, enhancing patient experience and wellbeing and building organisational capacity and capability. Evaluating these services, like all others, is based on delivering strategic and operational benefits that are best for patient and best for system. Other measures of impact include reductions in length of stay, enhanced patient safety, timely access to services, closely monitoring readmission rates, undertaking frequent patient surveys, reduced consumable costs, etc.

Mana Ake (a Māori language term meaning ‘Stronger for Tomorrow’), which provides mental health and wellbeing support for children aged five to 12 years old across Canterbury, was established on 22 February 2018, the 7th anniversary of the 2011 earthquake, and 14 months after the large (7.8 M) Kaikoura earthquake in November 2016. It is an initiative, funded by central government and co-designed through CCN that is delivered by 13 non-governmental organisations (NGOs) working as an alliance who provide 80 kaimahi (workers) across all primary schools in Canterbury and who provide individual support as well as advice, guidance and workshops for patients, whānau (extended family) and teachers. Kaimahi have a diverse range of skills and includes child psychologists, social workers, counsellors, teachers and youth workers to support children experience of a range of issues ranging anxiety, social isolation, grief and parental separation.

65.2.8 The Canterbury Health System Response to the Christchurch Mosques Terror Attacks

On 15 March 2019, during Friday prayer, a single gunman entered two Christchurch mosques and, in a period of less than 20 min, shot dozens of worshippers, leading to the deaths of 51 people (47 male and four female) and injuries to a further 49. Those killed were between 3 and 77 years old. The gunman, who had live-streamed the first shooting on Facebook, was arrested shortly afterwards.

St John Ambulance, which serves most of NZ, sent 20 ambulances to the scene, and 45 people were hospitalised on the day of the shooting and 118 were treated or admitted, a number of them facing multiple operations over many months. This was a terrorist attack that was large by world standards and unusual in that there is only one major emergency department for a city of Christchurch's size and all bar two patients (a child and her father) who were flown to Auckland after being stabilised were treated locally within the Canterbury health system (Kerdemelidis & Reid 2019). Despite the horrific injuries suffered, only two people died after arriving at hospital in an effective mass trauma response. The physical and mental support that is required for these patients and their families will be enduring, in some instances lasting years, and it is, in part, due to the robust relations between different sectors and agencies that such a comprehensive and supportive response was possible.

65.2.9 Was Vision 2020 Achieved?

Vision 2020 created a powerful direction towards an integrated health system but also illuminated significant challenges in managing demand and ageing that are common in health systems across the world. Based on growth patterns in 2007, Canterbury projected the need for an additional 450 acute hospital beds and 2000 aged care residential beds by 2020. To what extent did the integrated models introduced mitigate the expected growth?

The population projections of 2007 considerably underestimated population growth over this period for New Zealand and Canterbury largely due to greater immigration. Canterbury's population in 2006/07 was 479,360 with projections of 532,140 by 2021. In 2019/20, the population has reached 578,340, 8.7% (46,200) higher than projected despite earthquake disruptions to natural growth. While projections for older people were relatively close to reality, those for younger people were significantly lower than have eventuated, partially due to the arrival of the earthquake rebuild workforce.

Admissions grew from 71,586 in 2006/07 to 105,502 in 2018/19, which was 25,051 more than expected. Some growth was due to changes in model of care with increased use of emergency medicine admission for short-stay admissions. However, length of stay has also fallen considerably due to change of model of care and system efficiencies. Over this period, the average number of bed days per person fell from 1.0 to 0.7 days resulting in total bed occupancy 1.8 per cent lower in 2018/19 than 2006/07 despite the increases in population.

65.3 Integrated Health Systems in a time of Coronavirus

At the time of writing (mid-May 2020), coronavirus disease, an infectious disease caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), has become a pandemic which has left over 300,000 people dead, over 4.5 million infected and up to half of the global population in one or other form of lockdown. While it is difficult to be too prescriptive in the middle of a pandemic, and the NZ Government and Ministry are leading the national COVID-19 response, there are a number of lessons from the integrated Canterbury health system that may be transferrable to other health systems.

1. Think system rather than hospital. While hospitals around the world, often under extreme pressure, are doing a bigger version of what they do every day, it is the whole system response that will matter most. This particularly applies in the post-acute phase where experience from elsewhere shows that recovery will be longer and more complex (Thornton 2020).
2. Ensure good access to stocks and resources. This not only includes personal protective equipment (PPE) and other resources but reaching out to non-government organisations (the Third Sector), small and/or private providers to ensure that they do not feel vulnerable while the big system kicks into gear. Be in contact with them daily and pay particular attention to care home settings whose residents and their workforce are among the most vulnerable of all.
3. Remove the barriers to doing the right thing and in particular, trust and support the clinicians in service improvement and redesign.
4. Be clear on the guiding coalition that will influence and support the wider system to act as ‘one system’ (who are they; have they been given a clear mandate to act).
5. Have daily conference calls—identify issues early and delegate people to respond.
6. Encourage innovation and offer ‘forgiveness’ when things go wrong—as they inevitably will
7. Celebrate daily the staff’s actions, and promote ‘pay it forward’ type messages from the public
8. Be very clear on the responses of the system that matter to achieving recovery, and continually reinforce these messages. The NZ Government response to COVID-19 has been an early, clear four-stage alert system, and what to expect in each stage. This has helped significantly in clarifying what to expect for the public and has enabled a very high compliance and support rating.
9. Be bold—do not let it revert to the old normal. Be clear on a new normal opportunity, and drive towards this. This has been a time to test new models of care, such as, where clinically appropriate, video calls to patients rather than general practice and/or outpatient appointments. Defaulting, without question, to pre-coronavirus service provision will lead to lost opportunities for a rethink healthcare delivery.

10. Use the data to keep track of what the system does but also more importantly what it does not do. Canterbury has made use of its predictive analytics to identify the unintended gaps in care delivery which has allowed for comprehensive catch-up planning

This is in no way a definitive list or right way of doing things for every setting; however, in systems where there is a high level of integration borne of trust, it is easier to be nimble and to make things happen (Lewes & Ehrenberg 2020). In Canterbury, the COVID-19 response has built upon and overlaps with the existing system principles (see Box 4), hence the transition to this heightened state of alert.

65.4 Conclusion

Good enough never is and the Canterbury health system is on an ongoing journey for further improvement, and while much has been learned in the journey so far, much still needs to be done (Box 4). Canterbury seeks to stimulate the curiosity for making better in its people and for its population and continues to value patients' time as the most important currency in health care from which all things flow. Those working in the system continue to seek opportunities to reduce waiting and make things better for the people they serve. Canterbury leaders would be the first to say that what cannot be done is to transfer the Canterbury model wholesale into another health system. However, Love (2015) identified some transferrable attributes of the Canterbury health system and the underlying elements of principle-led change and adaptive leadership apply to all complex, adaptive systems (Box 4).

Box 4 Some learnings of the Canterbury Health System journey so far

- Clarify the mission: (Re)define the vision; set out the key principles to enable; empower people with a sense of purpose and permission to transition practice
- Ignite the passion of our people by: Reframing the language we use (shapes our identity and collective purpose); acknowledge the stories of change; encourage rapid testing of ideas (what is discussed today is implemented before we take on the next ideas); share the learnings (good and bad);
- Think whole of system: (NGO, Community, Primary Care, Secondary and Tertiary care). No one part of the system is an island, and solutions may exist outside your immediate influence. Encourage wide connections and sharing. Solve problems from a system perspective (not just organisation)
- Patient time is the unifying health system metric
- Shared and connected data: Supporting whole of health and wellbeing system thinking through the use of shared data to illustrate, plan and

inform improvement. Make this widely available with expert support to encourage informed decision making.

- Patient and staff stories encourage continuous improvement through shared insights, collision of isolated ideas or experiences and creates empathy building.
- Integrated networks trump organisational hierarchy for empowering and communicating the opportunity to try new ideas.
- Share the problems/issues widely. Trust in people to help enlighten the thinking to solve the problems. Empower people to deliver the solution
- Shared experiences enhance transformation: Create opportunities to learn new knowledge and thinking together in a multi-disciplinary manner. Investing in peoples' time is seeking fresh knowledge to support transformative thinking.

Each system has its own journey and is its own intricate web of layers of processes, plant and people. Bohmer (2016) noted that '[e]xamination of organisations that have achieved and sustained substantial performance improvements requires the relentless hard work of local operational redesign' and that 'major change emerges from aggregation of marginal gains' (p. 709). It is important to stress that in the decade since the original earthquakes, there has been sustained system performance from the Canterbury health system, reflecting an embedded ongoing way of working. Indeed, international visitors from other health systems consistently express surprise and pleasure with the extent of the shared ownership, language and vision among staff at all levels of the health system.

The reason may, in part, be found in an oft-cited Māori (the indigenous people of New Zealand) proverb 'He aha te mea nui o te ao. [What is the most important thing in the world?] He tangata, he tangata, he tangata [It is the people, it is the people, it is the people]. And in the end, that really is the most important thing in a health system that is built on trust.

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Building an Integrated Health Ecosystem During the Great Recession: The Case of the Basque Strategy to Tackle the Challenge of Chronicity

66

Roberto Nuño-Solinís

66.1 Introduction

This article provides an assessment and a forward-looking reflection on the development of integrated care in the transformation of the Basque health system. Special attention is given to the existing challenges and their potential impact in terms of equity, efficiency and sustainability, together with the organisational transformation undertaken during 2009–2019. The temporal evolution of Basque health care has not been linear, particularly in terms of per capita public expenditure. There was a strong expansionary cycle in the early 2000 and then a slowdown during the so-called Great Recession, followed by a recovery since 2014.

Within this context, a system-wide large-scale transformation of the healthcare model was implemented in the Basque Country. We review the main organisational, clinical, managerial and technological transformations conducted towards integrated care in the past decade.

66.2 The Role of Basque Health Care Within a Decentralised Health System

The Spanish National Health System (SNHS) is characterised by providing universal population coverage. It is funded by taxes and user contributions, and care is provided predominantly from within the public sector. Healthcare services are free

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at the point of delivery, with the exception of co-payments for outpatient pharmaceutical prescriptions and orthoses and orthopaedic prostheses.

General Health Law 14/1986 of 25 April 1986 (hereinafter GHL) was, without a doubt, the milestone that established the essential building blocks of the current SNHS. It enabled the transition from the old 'Bismarckian' social security model to a 'Beveridgian' National Health Service model.

Since the GHL, there have been important changes in the system. These culminated in the health system becoming decentralised, which implied that healthcare provision responsibilities were devolved to the autonomous regions (this process ended in January 2002). In the case of the Basque Country, effective devolution took place in 1988.

Within the SNHS, both the Spanish government and the autonomous regions organise and carry out the health actions in their remit according to applicable legislation. They are also responsible for healthcare delivery and planning through the health services of the autonomous regions. This includes all the centres, services and establishments of each region itself, provincial councils, city councils and any other authorities, which are managed under the responsibility of the respective autonomous regional governments.

Within this framework, the Basque health system covers all citizens and is financed by a single-payer (the Basque Government), together with user contributions in the form of co-payments. Public funding is obtained from taxes paid by all Basque citizens through the Treasury Department of the three historical territories (Bizkaia, Gipuzkoa and Araba). The Basque Government Health Department is responsible for health policies, planning and financing. Osakidetza is the name of the Basque Health Service (a public body subject to private law), and it is the only public healthcare provider in the Basque Country, including primary care, hospital care (both acute care and intermediate care), specialised outpatient services, emergencies and mental health. The Basque health system is one of the best funded in terms of per capita spending compared to other autonomous regions (per capita healthcare expenditure in the Basque Country was 1,673 Euros in 2018).

Health care and social care remain organisationally fragmented in the Basque Country, but there is a recent strategic plan for actively reducing this fragmentation both at the policy level and at the point of delivery. The new common strategy (2017–2020) was called 'Two Systems, One Objective: The People'. This common Strategy was approved by the Basque Government, the governments of the three historical provinces of the Basque Country, and EUDEL (the federation of all the municipalities in the Basque Country). They are all the public institutions with responsibilities in health care and social services, but social care is provided by a diversity of organisations (public, private for profit, NGOs…). As a consequence, social care in the Basque Country is particularly complex with a diversity of institutions involved: Basque Government, territorial governments (Biscay, Gipuzkoa, Alava) and municipal councils. At the point of service, health care is generally free of charge, but in social care, co-payments are high, and there is a great heterogeneity between territories.

Both the founding principles of the SNHS and the responsible exercise of the powers of the Basque Government have had major social stabilising effects in the face of the economic crisis, mainly due to the fact that citizens have maintained universal access to public health care and social services acted as a safety net for many vulnerable groups. All this has contributed to social cohesion and health protection, demonstrating its great value in times of economic crisis.

66.3 Demographic and Epidemiological Changes in the Basque Country

According to EUSTAT (Basque Statistics Institute) data (2019), with a total population of 2,188,017 people, and a life expectancy of 80.4 years for men and 86.3 for women, the Basque Country has one of the highest life expectancies of all developed countries. The combination of increasing longevity and decreasing birth rate is reflected in forecasts that predict that the percentage of elderly people in the population will increase dramatically.

The drop in birth rate is one of the most influential factors on ageing in the Basque Country. In 2018, the birth rate was 7.4 births per 1,000 inhabitants, which is among the lowest among EU-28 countries.

The Basque Country is one of the most aged regions in Europe in 2017, and 22.2% of the population were 65 years of age or older. Only some regions in Spain exceed this figure, such as Asturias, Castilla and León, and Galicia, which have higher percentages around 25%. The population over 85 years of age represented 3.9% of the population in 2017, although there were notable differences between men and women, with percentages of 2.5 and 5.1, respectively.

This is the first of the revolutions to which the Basque Country must adapt as a society. The achievement of increased longevity should be celebrated, but without overlooking the challenges and consequences that this entails at a social, economic, cultural and political level.

The ageing of the population has involved a change in epidemiological and social patterns. Thus, chronicity, multimorbidity, dependency, frailty, depression and loneliness have become twenty-first-century epidemics. Each of these issues poses important challenges, but they become extremely complex when they simultaneously affect significant population subgroups, whether it be totally or partially.

Chronicity represents the dominant epidemiological pattern, and it is linked to ageing. In the Basque Country, 42% of men and 46% of women report having a chronic disease. This figure rises to 81.7 and 79.9% in men and women, respectively, for population groups between 64 and 75 years old. And it reaches 92.3 and 93.2% for men and women over 75 years of age, respectively (ESCAV 2018). Chronic multimorbidity is present in 23.61% of the total Basque population and in 66.13% of those over 65 years of age. Patients with multiple chronic conditions represent 63.55% of total healthcare expenditure (Orueta et al. 2014). In short, chronicity and multimorbidity are compelling enough to warrant a rethinking of the existing healthcare delivery model to guarantee its efficiency and sustainability, as it will be shown in the following section.

66.4 Organisational Transformation of the Basque Health System to Tackle the Challenge of Chronicity (2009–2019)

66.4.1 Health Policies in the Context of the Great Recession

Not only economic crises impact health, but also the policies that are set up, whether they are marked by austerity, rationalisation or waste, and how they are implemented. In particular, the policies enacted in response to the Great Recession had effects on access to and use of health care that were more tangible and immediate than the actual effects on health. Royal Decree Law 16/2012 (hereinafter RDL), on urgent measures to guarantee the sustainability of the SNHS and improve the quality and safety of its services, contained most of the legislative measures identified as ‘cutbacks’ and transformed the existing co-payment system. Medicines for pensioners were no longer free of charge, and a contribution of 10% of the price of drugs (with a maximum monthly limit) was introduced. At the same time, the percentage of the price charged to employed people increased to 50 and 60%, depending on their income level. In addition, a large number of drugs (more than four hundred), mostly indicated for minor symptoms, were no longer covered by the public health system. But, undoubtedly, the most far-reaching decisions in the RDL were those related to excluding undocumented immigrants from publicly funded healthcare coverage.

In addition to legislative changes, budget cuts were pervasive. This was largely a result of initial recommendations and subsequent demands by international agencies for policies to streamline public healthcare spending. The context was an economic situation in which, after several years of GDP growth of above the European average, with a fiscal surplus and falling unemployment, the Spanish economy weakened rapidly between 2008 and 2009. The GDP dropped 3.6% and unemployment rose from 8.5% in 2007 to 18.6% in 2009. In 2010, a financial bailout seemed very likely; in that context, it is not surprising that public healthcare spending fell by 13.1% in real terms between 2009 and 2013 (López-Casasnovas 2017). The main adjustment measures can be tracked back to timid spending growth containment measures that began in 2010, which were enhanced with a major adjustment in 2012. These cutbacks affected mainly three areas: healthcare staff, whose number and wages were reduced; drops in the price of medicines; and lack of investment in modernisation of technologies and equipment. The pharmaceutical expenditure dropped by 22.4% in four years from 2009.

The approach to the execution of these measures (either in the form of linear cuts or as an opportunity to improve the efficiency and coordination of health organisations) was very different in various autonomous regions. The vast majority opted for indiscriminate cuts, while the Basque Country sought to implement an agenda of change, as exemplified by its health strategies.

As López-Casanovas (2017) wisely stated, beyond the reduction in spending (which was hypertrophied after a decade of very strong growth), the main problem was the lack of strategic direction and long-term vision during the recession. Basque health care is an excellent example in this regard, as it responded to the crisis with a commitment to preserving public health. This was done by fostering organisational transformation towards models of integrated care for chronicity and population health management. The work of Bacigalupe et al. (2015) was conclusive regarding this difference between the policies and strategies applied in the Basque Country compared to the rest of Spain. They evidenced that ‘the Basque Country had a positive attitude and veered towards little or no austerity and privatisation policies in the times of the economic crisis'.

66.4.2 The Need for New Healthcare Models: A Systemic Transformation Towards Integrated, Person-Centred Care

The current health systems are not prepared to meet the challenges of chronicity and multimorbidity (WHO 2015). The Basque health system, like other health systems in industrialised countries, was conceived to perform reactively in response to acute healthcare needs, and there is significant room for improvement in terms of care coordination between the different healthcare providers and long-term care social services.

Despite these areas for improvement, the starting point for the system had enviable strengths, including: a quality of service that was highly valued by users; *Osakidetza* was highly regarded by citizens as a reliable and well-managed institution; excellent professionals; adequate resources; and modern management practices based on the principles of total quality management;

Yet, in the face of the economic-financial crisis, the Basque Government decided to avoid complacency and begin a transformation of the healthcare delivery model with a long-term view.

66.4.2.1 Phase 1. The Strategy to Tackle the Chronicity Challenge in the Basque Country

In July 2010, the Basque Government's Department of Health and Consumer Affairs launched the Strategy to address the challenge of chronicity in the Basque Country. Given the increase of chronicity, the Strategy was aimed at meeting the growing needs of patients with chronic illnesses and their carers (offering them more integrated and continuous care, adapted to their needs); healthcare staff (making it possible for them to devote more work time to matters of high added value and facilitating access to the necessary tools); and citizens (as taxpayers, through a more efficient use of resources and as potential chronic patients, supporting them in preventing the development of chronic conditions and promoting their own health).

The Strategy was divided into five areas, which highlighted the essential elements of the proposed care model:

- A population health management focus;
- Prevention of chronic diseases;
- Patient responsibility and autonomy;
- Integrated care;
- Efficient interventions adapted to the needs of patients with chronic illnesses.

This vision was anchored in solid theoretical frameworks, which are worth identifying and exploring in detail. Chronicity is the key concept that provided the narrative necessary for the reform of the health system in the Basque Country. The epidemiological transition that the Basque Country was experiencing towards chronic diseases was understood as a 'challenge' for the health system. The objective was to place chronicity in its rightful place on the political agenda, in other words, 'to raise chronicity to the political level'. It should be borne in mind that the centre of attention was not 'chronic diseases' but 'chronicity', as a phenomenon, or 'chronic patients', as the main recipients of care.

It was recognised that care for chronic patients does not allow for their cure, but it improves their functional condition, minimises pain, reduces adverse events through secondary prevention and improves quality of life. The Strategy was not a compilation of recipes to deal with specific pathologies, but a systemic response for the entire population in the face of a challenge that went across the barriers of care, namely those of the social and health systems and those of the public and private spheres.

The Basque Strategy was strongly influenced by the Chronic Care Model (CCM) developed in 1997 by Ed Wagner and collaborators (2019) for the McColl Institute for Health Innovation in Seattle (USA). Approaches from systems theory and complexity science were also of utmost importance in the Basque Strategy. This meant that meeting the challenge of chronicity could not be accomplished through gradual adjustments to services and work modes. Rather, changes were needed that would impact the system as a whole.

The Chronicity Strategy ultimately aspired to be a new way of organising care provision with an impact on all dimensions of the *Triple Aim* (health outcomes, patient experience, quality of care and efficiency). This structural transformation went beyond the economic situation and required a long period of time before having a substantial effect on the system.

Policy-makers decided not to develop legislative or regulatory instruments at the beginning; they preferred to show the strategic direction by developing a shared vision and translating the transformation into fourteen strategic projects (see Table 66.1). Those projects contained a combination of top-down and bottom-up implementation approaches.

Table 66.1 Strategic projects of the Basque country's chronicity strategy

Population health management	Prevention and promotion	Patient autonomy	Integrated care	Tailored interventions
1. Stratification of the population	2. Interventions aimed at addressing the main risk factors	3. Self-management education programme 4. Social network for chronic patients	5. Unified electronic health record 6. Integrated care 7. Creation of sub-acute hospitals 8. Advanced nursing responsibilities 9. Social-healthcare coordination 10. Financing and contracting	11. OSAREAN: multi-channel centre (coordination of the provision of e-health services) 12. E-prescription 13. Creation of KRONIKGUNE: Research Centre for Chronic Health Services
14.- Bottom-up innovation (150 + projects)				

Source The Strategy for tackling the Challenge of Chronicity in the Basque Country, 2010

The processes of formulation and implementation of the Strategy for tackling the challenge of chronicity in the Basque Country were also quite innovative and were unequivocally distinct from the common bureaucratic dynamics of the Spanish public administration. Policy-makers were aware that far-reaching systemic change would require time, effort, leadership, vision and commitment, as well as a common narrative, inclusive methodology, interaction with local implementers, some level of improvisation and constant learning. Therefore, the usual command and control approach for the formulation and implementation of health policies was replaced by a consensual, collaborative and much more ‘emergent’ process (Nuño-Solinís 2016).

From the beginning, there was an attempt to support the reform with solid evidence about which interventions were effective for tackling chronic disease. Institutes or bodies were created with the aim of supporting the generation, collection and dissemination of knowledge. *Etorbizi* was launched with the aim of promoting social innovation, and *Kronikgune* was created for promoting health service research on chronic disease management and facilitate the dissemination of innovative care models. Two additional bodies were created or promoted that became key actors for change: (i) O + berri, the innovation institution that designed the Strategy, promoted innovative projects and was responsible for facilitating the implementation of most strategic projects; and (ii) the Chronicity Office, responsible for monitoring strategic projects. Each strategic project consisted of a team powered by a project leader.

The ultimate test of any systemic transformation project is that things begin to change on the ‘real world’. In the Basque Country, the assessments made by

Urtaran-Laresgoiti et al. 2018; Nuño-Solinís et al. 2013; and Toro-Polanco et al. 2015, identified the following advances for each strategic project:

(1) Stratification of the total population of the Basque Country by risk. The entire population covered has been risk stratified since 2012, and this identification is accessible by clinical staff through the EHR. The stratification was based on a model that predicts the next year's healthcare costs (as a proxy of healthcare needs) for each Basque citizen.
(2) The promotion of health and the prevention of the main risk factors for chronic diseases have been reflected in various projects. The Prescribe a Healthy Life initiative involves prescription of healthy lifestyles in primary care. It had particularly remarkable results and has been scaled-up.
(3) In promoting self-care, the Active Patient Programme stands out. It was based on Stanford University's 'Chronic disease self-management Programme'. This initiative is currently deployed through Osasun Eskola (School of Health).
(4) The Kronikoen Sarea platform was launched to activate patients with chronic illnesses through the use of social media. The platform was discontinued in 2013.
(5) Electronic health record was integrated and interoperable in all healthcare settings, and it facilitates access to all relevant patient's information as well as supports the decision-making process. Additionally, a personal health folder was available for each citizen.
(6) Innovation in healthcare integration has been reflected in shared care models, especially in patients with multiple chronic conditions. These new comprehensive care models were supported by organisational integration, with the development of local integrated care organisations (ICOs). In this model, primary care providers and local community hospitals have been brought together under a single management entity and a common contracting framework in order to provide health care to their catchment population. Bidasoa Integrated Health Organisation was the pioneer.
(7) Sub-acute hospitals were developed as an intermediate care level between conventional hospitals patients and nursing homes, an example being the new Eibar Hospital.
(8) The implementation of advanced nursing skills. As a result, the profiles of case managers and liaison nurses were created, trained and deployed.
(9) Coordination with social services based on the development of collaboration frameworks. This is a pivotal but complex axis of the current strategies. It involves multi-institutional agreements between municipalities, provincial councils and the Basque Government.
(10) Financing and contracting: a contract programme was developed to make it more operational, contributing to providing strategic direction and promoting quality improvement.
(11) OSAREAN, a multi-channel centre coordinating the provision of e-health services, health advice and online consultations, among other things. This is a high impact project that is highly valued by citizens.

(12) Electronic prescriptions, which have enabled secure and effective dispensing of prescriptions, and they are integrated in the EHR.
(13) The creation of the Chronicity Health Services Research Centre, *Kronikgune*, to identify, adapt, pilot and introduce the best practices to deal with the challenge of chronicity, generating contextual knowledge aimed at improving the health system.
(14) Bottom-up innovation by frontline clinical staff reflected in more than 150 bottom-up initiatives. These projects were the result of experimentation at the local level and were facilitated through the creation of the right conditions to innovate.

All the evaluations agreed that two years after the implementation of the Chronicity Strategy, one of the elements that gradually gained prominence was the need to have vertically integrated organisations with a population focus throughout the territory. This resulted in the consolidation of the ICO model, which is described in more detail below.

66.4.2.2 Phase 2. The Deployment of the ICO Model

The new integrated care organisations (ICOs) are a group of vertically integrated provider organisations (usually made up of a hospital and the corresponding primary care health centres in their geographical area). They are responsible for serving a specific population within a defined territory, under a contract programme signed with the Basque Ministry of Health. ICOs do not have legal personality; rather, they are part of the public body, *Osakidetza*.

The definitive consolidation of the model was established by Decree 100/2018, of 3 July, on integrated care organisations as part of the Public System, which established a global model of structural integration. Its preamble referred to Law 8/1997, of 26 June, on the Health Organisation of the Basque Country, which provided that suitable organisation of primary care must be guaranteed in each Health Area in coordination with hospital care. Accordingly, the strategic lines of the Department of Health referred to integrated care, especially in the face of the challenges of old age, chronicity and dependency. This is intended to give coherence and seek synergies between different levels of the health system (primary and hospitals) in order to make health care less fragmented, more efficient and, ultimately, to provide higher quality services. The integrated care derived from the strategic lines mentioned above involves a reformulation of the model provided by Decrees 194/1996 and 195/1996, of 23 July, which regulated the care structures of both hospital care and primary care, respectively.

The origin of the ICO model can be tracked back to the Agreement of 13 December 2010 by the Osakidetza Board of Directors. It created the Bidasoa Integrated Health Services Organisation, designed to bridge the gap between the traditional separation of primary and hospital care that stemmed from the Basque Health Organisation Act.

This vertical integration was intended to harmonise management and adopt a population health approach, optimise the management of human and financial resources, and create common strategies and plans. Each ICO develops its own strategic integration plan, which includes common objectives for both levels of care and specifies the source of financing. Next, each of the ICOs forms the technical commissions and joint committees to facilitate mutual learning and better communication between primary care and hospital professionals. The ICO model goes far beyond a mere unified management system, as it has sometimes been misconceived.

66.4.2.3 Phase 3. Progress Towards a Value-Based Integrated Care Model

The firm commitment to an integrated healthcare model is currently maintained by the Basque Government and has been extended to the collaboration with social services. The Basque Country Social Care-Healthcare Council, with representatives from the Basque Government, provincial councils and local councils, approved the 2017–2020 care coordination strategy. This aims to respond effectively to people with health and social needs, focusing on the most vulnerable groups, especially dependent elderly people. The main advances in this area include financing agreements for socio-healthcare beds between the Basque Government and provincial councils, the implementation of shared electronic records and coordinated prescriptions in nursing homes. Additionally, the initiative Euskadi Lagunkoia was launched by the Regional Ministry for Employment and Social Policies with Matia Institute as a proactive strategy to make living spaces more age-friendly, without physical obstacles and barriers.

In addition to these initiatives, it is worth highlighting the commitment in the Osakidetza strategy to incorporate value measurement frameworks and move towards value-based management (Porter 2010). This is aimed at configuring an emerging value-based integrated care model for individuals and populations (Valentijn and Vrijhoef 2017; Nuño-Solinís 2019) that can be defined as ‘the results in patient health and experience in the care process in relation to the cost incurred to provide accessible, comprehensive, coordinated services for a population group’. Due to the set of innovations developed and the results achieved, the Basque Country has been recognised as a *reference site* by the European Commission for its work on active and healthy ageing (EIP/AHA initiative) and has also been the subject of an international case study research (Nuño-Solinís 2019).

66.5 Conclusions

The impact of the Great Recession on the health of the Basque population has been limited, at least in terms of the effects that can be assessed during the time elapsed to date. That limited impact has multifactorial causes, but the effect of the institutional response to the economic crisis cannot be denied. This response was characterised by limited austerity measures and policies expressly aimed at compensating for the effect of measures adopted by the central government derived from RDL 16/2012 (co-payments and elimination of health coverage for undocumented immigrants). There was also an emphasis on organisational transformation and technological innovation as a response to the challenges derived from the crisis and those emerging from the change in the demographic, social and epidemiological profile.

These challenges and the need to continue working to reduce health inequalities have contributed to shaping an innovative health provision model characterised by integrated, person-centred care and an organisational architecture enshrined in a population-based approach. This model is based on a publicly funded health system where the inverse care law is almost negligible; in fact, it is more focused on the most disadvantaged population, even beyond what would be expected based on the morbidity burden.

Evaluations of the integrated care model have shown significant improvements in various indicators of quality of care, changes in the pattern of use of services and improved health outcomes. The changes undertaken have been recognised at EU level, as a reference region.

The transformation of the Basque health system has made inroads into complex and, at times, little explored areas, such as the evolution towards models of integrated care based on value, new channels of citizen participation and patient activation and configuration of models of shared social and health care.

All this transformation has been carried out preserving the founding principles of the SNHS and furthering the strengths of the Basque system, developed over more than three decades since healthcare planning and organisation competences were devolved. This essentially positive assessment should not belittle the enormous challenge involved in becoming one of the most aged regions in Spain, country which has been predicted to have the highest life expectancy in the world by 2040 (Foreman et al. 2018). This requires implementing a demanding agenda of in-depth reforms and permanent efforts to ensure efficient use of health resources, in the face of the foreseeable increase in chronicity, multimorbidity and frailty among the population.

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The Journey from a Chronic Care Program as a Model of Vertical Integration to a National Integrated Health and Care Strategy in Catalonia

67

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67.1 Introduction

The Spanish state is made up of the central state and 17 decentralized Autonomous Communities with their own governments and parliaments. Spain has a national healthcare system that offers nearly universal coverage. The system is mostly funded through general taxes. In 2002, the Spanish health system was fully decentralized and all health-related responsibilities were assigned to 17 regions. This resulted in 17 regional health ministries responsible for the organization and delivery of health care. However, the process of decentralizing health care to the regions started much earlier, with the Catalonian government becoming responsible for health care in the region in 1981 (Departament de Salut 2010).

The Catalan healthcare system provides serves a population of 7.6 million. One of the distinct features of the Catalan health system is the separation of planning and financing functions, allowing for commissioning of healthcare services from public and non-profit private centers including hospitals, intermediate care, mental health and primary care providers. The Catalan health system is based on a national healthcare system funded by taxes. The Catalan health system has universal coverage that is free at the point of use, although pharmaceuticals require a user co-payment.

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Catalonia has developed a network of 370 primary care centers and 97 postacute and long-term care facilities with 8.250 beds. These centers and facilities offer very good care in the community and are an important alternative to the acute hospital care provided in 69 centers. Every Catalan citizen is assigned to a family doctor (GP) and a community nurse, who act as gatekeepers to access secondary care.

Catalonia boasts excellent health outcomes achieved at reasonable health systems costs. Standardized mortality rates are decreasing, and life expectancy is continuously growing. In 2010–2013, mortality was reduced by 8.5% while life expectancy increased by 1 year both for males (80.8) and females (86.3). In 2016, life expectancy at birth was 83.6 and among the best in Europe; public health expenditure per capita was 2,137 US and total health expenditure was 7.6% of GDP. Hospital bed supply is 1.7 per 1000 population, well below the average of 3.7 in EU15 (WHO 2020).

Similar to most developed countries, Catalonia is facing demographic and epidemiological challenges that will require pragmatic and transformative responses for part of the health and care system (Bodenheimer et al 2009; Manchester and Schwabish 2010). With the Catalonian population aging, multimorbidity, frailty and dependency are becoming more prevalent. In some cases, this leads to complex health and care needs and palliative care requirements (Busse 2010; United Nations 2013; Contel 2015).

This challenge has implications for politicians, decision-makers, organizations and professionals that will be required to rethink and adapt to this new scenario and respond better to the needs of the people while containing cost. This implies a higher need of coordination and cooperation to develop a clear integrated care strategy and actions.

67.2 Integrated Care in Practice

67.2.1 Problem Definition

The **Health Plan** is the main strategic health-planning instrument for all health interventions of the Catalan government. Health planning in Spain takes place in the context of devolution enacted by the 1978 Spanish Constitution and initiated with the first competence transfers from the central government to the Catalan government (Generalitat de Catalunya). Since then, the Catalan government through the Department of Health, the Catalan Health Institute (ICS) and the Catalan Health Service (CatSalut) has regulated, planned and organized health services delivery (WHO 2020).

In 1990, the Parliament of Catalonia approved the Catalan Healthcare Order Act (LOSC), a legislative landmark that redefined the roles of planning, purchasing and provision of health care. The health plan sets out clear priorities, goals and expected results that aim to contribute to improving health outcomes and health equity and it does so through time-bound specific measurable targets. There is consistency across health plans in goals and directions while also accommodating new priorities, continually challenging the health system to move forward. From 1991 to the present, seven consecutive health-planning cycles have been completed with different forms and orientation. An important strength of the policy cycle is the translation of health plan priorities into service contracts elaborated by Catsalut, and thus, to budget allocation processes through CatSalut contractual mechanisms (Contel 2015).

Within this context, the Ministry of Health of the Government of Catalonia created a **Chronicity Prevention and Care Program at the end of 2011,** which we mention as "Chronic Care Program." This program introduced an integrated care vision within the new health plan, under Government management, explicitly entrusted by legislators to develop this program and make it operational, in conjunction with the Ministry of Social Welfare and Family. In addition, this program was one of the most important cornerstones of the **Health Plan 2011–2015** in order to take care of the increasing number of citizens with chronic conditions (Fig. 67.1).

Chronicity has been a challenge to all developed countries, so the Chronicity Prevention and Care Program has collected experiences from other geographical areas in our region and adapted them to our local realities.

Catalonia has some characteristics that have created the context and need for a chronic and integrated care plan:

- According to the projections of population estimated by the IDESCAT demographic institution for the period 2018–2030, Catalonia's population aged over 65 years will grow from 1,4 million in 2018 (18,8% population) to 1,78 million in 2030 (22,3%) and to 2,6 million in 2060 (29,8%). The population over 80 years will grow from 460,000 inhabitants in 2018 to 567,000 in 2030 and 1.173,000 in 2060. Life expectancy will increase; in 2030 it will be 83.2 years for men and 88 years for women (80.8 years and 86.3 years respectively in 2016) (IDESCAT 2018).
- An increasing number of people with multimorbid conditions: 38.4% of the population over 15 years suffer from a chronic problem (35.2% of men and 41.4% of women). In people over 65 years, the proportion of chronic problems surpasses 60%. Problems (ordered from more to less frequency) are related to: cardiovascular system, locomotion, headache, chronic allergies, anxiety and depression. The most common pattern of chronic diseases is as an high burden of multimorbid conditions distributed through population. Most of these multimorbid conditions are related to people with complex needs and difficulties in managing their care (Fig. 67.2).

- Catalonia has a multiprovision system with both statutory and nonprofit private providers commissioned by Catalan Health Service, which increases system complexity. It has been recognized that it is the role of CatSalut as Catalan health service and main health authority to create an integrated care environment and practice in each part of the country (regions and counties).

- Families in Catalonia are much more involved in taking care of the elderly than in other countries, although the situation is changing: 16.3% of men over 80 years old and 44.8% of women live alone. It has been estimated that about 175,000 people over 65 years experience non-desired loneliness (Departament Salut 2018).
- In spite of the increase of mean income (13,338 € per year and person) in 2018, this is only the first time that these numbers are higher than in 2009 (mean 12,733 € per year and person). There is an increasing number of people with economic vulnerability, risk of poverty or social exclusion: There were 1.831,000 persons (24.7% of the population) at risk of poverty or social exclusion last year (PAISS 2020).
- At the end of the last decade, the Spanish and Catalan economic situation was characterized by substantial healthcare cuts following the financial crisis, below European average expenditure on social protection, high unemployment (particularly hard-wearing among the young), below OECD average health expenditure per capita, increasing public debt, and high public deficit (Gallo et al. 2013).

Successful examples of transformation in the literature such as Kaiser Permanente and the Veterans Health Administration, and high-performing regional experiences like the Strategy to Tackle the Challenge of Chronicity in the Basque Country have been very inspiring models from which to extract and adapt some key features (Contel 2015). In addition, the Spanish Ministry of Health has drawn up a national chronic care strategy published one year ago with some common principles and aims to use as guides (MSSSI 2012).

In 2016, an updated Catalonia Health Plan for 2016–2020 incorporated and reinforced three important points: person-centered approach, chronic care policy actions and intersectoral policy and actions related to integrated care (Fig. 67.3).

67.2.2 Description of the Model

67.2.2.1 The Beginning of the Integrated Care Model in Catalonia—The Chronic Care Program

The Chronic Care Program was developed as a model of “vertical integration” within the health system tailored to offer better care to people with chronic conditions and complex needs. This Chronic Care Program has introduced some interesting key drivers:

- **Chronic and integrated care policy-driven orientation at highest policy level** with strong commitment of the Ministry of Health and now Ministry of Welfare
- **Primary Health Care** as the cornerstone of the new chronic and integrated care approach. Primary care teams have had very strong involvement in proactively managing complex patients and steadily introducing case management strategies.

- **Proactive identification of chronic complex patients (CCP) and persons with advanced chronic disease (ACDP)** by family doctors, nurses and case managers in primary health care. After identification and registration with newly introduced specific code and label, an electronic personalized and shared care plan for each individual complex patient is being written by his or her family doctor and community nurse. A basic and published **person-centered intervention plan (IP) generated in an electronic Key Information Summary** is uploaded to the eHR, which is accessible to all providers. This includes emergency and out-of-hours services who take care of exacerbations after regular business hours. When a patient calls during an exacerbation in a 24/7 scheme, a "warning alert" activates staff in the call center room. The electronic IP is accessible to professionals working in the call center to facilitate basic information and decision-making. The IP includes key information related to: medical problems, current medication, multidimensional assessment tests performed (updated last functional, cognitive and social test) and identification of different services involved (home care, telecare). It further contains recommendations agreed between clinician and patient in case of a crisis (important issue for complex patient who potentially could have frequent exacerbations) and an advanced care plan for patients who require palliative care, including recommendations based on patient's values, wills and preferences, to be shared with other clinicians and professionals in out-of-hour periods. Additional information can be seen in the eHR.
- Introduction of **stratification and predictive modeling** according to future services utilization and death probability for the entire population of Catalonia. Some years ago, we started using clinical risk groups (CRGs). After the use of this commercial solution, our own analytical service at the Department of Health (DoH) created its own home-made stratification tool called GMA (Adjusted Multimorbidity Grouper). Analytical services provide individual stratification scores for all providers, and it is published in the eHR shared by all clinicians. The entire Catalan population is classified in different morbidity group clusters with risk scores assigned related to future potential risk of emergency admissions, death, intensive use of primary health care and high consumption of drugs. This work was possible because of the construction of an aggregate data base that is fed by compulsory minimum data sets from primary health care, hospitals, nursing homes, the mental health network and pharmacy. Additional functionalities have been developed like using stratification for adjustment of the per capita payment system or resources allocation in primary health care. Interesting developments are also introduced in some eHealth record with the possibility of each clinician and case manager to perform case finding strategies querying a list of patients with higher risk scores to initiate proactive care management (Monterde 2019).
- High commitment of **clinical leadership** involved in **design and implementation of local integrated care pathways**. Local agreements for comprehensive and proactive care of patients with complex chronic disease and advanced chronic disease were designed and implemented. This ensures a 24/7 coverage

model with a good response to potential exacerbations of this patient group, in some areas covering additional rapid response initiatives during nights, bank holidays and weekend time.

- **Replacement of acute conventional hospitalizations with other alternatives**: such as sub-acute facilities, day care facilities with fast track access agreement in case of exacerbation, a more proactive home care program and case management in primary health care, and transitional care initiatives like liaison nursing services to plan better hospital discharge.
- **Increased interoperability initiatives in information and communication technologies (ICT)** between organizations and between patients and professionals thorough econsultation channels.
- **New joint cross-cutting targets** among primary and secondary care, like avoidable hospital admissions or readmissions, where all providers from different sector are expected to become co-responsible.
- **Reinforced community care orientation** promoting more care at home avoiding unnecessary emergency admissions and institutionalizations, and self-management policies. **A national platform has been extensively deployed** through all primary healthcare centers called "Mapa Actius Comunitaris" (Community Resources Map). It incorporates a high number of community initiatives which could be directly prescribed electronically from primary health care through the eHealth record.
- New **information system tools** to monitor indicators related to this program, especially avoidable emergency admissions related to ambulatory care sensitive conditions (ACSC) (based on the American Healthcare Research and Quality Agency) and prevalence of chronic conditions identified by providers. Indicators are updated monthly and accessible to providers. The indicators can be calculated for specific populations based on aggregated information at the level of regions, county and primary healthcare catchment area.
- Successful introduction of an **Expert Patient Program Catalonia (EPP)** which includes over 9,000 patients to date. This program comprises a structured methodology where experts and trained patients coach and lead equals to stimulate healthier behaviors. It comprises different chronic diseases such as diabetes, COPD, heart failure and dementia caregiving.

67.2.2.2 The evolution of the concept—From Vertical Integration to an Integrated Health and Care Strategy in Catalonia—PAISS

Since the beginning of the Chronic Care Program, it was recognized that social care services needed to be involved in the management of care for people with chronic conditions, especially those with complex health and social care needs.

At the end of 2016, a new Integrated Care Plan was created, launched jointly by the Department of Health, Department of Welfare and also the Department of Presidency (Generalitat Catalunya 2016). Some work was done related to the established priorities:

- Design of a new model of residential care that aims for stronger involvement of primary care in the care of people living in residential homes attached to each Primary Health Centers' catchment area. Additional changes involve the high-quality prescription that is expected for this population.
- Define a new integrated home care vision and model where primary health centers, home health care and social services that commission home help could work more collaboratively at the community level.
- New interoperability in information systems has been developed in the city of Barcelona that enables the exchange of information between electronic clinical records and social care records. The information comprises a minimum data set that is considered necessary and valuable to be shared between sectors. Additionally, a new catalog for a minimum data set related to social care services based on SNOMED interoperability language has been created as there is no international code system related to social problems (TIC Salut iI Social 2020) (Fig. 67.4).

- Create collaborative work between health, social care services and public health agencies to cope with frail populations in a community-based model. A frailty strategy consistent with the integrated care vision has started to develop in five pilot projects throughout Catalonia (Fundació Salut i Envelliment 2020).
- For some years now, there has been progress in deinstitutionalizing people with mental health problems, especially people with complex needs. Strong community mental health networks have been developed, working in proximity to primary health centers and in some cases under the same roof (Departament Salut 2017).
- Some counties in Catalonia have developed an integrated care health and social care strategy although this model of horizontal, intersectoral integrated care requires more time than other forms of vertical integration.

In 2018, government approved a Plan for the XII Legislature launched on September 25th 2018, where the Government of the Generalitat of Catalonia undertook to "approve and deploy a unique strategy of integrated social and health care for the elderly or with complex needs, which promotes personal autonomy and facilitates permanence in the usual environment and their social inclusion."

To achieve this goal, an Integrated Social and Health Care Plan (PAISS) was approved on June 25, 2019 (Generalitat 2019). The PAISS is, therefore, a new, updated strategic instrument that should facilitate the promotion of person-centered care from an integrated health and care model working for the same people with complex needs.

Some of the projects that have been planned are (PAISS 2020) (Fig. 67.5).

(1) Better care for elderly, disabled and people with mental disorders in Residential Care

This project aims to move forward with new regulations and better care and prescription policy, and real change in residential care provision by increasingly engaging Primary Care teams as key health workers.

(2) Integrated care for people using day care facilities

This project aims to develop a model of integrated care for people in day care facilities, especially for persons with cognitive deterioration.

(3) Integrated home care services

This project aims to create better coordination strategies between health and social care services to manage people who require care at home. Both, home health care and home help services will be harmonized to avoid unnecessary emergency admissions and prevent institutionalization, and facilitating better care transitions to home.

(4) Integrated care between primary health care and social care services

This project focuses on better collaboration and joint working between primary health services and social care services, especially with vulnerable people and populations with complex health and social care needs.

(5) Redefinition long-term care facilities

This project aims to design a new scenario of long-term care in Catalonia including groups of population in need of intermediate care, mental and residential care.

(6) Integrated or interoperable ICT system to share health and social care system

This project tackles one of the most challenging and demanding areas and is expected to focus on: a) reinforcing a second wave work on a new nationwide social problems codification and standardization system based on "SNOMED" interoperability language, 2) new interoperability work in different geographical areas with diverse electronic social care records to exchange health and social care data, 3) validation of the Self-Sufficiency tool as an instrument to screen and assess in practical terms "social complexity" to be included systematically in the electronic social care record (Lauricks et al. 2013).

(7) Integrated management of frailty and pre-frailty to prevent disability

This project reinforces an earlier pilot strategy to manage frailty as a joint effort between health and social care services and the public health agency and extends the strategy throughout Catalonia. It is expected to promote autonomy and delay in disability.

(8) **Integrated care for children with disability and rare illnesses**

This project aims to incorporate an integrated care vision for children with these conditions to avoid managing them separately by different networks involved in their care.

(9) **Integrated care for people with complexity and mental health disorders**

This project focuses on managing people with both complex organic and mental health needs in an integrated care approach, balancing responsibility according to weight of needs. Close collaboration between primary care and mental health networks is expected.

In addition, a WHO recommendation based on the evaluation of the 30-year Health Plan in Catalonia states that health plans should prioritize and develop key intersectoral projects such as PAISS and intersectoral work in public heath involving other ministries. They should further demonstrate strong links to the Government Plan of Catalonia and the "Agenda 2030: Transforming Catalonia, improving the world" (WHO 2020).

67.3 Experimental Implementation and Impact

67.3.1 Dissemination and Replication

Both the Chronic Care Program and now PAISS aim to achieve the triple objective of better health, higher satisfaction and lower cost. They target the group of patients who have high complex needs and are high users of services, especially emergency admissions, thus driving health system cost (Contel et al. 2015).

In general terms, these programs have contributed to conditions that achieve better outcomes for chronic patients.

We would like to emphasize some positive achievements to date:

- There has been strong governmental leadership and commitment through the Health Plan and the Chronicity Prevention and Care Program which has been a catalyst to encourage real integrated health care.
- Primary care teams participating in the program have identified 3% of the general population as chronic complex patients and 0.5% as advanced disease chronic disease patients. This population has been analyzed as to their complex needs and their utilization of services, especially emergency admissions (Fig. 67.6).

- During the second wave of the program between 2016 and 2020, a new conceptualization of complexity has been developed incorporating clinical, social and system domains of complexity.
- Redesigning the model of care in Catalonia should be considered a major progress, especially for patients with complex needs. Integrated care pathways led by both commissioners and clinical leaders were a great driver for collaboration between professionals from different sectors.
- There has been a recognized need to reinforce a joint strategy of managerial and clinician leadership. Earlier hidden clinician and professional leadership talent has emerged and has been incorporated in the strategy across different counties.
- Complex chronic care has focused strongly on aligning commissioning authorities, providers and clinical leaders.
- Care model redesign has been combined with instrumental tools such as an integrated information system and commissioning and contracting policy. One strategy has reinforced the other.
- All counties have developed integrated care pathways especially for complex chronic care.
- A 24/7 vision has been incorporated everywhere, involving emergency and out-of-hours services in the overall strategy, and in some cases creating rapid response teams. This will support better decisions in an out-of-hours care for acute exacerbations in complex patients. This 24/7 strategy is a key issue explicated within each pathway.
- Some integrated health and social care pilots have identified lessons and areas of improvement for the new Integrated Health and Social Care Plan (PAISS).
- The Chronic Care Program and the PAISS Unit have worked closely with the Information System Unit and the Commissioning Health Authority Unit at the Department of Health to coordinate the implementation strategy.

Despite these successes, we also have identified some barriers that require further examination:

- Hospital volume activity-based payment should be changed since they provide an incentive for hospitals to have all rooms full. In the future, new models of pooled budgets should be incorporated to reinforce integrated care.
- Social services should be more involved in the integrated care strategy in an increasing number of counties throughout Catalonia. PAISS should work more intensively in the care model, redesigning alignment of the information system and commissioning strategy at both the Department of Health and the Department of Welfare.
- Commissioning Health Authorities should involve much more clinical leadership in commissioning bodies, in the same way as Clinical Commissioning Groups in England. A balanced managerial and clinical approach is expected in order to guarantee real implementation.
- It is not sustainable to maintain strictly two separated health and social commissioning authorities. It is expected that the new PAISS encourages a new joint

health and social commissioning authority as model of governance at regional or county level, modeled after the Health and Wellbeing Boards in England.
- Commissioning Health Authorities must mandate all providers, through reinforced contractual schemes, to upload key information and data to be shared to the national platform and to develop new ICT solutions.
- There should be additional and appropriate alignment between pay per performance (PxP) scheme to finance organizations and individual professional's payment scheme developed by organizations, transferring and sharing responsibilities to first line workers
- A better understanding of complex patients should be developed. Current stratifications algorithms do not explain complexity patterns enough. New clinical and social data should be included in the stratification process improving prediction capability as support tool for clinicians, although clinician judgment should be established to validate patients' complex conditions.
- There are real problems related to strict regulations around data protection which do not allow sharing health and social information in a unique or shared electronic Health and Social Care Record. New national and European regulation must facilitate and go forward with this important issue.

It is necessary to develop new instruments to measure experience of care in patients and caregivers as a part of a person-centered care strategy and a Triple Aim evaluation.

67.3.2 Lessons Learned and Challenges Ahead

Implementation of a successful chronic and integrate public policy requires perseverance, time, having a humble attitude and continuing learning efforts. Based on our experience, we would like to highlight the following lessons learned.

Firstly, Catalonia has a large number of different political legislatures and ongoing deep changes in internal organization at Department of Health and other departments. Integrated care needs some stability in policy action and doesn't like continuous change in strategy. Another important point is that no unique action can change the system sufficiently; rather, it is necessary to combine different strategies and actions to achieve the desired impact. The more actions are performed in a coordinated and population-based orientation, the more impactful they will be. There is a lot of literature related to the potential impact of individual interventions such as integrated care pathways, case management or stratification. However, there is little evidence related to implementation of a minimum core set of interventions. Therefore, it would be desirable to generate evidence related to a "multi-intervention" approach, both in a population-based approach and with specific groups of vulnerable or complex needs populations.

Another lesson we learned from our journey is that we require top-down and bottom-up strategies. Also, we need to embrace an organizational learning approach based on innovation and evaluation. There is different knowledge at the top or the government versus in organizations and at the front line. Knowledge should be incorporated from all levels to adjust and update policies and actions. One example is the stratification of population data. We do not have enough structured variables in the electronic health record to provide a perfect predictive model. However, we should use this kind of tool to support both clinicians and decisions-makers to take the best decisions at individual and population level.

This kind of programs and plans that we aimed to implement require the involvement of managers and clinical leaders in a very collaborative way to jointly built solutions. There were many barriers to successful collaboration that need to be overcome. Overall, the style of management should be more collaborative, distributive, participative and democratic to generate mutual trust and innovation, and to overcome outdated authoritative and hierarchical management styles. Literature should generate more evidence related to management and clinical leadership styles required to achieve better integrated care policy.

The importance of paying attention to details should be highlighted. When implementing actions, it is important to also consider the “how to.” For example, we may be able to design a very good integrated care pathway with nice flowcharts but may fail to consider what happens during nights and weekends when patients experience an exacerbation and their regular providers are not accessible. Including details on continuum of care during regular hours as well as during times of disruptions is essential.

Finally, we should pay much more attention to intersectoral policies. Integrated care requires more determined action to design and implement intersectoral policies and programs. This would facilitate the sometime difficult work of collaborating across a large number of network of agencies and professionals to serve our people more effectively.

67.3.3 Applying Lessons Learned to a COVID Crisis Scenario

Time and efforts dedicated to work in Chronic and Integrated Care programs have given us key elements to be used in scenario of crisis. We currently face a very challenging situation, coping with increasing numbers of patients with COVID disease. It has been helpful to use these lessons to organize care in a different way based on principles of integrated care.

Some actions generated in this first steps are (Servei Català Salut 2020).

- We established a **new classification of patients** according to situation: (1) Critical care profile, (2) Semi-critical care profile, (3) Patients who require hospitalization (not critical care), (4) People in intermediate care facilities, (5) People living in residential care or living at home and managed by primary health care and social services and 6) People relocated in hotels who could not remain at home.
- We introduced a classification of three categories of intermediate care facilities:

- Intermediate care centers behaving as subacute and postacute facilities that have a high capacity to manage COVID patients with complex conditions referred from primary health care and residential homes and can facilitate quick and safe transition from acute hospitals for patients who require some time of recovery
- Intermediate facilities type 2 as a second supplementary network taking on some of the caseloads of overburdened type 1 facilities
- A third category of intermediate care facility with medium and low-profile giving support for non-COVID patients or recovered COVID patients that could not been discharged to home

A stratification of residential homes was developed based on their potential response related to intensity of care and isolation. Three categories have been established:

(a) Type A with health and care personnel and possibility to create a separated isolated area and implement current "COVID residential home guidelines"
(b) Type B with health and care personnel but limited capability to isolate patients and implement current "COVID residential home guidelines"
(c) Type C with no capability to create an isolation area and therefore to implement current "COVID residential home guidelines"

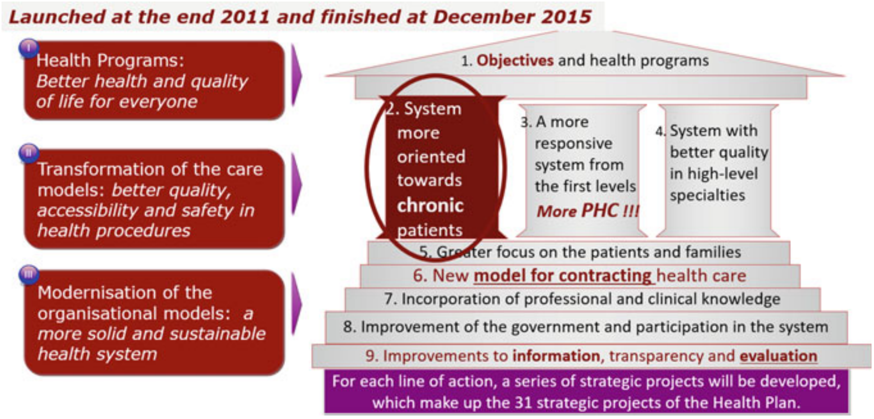
- Primary healthcare teams performing home care programs and other community resources such as Support Palliative Care and Hospital at Home teams are reinforcing support and care for residential home patients.
- Day care facilities have been closed during crisis.
- It is expected that patients can be quickly transferred between residential care and intermediate care facilities if a person is entering into an acute situation or end of life condition.
- The role of primary health care is reinforced by taking care of an increasing number of people at home, increasing number of virtual visits and more involvement in residential care of their catchment area.
- Additionally, people relocated to hotels are managed by primary care and Hospital at Home teams according to complexity.
- Mental health teams, Palliative Care teams and Hospital at Home projects are key support teams for complex patients.
- In social services, home help aids are being relocated from home care services as some family caregivers could cope with the elderly at home. Home help aids are supporting the workforce in residential care where staff numbers have been declining due to illness. Social services are managing the relocating of their own or outsourced workforce in a very flexible way.
- Telecare contracted by social services that is covering 12% of population over the age of 65 is being better coordinated with 061 Emergency Health Call Center, especially for people with COVID-related symptoms that require quick clinical assessment and follow-up by health services. New elderly people living alone or vulnerable people are being incorporated in these schemes during this period.

67.4 New Proposals to Reinforce Integrated Care as a Prioritized Policy in Catalonia

Although considerable work has been accomplished in Catalonia, much still needs to be done. Maybe one of the most important points will be to generate a real **person-centered care narrative** with practical work in this area, launching the **co-creation** of plans based on joint leadership between citizens and professionals, programs and projects. There should also be ongoing development of **policies and actions to create a good context and environment for integrate care.** This may include updated integrated care pathways, better transitional care programs to facilitate transfer from hospital to home, prioritization of integrated home care strategies, or effective case management strategies for complex patients. All these things could contribute to transforming the model of care and enhancing the relationship among all the agencies and professionals working in the same place. It will further be important to continue the development of **tools and instruments that facilitates integrated care**, such as an integrated ICT with diverse functionalities (virtual work, messaging, electronic consultation, "one person-one unique plan" tools), high-performing and adjusted stratification algorithms and individual assessment tools.

More effort must be dedicated to work steadily in areas of difficult implementation like **governance** and **financing**. Intersectoral projects need to design and implement new governance arrangements that balance the power among authorities including this involved in financing schemes and models of payment. These new governance arrangements would support integrated care by overcoming current drawbacks of payment models based on volume or activities, especially in acute hospitals.

We need to take our own lessons learned based on a real multi-intervention approach and continue to generate a multilevel and multi domain strategy to promote a whole systems transformation approach. However, these complex programs require time and patience for implementation and to achieve results. We have observed some successes in areas with strong and persistent focus, where the energy has been maintained over 10 years. Despite these ongoing efforts, there is no conclusive evidence that the new Catalan Integrated Chronic Care Program is superior to other existing programs. There is also no confirmation that programs designed and implemented in a specific healthcare context could be easily exported to other settings and countries (Nolte et al 2008) (Oxman et al 2008). This highlights the need for ongoing assessment, monitoring and evaluation.



Launched at the end 2011 and finished at December 2015

I Health Programs: *Better health and quality of life for everyone*

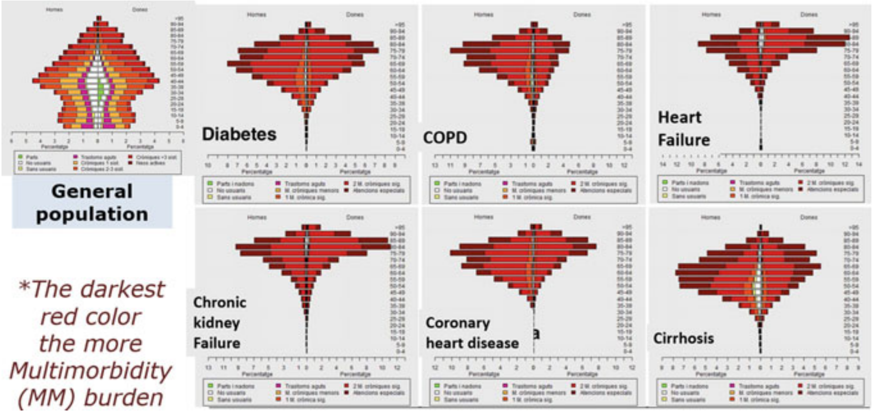
II Transformation of the care models: *better quality, accessibility and safety in health procedures*

III Modernisation of the organisational models: *a more solid and sustainable health system*

1. **Objectives** and health programs
2. System more oriented towards **chronic** patients
3. A more responsive system from the first levels *More PHC !!!*
4. System with better quality in high-level specialties
5. Greater focus on the patients and families
6. New **model for contracting** health care
7. Incorporation of professional and clinical knowledge
8. Improvement of the government and participation in the system
9. Improvements to **information**, transparency and **evaluation**

For each line of action, a series of strategic projects will be developed, which make up the 31 strategic projects of the Health Plan.

Fig. 67.1 The catalan health pan 2011–2015



**The darkest red color the more Multimorbidity (MM) burden*

Fig. 67.2 Age-related morbidity burden related to chronic conditions

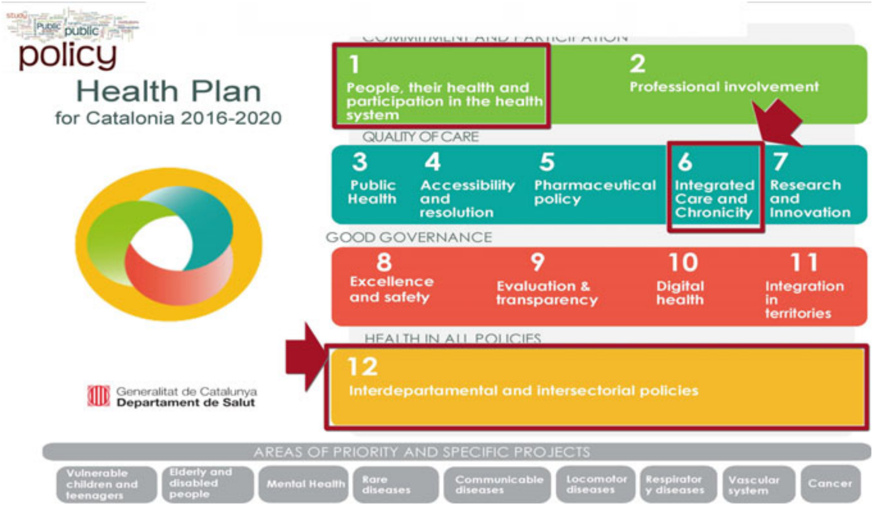
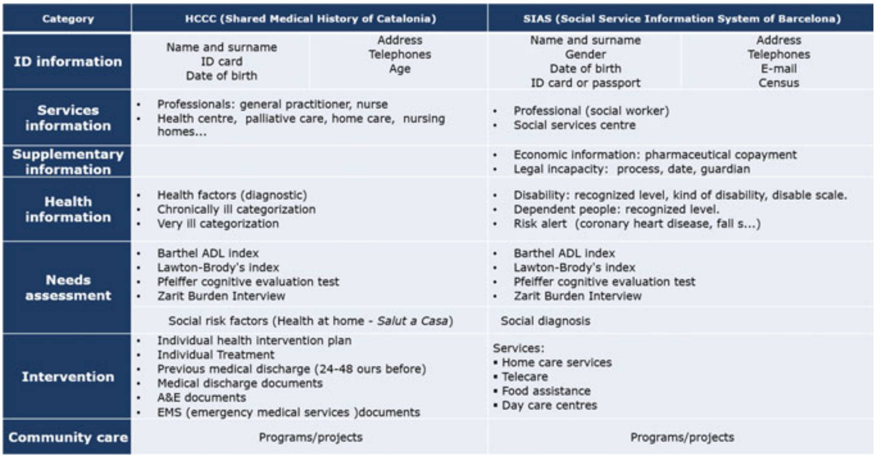


Fig. 67.3 Health plan 2016–2020



Category	HCCC (Shared Medical History of Catalonia)		SIAS (Social Service Information System of Barcelona)	
ID information	Name and surname ID card Date of birth	Address Telephones Age	Name and surname Gender Date of birth ID card or passport	Address Telephones E-mail Census
Services information	• Professionals: general practitioner, nurse • Health centre, palliative care, home care, nursing homes...		• Professional (social worker) • Social services centre	
Supplementary information			• Economic information: pharmaceutical copayment • Legal incapacity: process, date, guardian	
Health information	• Health factors (diagnostic) • Chronically ill categorization • Very ill categorization		• Disability: recognized level, kind of disability, disable scale. • Dependent people: recognized level. • Risk alert (coronary heart disease, fall s...)	
Needs assessment	• Barthel ADL index • Lawton-Brody's index • Pfeiffer cognitive evaluation test • Zarit Burden Interview		• Barthel ADL index • Lawton-Brody's index • Pfeiffer cognitive evaluation test • Zarit Burden Interview	
	Social risk factors (Health at home - *Salut a Casa*)		Social diagnosis	
Intervention	• Individual health intervention plan • Individual Treatment • Previous medical discharge (24-48 ours before) • Medical discharge documents • A&E documents • EMS (emergency medical services)documents		Services: • Home care services • Telecare • Food assistance • Day care centres	
Community care	Programs/projects		Programs/projects	

Fig. 67.4 Health and social information sharing in Barcelona

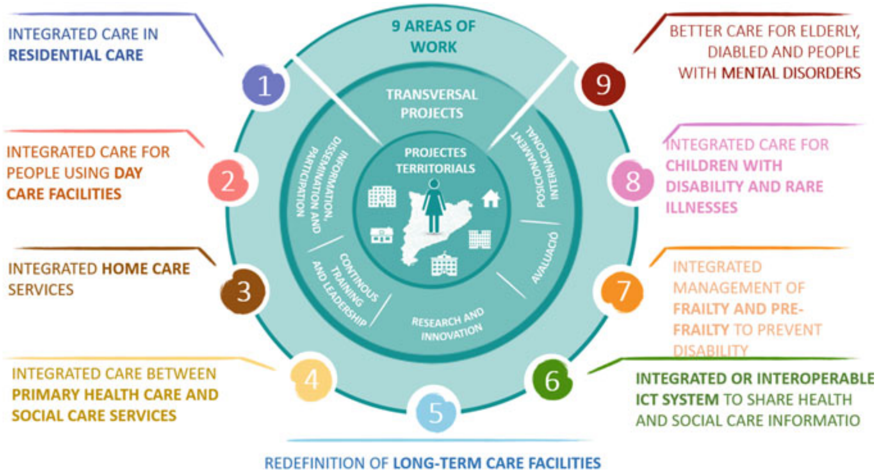


Fig. 67.5 New integrated health and social plan ("PAISS")

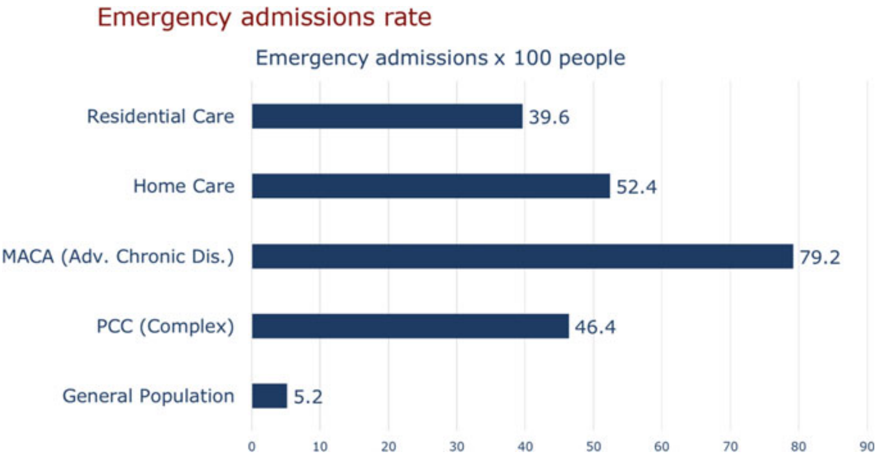


Fig. 67.6 Utilization of services of people with complex needs

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Integrated Care in the Autonomous Community of Madrid

68

Ana Miquel Gómez and Ana I. González González

68.1 The Spanish National Healthcare System

The right to health protection for all citizens was formally recognized in the Spanish 1978 Constitution (Sect. 43). This right and the right of universal access to health care were later specified and developed in the 1986 General Health Law, which is still the main national common legal act regarding healthcare matters and the organization of delivery of services. The right to health protection for all citizens and the right of universal access to health care and strong primary care are remarkable elements of the Spanish National Healthcare System.

The Spanish state is made up of the central state and 17 decentralized regions named Autonomous Communities (ACs), with their own respective governments and parliaments. The ACs are responsible for payment with public funds as well as healthcare budgeting and organization of service delivery. The national Ministry of Health and Social Policy (MSPS) holds authority over certain strategic areas, such as pharmaceutical legislation, and is the guarantor of equitable functioning of health services across the country. This includes the minimum benefit healthcare package that must be delivered.

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In the well-known World Health Organization (WHO) Report (2000) (1), which measured and compared healthcare systems performance based on eight dimensions of attainment and performance (including healthcare expenditure per capita), Spain ranked seventh out of 191 countries in the world. In 2015, 62.7% of the citizens favourably valued the performance of the Spanish NHS, stating they considered it as working "quite well" or "well", although "some changes would be needed". Seventy-seven percent of Spanish citizens rate the quality of health care that they receive as of "good quality".

According to WHO's World Health Statistics, in 2015 life expectancy at birth in Spain was 82.8 years, the third highest in the world(2). The top causes of death in Spain are disease from the circulatory system (30.1% of total deaths) and cancer (28.4%). Spain is among the four European Union (EU) countries with the lowest death rate from ischemic heart disease and cerebrovascular disease.

Healthcare accounts for 30% of AC's total budget. Healthcare expenditure in Spain has followed the upwards international trend, reaching 9.1% of gross domestic product (GDP) in 2014. Total expenditure per capita amounted to 2,058 Euros in 2014. Public health care is funded primarily through general taxation.

In Spain, the more advanced regions have been pursuing integration and chronic care management and promoting an overall culture of health care for their population, but with different strategies and a different package of policies, tools, and innovations in each region.

In this subchapter, we describe some of the innovative strategies and projects that have been implemented in Madrid region with a description of their main elements, and some of the results that have been achieved.

68.2 Madrid Region

Madrid region, with a population of almost 6.5 million inhabitants in a quite small geographic area, has one of the highest GDP / per capita of Spain, but also low public healthcare expenditure per capita (compared with other regions)(3). A remarkable statistic is that life expectancy is one of the highest in the world with 84.8 years in 2018 (see Table 68.1).

In general, the data suggests that the prevalence of the different chronic conditions is high and very similar to the rest of Spanish regions (see Table 68.2). In fact, chronic conditions represent 70% of total healthcare expenditure in Madrid region.

The Madrid healthcare service (ServicioMadrileñode Salud—SERMAS) has a network of integrated and organized healthcare services including 400 + primary care centres, 35 hospitals, and 80,000 + professionals across primary and specialized care. The public healthcare system of Madrid serves the region's 6.5 million inhabitants, of which 3.5 million live in the metropolitan area.

Unlike the other ACs in Spain, where health care is territorialized and organized by geographic areas, in 2009, the healthcare administration of Madrid created the "single area" of Madrid. The aim was the full achievement of patient's free choice,

Table 68.1 Demographic, economic and epidemiological data

	Spain	Basque country	Catalonia	Madrid
Population (2015)	46.4 million	2.189 million	7.519 million	6.454 million
Geographic size	504,645 km^2	7,234 km^2	32,102 km^2	8,030 km^2
GDP/per capita (€) (2016)	26,607	35,304	31,735	36,323
Public health expenditure/per capita (€) (2014)	1,603	2,056	1,613	1,513
Life Expectancy (2018)	83.5 years (80.7 men, 86.3 women)			84.8 years (82.1 men, 87.2 women)

Source health sector figures: Annual Report on the National Health System of Spain, 2016
Source of GDP per capita: INE, Producto Interior Bruto Regional, 2016. Contabilidad General de España base 2010
**2014 data*

Table 68.2 Prevalence of chronic conditions (%)

	Spain	Basque country	Catalonia	Madrid
Hypertension (15 + years old)	18.4	17.4	19.2	16.3
Hypercholesterolemia (15 + years old)	16.5	18.5	15.7	16.5
Diabetes mellitus (15 + years old)	6.8	5.8	7.1	5.4
Limitation in basic activities of daily living (65 + years old)	20.7	16.8	21.1	17.9
Limitation in instrumental activities of daily living (65 + years old)	47.2	48.3	54.3	45.0
Obesity (18 + years old) (2014)	16.9	13.0	15.0	14.6
Daily Tobacco use (15 + years old) **	23% (27.6% males, 18.2% females)	22.8 (28.5% males, 17.4% females)	23.7% (29.8% males, 17.8% females)	23.2% (25% males, 21.1% females)

Source health sector figures: Annual Report on the National Health System of Spain, 2016

opening the way for patients to choose their primary care centre or general practitioner and specialized physician (the latter if needed) among the public healthcare providers in the region. This “new” organization represented the need and challenge to develop integrated care in the region. The implementation included the promotion of projects like the *shared electronic health record*, or the creation of *continuity of care directors* in each hospital to coordinate care with the primary care centres.

In the last few years, the *strategy of care for people with chronic diseases* in Madrid region (4), as noted in other Spanish regions (5,6) and the literature(7), has represented the strategic framework to drive development of integrated care initiatives. The model's goals are the following: (i) to avoid healthy people from getting sick, (ii) to reduce the prevalence of chronic conditions and chronic limitations, (iii) to avoid those who are sick from worsening, (iv) to prevent the further deterioration of those who are sick in terms of functional capacity, complications, and premature mortality, and (v) to improve the quality of life of people with chronic diseases and their caregivers. The implemented initiatives include interventions that have proven to be effective and efficient. The care model has also been adapted to the needs of the patient, translating the Kaiser model through concrete projects. Among these innovative projects, we have selected the following: (i) *stratification of the population,* (ii) *adaptation of primary healthcare portfolio through the adjustment of protocols to needs of the patients,* (iii) *integrated care pathways for patients with complex needs, and iv)shared electronic health record accessible for all health professionals and patients.*

Another remarkable innovation and a typical example of integrated care is the *Palliative Care (end of life) organization of Madrid region*. Considering Palliative Care as a priority, providing care seven days 24 h a day is the main goal, with multi-professional coordinated assistance that shares all the clinical and social information between all participants inside and outside public services.

Added to these top-down strategies, we find significant projects of integrated care in different territories. Somewhere the result of implementation of global strategies in each territory, while other projects were generated in each territory and recently extended more broadly (*bottom-up initiatives*).

68.3 Strategy of Care for People with Chronic Diseases in Madrid Region

In the following, we describe the most relevant elements developed within the framework of strategy of care for people with chronic diseases in Madrid region.

68.3.1 Stratification of the Population

The first step for implementing the model was the project to stratify the population in the Madrid region. This step evaluates the population and breaks them into groups. The stratified data is then used for planning of resources and budgets (e.g. it is used for calculating the pharmaceutical budget) and to aid professionals in adapting care plans to the needs of patients.

For the stratification of the population in Madrid region, we used the "Morbidity Adjusted Groups" designed in Catalonia, piloted in Madrid, and extended to other 13 ACs in Spain(8).The *risk level* assigned to patients by the "Morbidity Adjusted

Groups" depends fundamentally on their morbidity (number of chronic conditions) and on their complexity (risk of events such as visits to healthcare providers, emergency admissions, and death). This tool was able to identify that in the Madrid region, according to their *risk level*, there were i) 3,009,219 people with a chronic condition of low risk, for which the care model will seek to improve ability for self-management, ii) 559,129 people with one or more chronic conditions of medium risk that may require disease management, and iii) 180,347 chronic patients whose conditions are of high risk and that may need individualized management with a greater degree of coordination to provide the best possible continuity of care (case management and complex care). The *risk level* assigned is shown in every patient's electronic health record both at the primary care level (though a website called AP Madrid) and the specialized level (though a website called HORUS) (Fig. 68.1).

After establishing the *risk level*, information from the stratification tool is used to establish the *intervention level* by physicians, nurses, and other healthcare providers and to adapt protocols to the needs of the patients. Once the *risk level* is calculated and shown in the electronic health record of any patient, it is the duty of healthcare providers such as physicians and nurses to assign the *intervention level*. This choice is made considering the assumption that the healthcare provider knows the patient better (his/her personal, family, and social circumstances) and his/her care needs and the electronic stratification tool that assigns the *risk level* just considers a few variables available from the electronic health record of the patient and may miss relevant information that has not been registered (e.g. social and functional characteristics). The *risk level* that appears in patient electronic health record acts as a decision aid and a reminder for the healthcare provider that the assignment of an *intervention level* is pending. Assigning an *interventional level* involves choosing

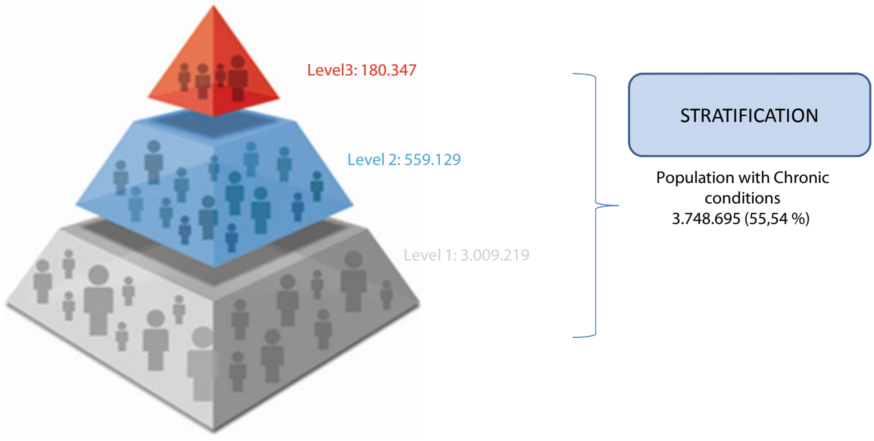

Fig. 68.1 Stratification of the population in Madrid region. *Source* Intranet Madrid Health Service. 31 diciembre 2017

an individualized care plan tailored to the needs of each patient. According to this, patients that may have been assigned by the tool as having a high-*risk level* can be assigned by their healthcare provider to a lower *intervention level* may be because they have a good support network around that diminishes the care needs. This differentiation (risk *versus* intervention) has been shown to be useful and, in fact, has been extended to other regions (9).

Thus, the *intervention level* is assigned by the healthcare provider to each patient according to his/her care needs and, therefore, will classify each patient to receive any of the following individualized care plan types:

- Promotion and preventive care plan (patients with no chronic conditions)
- Self-management care plan if classified to receive low-level intervention
- Disease management care plan if medium-level intervention
- Case management and complex care plan if classified at high-level intervention.

The risk level and the *intervention level* are accessible in the electronic health record for every patient in Madrid region.

By February 2019, 1,391,380 people were classified in a specific level of intervention. Of these, (i) 254,130 people were included to receive promotion and prevention, (ii) 850,716 people with at least one chronic condition were classified to receive a low level of intervention, (iii) 268.985 people were included in a medium level, and (iv) 17,939 were classified as high level, and therefore, as complex patients. (See Table 68.3).

68.3.2 Protocols for Patients with Chronic Diseases Adapted to Their Needs

By establishing *risk level* and *Intervention Level* of the population, the next step was to adapt the care model to the needs of each person through the *adaptation of the portfolio of primary care standardized services* project(10), including "adapted to the intervention level" protocols for hypertension, hypercholesterolemia, chronic

Table 68.3 Relation between risk level and intervention level

		Intervention levels				
		3—High	2—Medium	1—Low	0—PPS	TOTAL
Risk levels	3—High	13,463	77,503	26,664	897	118,527
	2—Medium	3,286	136,766	177,831	10,733	328,616
	1—Low	1,190	54,716	646,261	242,500	944,667
	Total	17,939	268,985	850,756	254,130	1,391,810

Source eSOAP (Balance Score Card) Madrid Health Service. February 2019
PPS Prevention and Promotion Services

heart failure, ischemic heart disease, COPD, diabetes, asthma, and obesity. These medical protocols have been translated to standardized formularies included in the electronic health record (AP Madrid) as computerized system aids, and the results of the use of these formularies are evaluated periodically as part of the routine clinical practice. These adapted protocols have been applied to 1,391,810 people that have been assigned so far to a specific *intervention level.* Furthermore, other updated protocols such as those for frail patients, for patients with dementia, and those in Palliative Care have been implemented.

All these standardized services and their protocols include different criteria depending on the disease, and in general, all of them comprise inclusion criteria, follow-up criteria, physical examination, tests to be applied, compliance review, and care plan. Depending on the intervention level, the periodicity of the activities is more or less intense, and also, some levels include specific activities. This is the case of high level of intervention that include all the activities that are part of the integrated care pathway for patients with complex needs described below.

With respect to the impact of the application of the intervention level and the specific protocols, a recent project made in Madrid region in patients with diabetes ($n = 279$) showed that those that were assigned an intervention level have better outcomes regarding the degree of diabetes control (48%) than those not assigned (32%), and this difference was statistically significant ($p < 0.001$)(11).

68.3.3 Integrated Care Pathways for Patients with Complex Needs

Development and implementation of the *integrated care pathway for patients with complex needs* include i) a single entry, ii) social support evaluation, iii) proactive follow-up where needed (at home, at the office, by phone), iii) continuity of care and hospital discharge planning, iv) early detection of exacerbations, and v) multi-professional assistance including healthcare professionals (including social workers).

A process map was developed (see Fig. 68.2). Each sub-process includes what to do, who must do it, and how to do it.

In summary, the pathway includes.

- *Single entry*: Complex patients can be identified by every health and social care professional and communicated to the general practitioner and practice nurse who are in charge of including the patients in the pathway
- *Social support evaluation* can be made throughout the pathway.
- *Discharge planning and follow-up after discharge* are key elements in transitional care. For continuity of care, the nurse plays a key role keeping the contact between hospital and primary care professionals.

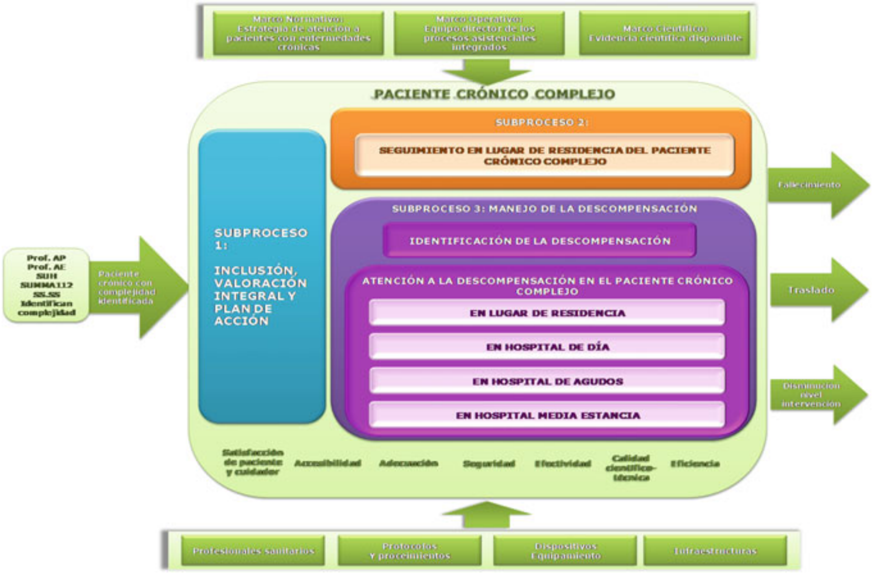

Fig. 68.2 Process map for patients with chronic needs

- *Proactive follow-up* can be completed by the general practitioner and the practice nurse (primary care) by phone, at the office or at the patient's house. Follow-up occurs according to standard protocols adapted to the patients' conditions and allows early detection of exacerbations.
- *Treatment of exacerbations* can be made at home, in an acute hospital (specific units) or in an intermediate hospital. A hospital specialist helps primary care with decisions.

By February 2019, 17,939 patients had been included in this integrated pathway. This common process has been complemented by specific integrated care pathways with specific activities for patients with chronic obstructive pulmonary disease and chronic heart failure.

One important aspect is that all pathway activities are captured in the primary care electronic health record named "AP Madrid". This allows to monitor advances in the implementation of these protocols and processes, evaluating and translating the data to a balanced score card and to the "Observatorio de Resultados de Madrid" (Data Observatory of Madrid Region)(12).

68.3.4 Shared Electronic Health Record

Another relevant innovation is the Madrid *Shared Electronic Health Care Record* (*HORUS platform—visor for both specialized and primary care and AP Madrid platform—the specific electronic health record for primary care)*. Using *HORUS*, providers can instantly view a patient's consolidated records from all aspects of the Madrid health system, including demographic information, contact information, referral documents, detailed reports and images for procedures, clinical information from primary care, vaccinations, medication, allergies, clinical orders, etc. HORUS has three goals: *clinical efficiency*, *shared knowledge*, and *care transformation*. The system contains more than 15 million records for over 26,000 clinicians and is considered a key element for transforming Madrid's health system infrastructure to support population health management.

In addition, some other tools have been developed and implemented to allow non-face-to-face communication between professionals. An example is the *"e-consulta*" (e-consult), established to allow consultation of general practitioners and practice nurses with hospital consultants. This is implemented now in most of the Madrid regions, with many of the main specialties, and includes the possibility of sharing images, test results, etc.

Finally, patients can access most of this information through *"Mi carpeta de Salud"* (My Health Folder) that includes dates, reports, vaccines, active treatments, laboratory results, and the most relevant data of the shared electronic health record.

68.4 The End of Life Care (Palliative Care)

A remarkable innovation and a typical example of integrated care are the Palliative (end of life) organization of Madrid region.

With the second version of the government *Palliative Care Plan 2010–2014,* a multi-professional integrated care process was implemented in the community of Madrid, ensuring seven days a week 24 h a day care.

The integrated care process involves a network of specialized teams that support primary care and hospital assistance such as home support units, hospital support units, end of life hospitalization units, and phone support units (call PAL 24). All these units work in an integrated way with the other professionals in Madrid health service around the needs of patients and their families. They all share the electronic health record, named INFO-Pal, that includes specific protocols and information.

In 2017, 9,000 adult patients with Palliative Care needs were included in this program and 7,500 patients were taken care of at home.

68.5 Implementation in Specific Territories and Bottom-Up Initiatives

68.5.1 The Case of Rey Juan Carlos Hospital

Many of these strategic projects have been translated to the different territories in Madrid with differences in the speed and impact of implementation. This underlines the importance of analysing and improving *implementation processes*. Specifically, we have analysed (published elsewhere) the Western area of Madrid, in particular the catchment area of the “Rey Juan Carlos” Hospital.

With 174,000 inhabitants distributed among 18 municipalities, health care is offered in this territory by one hospital (public hospital managed by a private company) and by 21 public primary care centres distributed in urban and rural areas and 45 nursing homes for elderly and mentally disabled individuals. We have selected this territory because it was one of the more advanced in the implementation of new integrated pathways and tools (since the creation of the hospital in 2012) including a social and healthcare plan for integration among hospital and nursing homes that began in 2015.

The key integrated initiatives that have been implemented include (i) *new roles* (e.g. to help general practitioners in decision-making or to participate in the care of more complex patients), (ii) *new services* (some of them to develop more efficient transitional care, like the automatic delivery of discharge reports to each practice nurse and general practitioner and the follow-up after discharge by the practice nurses), and (iii) *new tools* (most of them to share information and improve communication), and also some coordination structures (See Table 68.4).

This territory has been the focus of research through the evaluation of the implementation process and the impact of this integrated care initiatives that will be published shortly. As part of this research into the implementation process, we found a good number of disseminating and training initiatives and a progressive increase in the use of new services and tools (highlighting the use of the *Shared Electronic Health record*).After analysing the professional experience through a specific survey, we concluded that the perception of utility of the new interventions and the role of the managers as leaders in this change received the highest scores of factors that favour the implementation and therefore the change in management.

With respect to the assessment of the impact in this concrete territory, among the positive results that we founded are.

- Increased number of patients included in programs of promotion and prevention, diabetes, chronic heart failure, chronic obstructive pulmonary disease, and number of patients assisted at home with care plans.
- Improvement in intermediate health outcomes like hypertension control, diabetes control, and anticoagulated patient’s control.
- Patient satisfaction and experience of care have increased and are significantly better than in the rest of Madrid region.

Table 68.4 Integrated care initiatives implemented in Rey Juan Carlos territory

New roles	New ICT tools
Specialist as consultants	Access to hospital clinical record from primary care and nursing homes
Face-to-face consultants of psychiatry	Access to primary care clinical record from public nursing homes
Nurse-led	Hospital website for primary care
Reference specialist: geriatrician for nursing homes, internist for complex patients at home	Hospital website for nursing homes (socio-health website)
New services	Virtual consultation by telematic means sharing clinical data (and e-consultation)
Non-face-to-face communication between the hospital and primary care professionals and nursing homes	Telemedicine: video sessions, videoconferences, anticoagulation management, tele-rehabilitation, tele-consultation with nursing homes, with half-stay hospitals
Identification of fragile and complex patients (circuit adaptation)	New bodies / coordination structures or communication
Coordination of within hospital services for complex / fragile patients by reference specialist and nurse-led	Sector commission (with those responsible for hospital and primary care)
Discharge planning	Director of continuity of care
Proactive follow-up after discharge	Commission of pharmaceutical continuity
Home hospitalization in nursing homes and homes	Continuity of care commission
Programmed admissions from nursing homes and homes	Socio-health commission
Early discharge planning for nursing home patients	Face-to-face meetings with health centres and nursing homes (monthly)
Continuity of care in nursing homes	Teaching activities shared between hospital, primary, and with nursing homes
Continuity of care for complex / fragile patients	

- Better results than rest of Madrid in potentially avoidable hospitalizations.
- Improvement in the activity of the primary care physicians and nurses.
- Lower average stay in hospital in comparison with region's hospitals of the same complexity.
- Increase in satisfaction in professionals from primary care and the nursing homes.

All these results and others about this research will be published proximately.

68.5.2 "Mapeando Carabanchel Alto" (Mapping Upper Carabanchel)

"Mapeando Carabanchel Alto" is an active community-based project that started in 2014 promoted by the primary care health centre and that nowadays includes 32 health social and community organizations of eight districts in the south of Madrid that constitute a coordination committee. This committee has structured meeting every month, with the assistance of every member of the district that wants to participate. Currently, the initiatives of this project are developed by seven working groups.

As an example of the results from this project, we have selected the following:

- A blogspot that allows the dissemination of all the health, community, and social activities. As an example of these activities during COVID-19 pandemic, the blog has informed about virtual teaching activities, challenges, and relevant resources to support women that suffer gender violence, added to all the information to prevent and to receive health care (13).
- Mapping of health actives with 308 references including health, education, sport, youth, elderly, religion, and end vicinity associations.
- Shared community initiatives with participation of all the organizations and high acceptance of the population. Examples of these activities are a "Health Orchard", manifestations against gambling places, or specific activities to inform about mental diseases, etc.

The success of the project in the population has promoted its extension to other districts in Madrid, like the Latina district, and it is now considered a model project to be extended to all districts. In addition, the Spanish Minister of Health has considered it a "good practice" and used it as a success reference to propel community health and social projects in the rest of Spain(14).

68.5.3 "Vallecas Activa" (Vallecas Active)

CHRODIS PLUS Joint Action, an European project funded by the European Union in the framework of the Health Programme(2014–2017), produced a summary report on good practices in health promotion and primary prevention of chronic diseases across Europe(15). Among these 41 good practices, the strategy of care for people with chronic diseases in Madrid region and the project "Vallecas Activa" (Active Vallecas) were selected.

"Vallecas Activa" is a community and interdisciplinary intervention project with joint participation of all professional categories of the primary healthcare sector along with professionals from sports science, education, and social services. "Vallecas Activa" took place in "Entrevías", one of the most disadvantaged neighbourhoods in Madrid, and was recently extended to the rest of the Vallecas district and to many other districts in Madrid as well as to other Spanish regions (16).

The general objective was to promote an active lifestyle in the population of the surroundings of the Municipal Sports Centre, in collaboration with Madrid's Municipal Health Centres and Primary Healthcare Centres and hospitals of Madrid's Regional Health Service. Health professionals (of the Primary Healthcare Centres of the Madrid's Regional Health Service and Madrid's Municipal Health Centres) prescribe a programme for lifestyle change to people with diagnosed risk factors. A physical activity programme is run by sports professionals of the Municipal Sports Centre of Entrevías (City Council of Madrid) and adapted to the population's health situation, plus a health education programme, run and coordinated by health professionals of the participating health centres. It comprises other different health programmes, depending on the target population:

- "Healthy Habits": with the aim of changing physical activity and eating habits of patients with diabetes risk, cardiovascular risk, or adult obesity.
- "Families + Active": with the aim of treating children with overweight or obesity with a family perspective, combining health education for parents and physical activity for children, by age groups.
- "Exercise, Moms, and Babies": combined programme of health education, parenting support and breastfeeding promotion, and a physical activity programme with postpartum recovery exercises, hypopressive exercises, pelvic floor recovery, and early child stimulation.
- "Healthy Walks": tackling sedentary behaviour with organized healthy walks, as a way of including social commitment and social reinforcement as improvement tools of programme adherence.

Added to the consideration of good practice by the European Union, this project received a special prize by the Ministry of Health in 2014. In the last years, the project has been extended to other districts by Madrid Municipality.

68.6 Conclusions

From all the information above, we can conclude.

- Madrid region is an Autonomous Community (AC), characterized like the rest of ACs in Spain by a *very well positioned health system with strong primary care,* a *very high life expectancy* and a *high prevalence of chronic conditions.*
- A unique element is the existence of *free choice* of healthcare provider (general practitioner, practice nurse, and specialized care physician) that originated the initial force to develop some tools like the shared electronic health record.
- The *strategy of care for people with chronic diseases* in Madrid region has represented the main strategic framework to drive the development of integrated care initiatives.

- The main innovative projects implemented with this strategy are (i) *stratification of the population,* (ii) *adaptation of primary healthcare portfolio through the adjustment of protocols to the needs of the patients,* (iii) *integrated care pathways for patients with complex needs, and iv)shared electronic health record accessible for all health professionals and patients.*
- Atypical example of integrated care is the *Palliative Care (end of life) organization of Madrid region*. Considering Palliative Care as a priority, providing care seven days 24 h a day is the main goal, with multi-professional coordinated assistance.
- Many of these strategic projects have been translated to the different territories in Madrid with differences in the speed and impact of projects, depending on *the implementation processes* in each sub-territory.
- In addition to these *"top-down"* projects, there are other *"bottom-up"* successful projects that originated in a specific district and were recently extended to other districts. We consider "Vallecas Activa" and "Mapeando Carabanchel Alto" as model examples.

All these remarkable examples show part of the changes towards integrated care implemented in the Madrid region. Some of them show real impact in the organization of public health care that has positioned Madrid very well with respect to other regions and countries.

However, we think it is necessary to consider integrated care as a strategic priority that needs time and constancy, notwithstanding any changes in personnel designing and implementing policies. We also think there is a long way to go in elements related to the integration of health and social care services and population participation in the design of integrated care services.

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Integrated Care in Germany: Evolution and Scaling up of the Population-Based Integrated Healthcare System “Healthy Kinzigtal”

69

Oliver Groene and Helmut Hildebrandt

69.1 Integrated Care in Germany

Germany´s health system is based on social health insurance (SHI) contributions and provides universal access to a comprehensive basket of services. Residents can freely choose their social health insurance fund. A risk compensation mechanism balances differences in the age and morbidity structure of the pool of insured between the insurance funds in order to prevent excessive risk selection (Busse and Blümel 2014, Gesundheitsfond 2008).

Ambulatory care is mainly delivered by office-based primary and specialist care physicians who are paid via a combined capitation and fee-for-service basis. Patients have the freedom to choose any provider in the ambulatory care sector and some choice of hospital upon referral (Kringos et al. 2015a, b). Hospitals receive activity-based reimbursement of services based on a diagnosis-related group (DRG) system (Busse et al. 2011). International comparisons demonstrate that the system provides high-quality health services independent of income and has low access barriers (Rietberg and Wörtz 2008). However, the German health system is also amongst the most expensive in the OECD (national health expenditure was 11.0% of GDP in 2013, compared to the OECD average of 8.9%) but the system only performs average on overall population health indicator status compared to similar high-income countries (OECD 2015). The reasons are largely seen in the disincentives embedded in the organisation of health services that are not fit to cater to the needs of chronically ill patients (OECD 2015).

The strict separation of primary and secondary care with insufficient care coordination is widely seen to be at the core of the problem, shown to lead to unnecessary duplication of services, poor care coordination and suboptimal health

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outcomes, despite the high level of funding for health care in Germany (OECD 2015). Various solutions have been proposed to overcome care fragmentation towards the development of more integrated care approaches and population-oriented care provision (SVR 2007, SVR 2009, SVR 2012). However, these have yet to be implemented at large scale, partly because of the continued complexity of a system that is characterised by incentives that reward acute care rather than health promotion and disease prevention, along with a lack of alignment of budgets, and payment systems across multiple SHI funds, hospitals and ambulatory care providers (Amelung 2011).

Reforms since 2000 have given purchasers and providers more options to develop contracts to overcome fragmentation and to improve the quality of care. These included the 2000 Health Care Reform Act, which introduced provisions for the delivery of more integrated care, the 2001 Risk Structure Compensation Reform Act, which introduced disease management programmes, the 2004 Social Health Insurance Modernisation Act, which introduced a legal framework for integrated care provision and strengthened primary care, and the 2008 Long-term Care Act, which introduced provisions that permit delegation of tasks that were traditionally performed by doctors to non-medically trained staff. More recently, the 2012 Health Care Reform Act and the 2015 Act to Strengthen Care Provision within SHI sought to strengthen primary care further, with the 2015 reform additionally establishing an innovation fund to support the scaling-up of innovative forms of care delivery. Of these, the 2000 and 2004 reforms can be seen to be pivotal to introducing integrated care approaches in Germany. Specifically, the 2004 reform required SHI funds to allocate 1% of their total income to selective contracts with GP-centred or integrated care networks, and to thus facilitate establishing such networks (Amelung et al. 2012).

Between 2004 and 2008, some 6,400 integrated care contracts were set up under this scheme, covering approximately 4 million insured, with a healthcare expenditure of 811 million Euros (Grothaus 2004). The participation in such schemes was voluntary for both patients and providers. The majority of contracts addressed specific target populations in the field of cardiology, neuro-surgery or emergency orthopaedic care, for example, introducing surgery in the ambulatory setting or other interventions that were previously performed as inpatient care. Only a small number of contracts sought to introduce more sector-wide approaches across the patients′ pathway and even amongst these, the majority only targeted parts of the pathway (e.g. integrating hospital and post-hospital rehabilitation services). Moreover, a large number of contracts were terminated when the start-up financing ran out after 2008. We here report on one model of integrated care, the “Healthy Kinzigtal (HK)”, in operation since 2005 can be seen to be the sole population-based integrated care contract in Germany that provides care across all sectors and disease areas and has been subject to rigorous external evaluation.

69.2 Case Study: Healthy Kinzigtal (HK)

The integrated care contract HK sought to systematically address fragmented service delivery, which was seen to place patients at particular risk of suboptimal outcomes, in particular those with chronic conditions and frail older people. There was a particular perception that care delivery was overly focused on (cost-intensive) services to treat disease and its sequelae, rather than incentivising more cost-effective approaches to prevent them.

The Healthy Kinzigtal model seeks to address these inefficiencies. It is based on the triple aim approach, which seeks to simultaneously pursue three aims: (1) improving the patient´s experience of care (including quality and satisfaction), (2) improving the health of the population and (3) reducing the per capita cost of health care (Berwick et al. 2008). The triple aim approach posits that the three dimensions are not independent of each other and need to be balanced in order to ensure sustainable achievements at the health system level. In line with the triple aim approach, the principal components are (a) the identification of a specific population that is covered by the integrated care system (b) minimising the risk of adverse selection (ideally by a total budget for the population served) and (c) the establishment of an "integrator" who has the know-how and competences to guide the development and implementation of health improvement programmes (McKarthy and Klein 2012). For HK, the triple aim approach was seen to provide a valid conceptual model to guide the design of the interventions targeted at patients, populations and providers, but also to provide a framework for the evaluation studies of the initiative.

69.2.1 Governance and Participation

The population-based integrated care health system is coordinated by Healthy Kinzigtal Ltd, a regional integrated care management company founded in 2005 by the then existing physician network "Medizinisches Qualitätsnetz Kinzigtal" (MQNK) and OptiMedis AG, a German healthcare management company. OptiMedis AG provides the management know-how, investment capacity, public health and health economics knowledge, and state-of-the-art data warehouse and health analytics. Healthy Kinzigtal Ltd is owned two-thirds by MQNK and one-third by OptiMedis AG. Cooperating organisations of Healthy Kinzigtal currently (2020) include 24 general practitioners, 41 specialists, 3 psychotherapists, 7 hospitals, 11 physiotherapists, 10 nursing homes, 5 home care services, 16 pharmacies, 38 sports clubs and associations and 8 gyms. Recently, eight small- and medium-sized companies have joined this network in order to offer classes in health promotion to their 3,500 employees and to reorganise their structure towards a healthy company approach.

69.2.2 The Business Model of Healthy Kinzigtal

The business model of HK has some distinctive characteristics: at its core is a value-oriented population-based shared savings contract (Hildebrandt et al. 2010). This model maintains existing reimbursement schemes and financial flows, but the integrator (Healthy Kinzigtal Ltd) assumes virtual responsibility for the development of the so-called contribution margin. The contribution margin is the difference between the amount the social health insurance company receives from the central health care fund for the expected (risk-adjusted) mean costs of care of all SHI insured and the costs that were actually incurred by their population, adjusted for baseline differences before the start of the intervention. A positive contribution margin is then shared between the insurance companies and the integrator. Another key characteristic of the model is that Healthy Kinzigtal Ltd is financially accountable for all people in the population served, not just for those that are registered members or receive care from physicians that form part of the network. HK thus serves a clearly defined population, works on a global budget and draws on the support of Healthy Kinzigtal Ltd, who—with the support of OptiMedis AG—acts as the regional integrator. The financial goal is thus to increase the insurer´s contribution margin which will provide the stimuli to integrate care delivery and engage all partners in working towards the triple aim (via "shared savings", see Fig. 69.1).

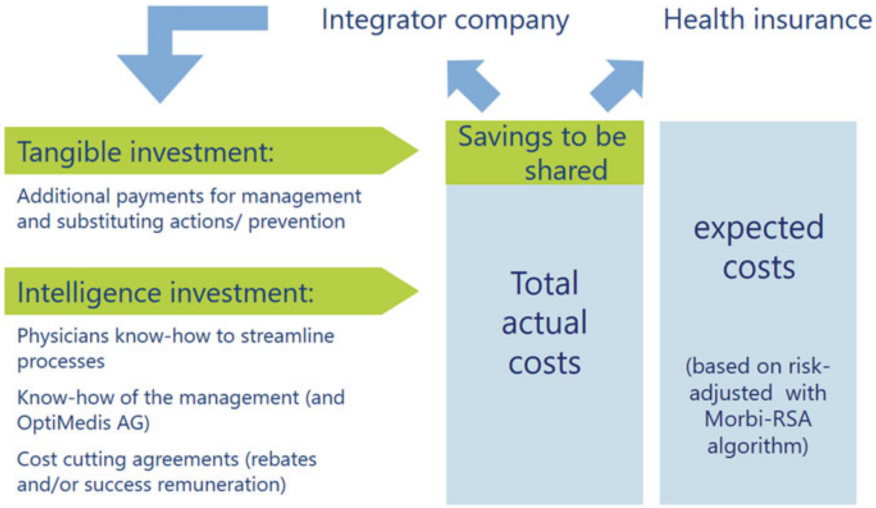


Fig. 69.1 Business model of Healthy Kinzigtal: the shared savings approach. Adapted from: Hildebrandt et al., Gesundes Kinzigtal Integrated Care 2010, p. 6

69.2.3 Coverage and Programmes

The valley of Kinzigtal has about 71,000 inhabitants; of these about 33,000 are members of the regional SHI (AOK-BW), a SHI fund that traditionally insured blue-collar workers and has a less favourable risk pool, while about 1,700 are members of the LKK-BW, a SHI fund for farmers, farm workers and their dependents, which has a similar risk pool as the AOK-BW. By 2015, of those insured by AOK-BW and LKK-BW nearly 10,500 were registered members of Healthy Kinzigtal.

In order to reach the triple aim, a set of activities and programmes were established, which all draw on a common set of underlying features: (a) individual treatment plans and goal-setting agreements between doctors and patients, (b) enhancing patients′ self-management and shared decision-making, (c) care planning based on the Chronic-Care Modell (Barr et al. 2003), patient coaching and follow-up care, (d) providing the right care at the right time and (e) overarching support through the introduction of a system-wide electronic patient record (18). A list of current prevention and health promotion programmes is shown in Box 1.

Box 1 Prevention and Health Promotion Programmes that have been developed so far:

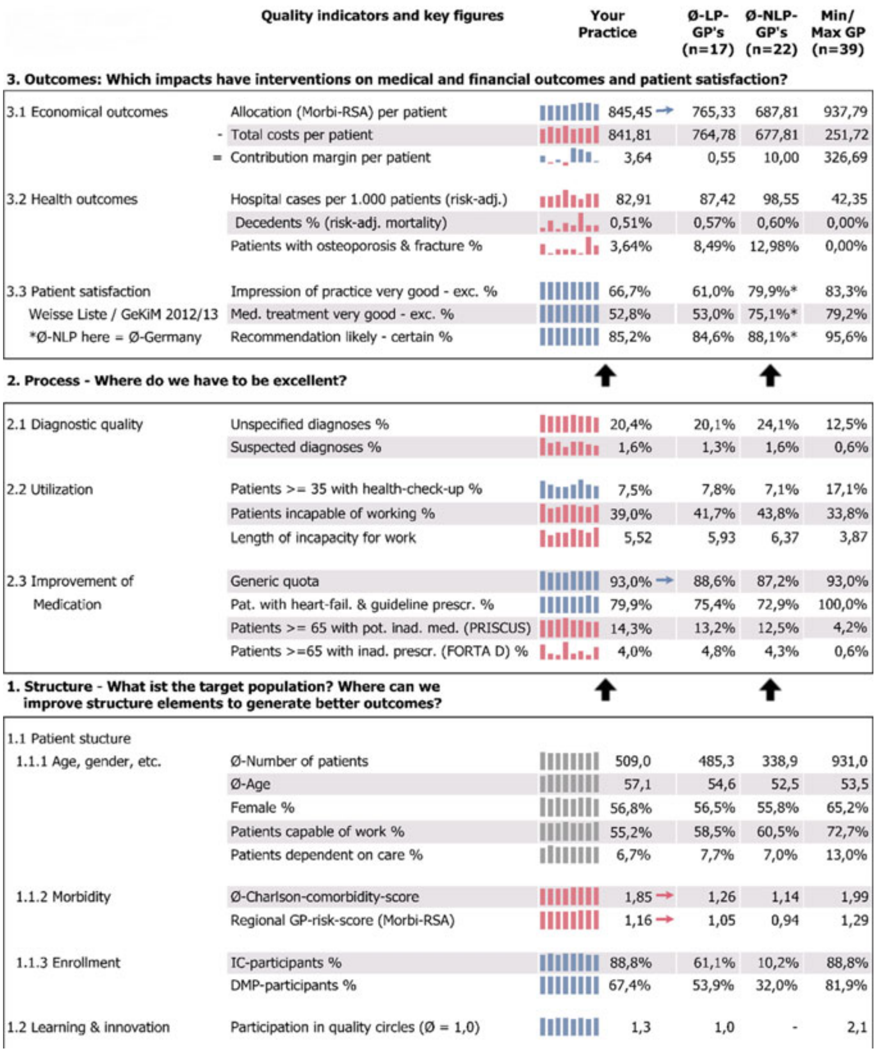
- Strong heart (programme targeting heart failure)
- Healthy weight (for metabolic syndrome, including diabetes)
- Good prospects (care services for children)
- In balance (blood pressure)
- Strong muscles—solid bones (osteoporosis)
- Staying mobile (treating early stage rheumatism)
- Strong support—healthy back (chronic back pain)
- Better mood (depression)
- Good counselling (help, advice and support in critical times)
- Psycho acute (acute psychological issues)
- Disease management programmes
- Smoke-free Kinzigtal (including pre-surgery smoking cessation)
- Social support (to reduce stress where patients are in critical situations)
- Liberating sounds (in tune with music) and
- New: a self-management training programme (based on the Stanford Chronic Disease Self-Management Programme).

While the local planning and implementation of the disease prevention and health promotion programmes are conducted by Healthy Kinzigtal Ltd, OptiMedis AG provides the overarching management support, business intelligence and health data analytics, whereby the data-driven health analytics both propel the planning of health programmes and guide local practice improvements via feedback reports to participating physicians.

An example of the latter is shown in Fig. 69.2, which illustrates a quarterly performance feedback report (dashboard) (Pimperl et al 2013) (Fig. 69.2). These reports are based on a balanced scorecard approach, which uses structure, process and outcome indicators and is designed to be interactive in that it allows users to select indicators to retrieve more detailed information. Some indicators are supported by targeted improvement activities. For example, the dashboard indicates problematic prescription behaviour (e.g. a high proportion of drug prescription according to the PRISCUS or FORTA D classification models for potentially hazardous prescriptions for older people) (Holt et al 2010, Kuhn-Thiel et al 2014). This indicator is supported by two monthly geronto-pharmaceutical consultation meetings for which physicians prepare a patient case report and which discusses potential problems jointly with a pharmacologist to optimise medication regimes. The infrastructure utilised to produce the dashboards has the capacity to integrate and transform multiple data sources (such as claim data, health records, patient survey), to analyse the potential effectiveness of a programme or identify high-risk patients, and provide automated benchmark reports to participating physicians. This business intelligence solution was awarded with the Best Practice Award Business Intelligence by the German Business Application Research Center (BARC). Since then, we have substantially improved our analytical capabilities and applied advanced methodological approaches to assess and improve programme impact and prescription algorithms (Schulte et al 2019).

69.2.4 A Cross-Cutting Theme: People Involvement / Service User Perspective

The patient-centred care approach is paramount to the success of HK and embedded at three levels: at the structural level, in the planning of interventions and in the interactions between physicians and patients. At the structural level, patients are represented in patient advisory boards, which elect their representatives on a biannual basis and are given the opportunity to contribute to identifying and developing new programmes. At the level of intervention planning, there is a strong focus on shared decision-making and self-management support, which is embedded in design and development. At the level of individual interactions of patients with health professionals, patients joining HK first undergo a comprehensive health check (including a self-assessment questionnaire) based on which they may be offered to participate in any of the health promotion and disease prevention programmes offered by HK. Patients are also given the opportunity to develop health-related goals (such as engaging in more exercise, quitting smoking, reducing alcohol consumption or losing weight), which are discussed with the doctor and



	Quality indicators and key figures	Your Practice	Ø-LP-GP's (n=17)	Ø-NLP-GP's (n=22)	Min/Max GP (n=39)
3. Outcomes: Which impacts have interventions on medical and financial outcomes and patient satisfaction?					
3.1 Economical outcomes	Allocation (Morbi-RSA) per patient	845,45 →	765,33	687,81	937,79
-	Total costs per patient	841,81	764,78	677,81	251,72
=	Contribution margin per patient	3,64	0,55	10,00	326,69
3.2 Health outcomes	Hospital cases per 1.000 patients (risk-adj.)	82,91	87,42	98,55	42,35
	Decedents % (risk-adj. mortality)	0,51%	0,57%	0,60%	0,00%
	Patients with osteoporosis & fracture %	3,64%	8,49%	12,98%	0,00%
3.3 Patient satisfaction	Impression of practice very good - exc. %	66,7%	61,0%	79,9%*	83,3%
Weisse Liste / GeKiM 2012/13	Med. treatment very good - exc. %	52,8%	53,0%	75,1%*	79,2%
*Ø-NLP here = Ø-Germany	Recommendation likely - certain %	85,2%	84,6%	88,1%*	95,6%
2. Process - Where do we have to be excellent?		↑		↑	
2.1 Diagnostic quality	Unspecified diagnoses %	20,4%	20,1%	24,1%	12,5%
	Suspected diagnoses %	1,6%	1,3%	1,6%	0,6%
2.2 Utilization	Patients >= 35 with health-check-up %	7,5%	7,8%	7,1%	17,1%
	Patients incapable of working %	39,0%	41,7%	43,8%	33,8%
	Length of incapacity for work	5,52	5,93	6,37	3,87
2.3 Improvement of Medication	Generic quota	93,0% →	88,6%	87,2%	93,0%
	Pat. with heart-fail. & guideline prescr. %	79,9%	75,4%	72,9%	100,0%
	Patients >= 65 with pot. inad. med. (PRISCUS)	14,3%	13,2%	12,5%	4,2%
	Patients >=65 with inad. prescr. (FORTA D) %	4,0%	4,8%	4,3%	0,6%
1. Structure - What ist the target population? Where can we improve structure elements to generate better outcomes?		↑		↑	
1.1 Patient stucture					
1.1.1 Age, gender, etc.	Ø-Number of patients	509,0	485,3	338,9	931,0
	Ø-Age	57,1	54,6	52,5	53,5
	Female %	56,8%	56,5%	55,8%	65,2%
	Patients capable of work %	55,2%	58,5%	60,5%	72,7%
	Patients dependent on care %	6,7%	7,7%	7,0%	13,0%
1.1.2 Morbidity	Ø-Charlson-comorbidity-score	1,85 →	1,26	1,14	1,99
	Regional GP-risk-score (Morbi-RSA)	1,16 →	1,05	0,94	1,29
1.1.3 Enrollment	IC-participants %	88,8%	61,1%	10,2%	88,8%
	DMP-participants %	67,4%	53,9%	32,0%	81,9%
1.2 Learning & innovation	Participation in quality circles (Ø = 1,0)	1,3	1,0	-	2,1

Fig. 69.2 Health services dashboard for a GP practice. Adapted from Pimperl et al., Case Study Gesundes Kinzigtal 2013, p. 27

then monitored over time, accompanied by individual support and participation in patient education and self-care programmes as needed. In order to support the patient-centred care approach, physicians, other health professionals and practice staff are offered training. Underlying all these efforts is an understanding of the patient as a co-producer of their health (Batalden et al 2015).

69.3 Impact

The HK has been subject to rigorous evaluation in order to assess its impacts focusing, in line with the triple aim approach, on improving patient experience, improving population health and reducing per capita costs of care. External evaluations are conducted by independent research institutions, which are coordinated by the "Evaluation-Coordination Function Integrated Care" at the University of Freiburg and include two main evaluation studies: first, a survey of a representative random sample of HK members assessing their perceived health and satisfaction, along with self-reported changes in health behaviours, health-related quality of life and levels of activation, conducted every second year (Siegel and Stößel 2013), and second, an analysis of over-, under- and misuse of health services using routine SHI claims data. This analysis is conducted as a controlled quasi-experimental study comparing the intervention population to a random sample of about 500,000 members of AOK-BW and LKK-BW not resident in the Kinzigtal region (Hildebrandt et al 2015). These evaluation studies are complemented by further research studies, including European Union-funded research projects. In addition, the AOK-BW and OptiMedis AG each conduct internal evaluations of the impact of the HK integrated care system. The financial results are assessed in relation to the development of the contribution margin described above. Key findings of the range of evaluation studies that have been carried out thus far are summarised in Table 69.1.

69.4 Dissemination and Replication

The Health Kinzigtal integrated care contract was initially negotiated for a period of 10 years (2005 to 2015). Renewed in 2016, it now runs, based on the positive evaluations, as an unrestricted contract, thus providing a stable context to pursue long-term health interventions in the region. In addition, an expansion of the model to various other regions in Baden-Württemberg and other parts of Germany is being discussed. Key questions that remain to be answered include the extent to which the positive results of the HK can be attributed to the specifics of the HK region or their population, and how can similar results be achieved elsewhere (Kringos et al 2015a, b)? While all regions will have their idiosyncratic features and particularities, we argue that the general model, interventions and evaluation frameworks are widely applicable. For example, all key aspects of the model are deeply rooted in the scientific literature and in models that have shown to be effective elsewhere, such as the triple aim approach (Whittington et al 2015), the chronic care model (Barr et al 2003), audit and feedback strategies (Ivers et al 2012), the focus on patient activation (Hibbard 2015) or pharmacological consultations to improve the safety of drug prescriptions (Phatak et al 2015). The results of HK are based on and consistent with the scientific literature.

Table 69.1 Selected evaluation findings of impacts of the Health Kinzigtal integrated care system

Triple aim	Method	Result
Improving the patients´ experience of care	• Random, postal survey amongst the insured • Questionnaire with items regarding perceived health, patient satisfaction, changes in health behaviour, health-related quality of life and levels of activation • Participants: 3038 GK members, response rate 23.6% • First assessment in 2012, since then biannual trend study	• Very high levels of overall satisfaction: 92.1% state they would recommend joining Healthy Kinzigtal • Health-related goal setting: 25.1% of risk patients voluntarily agree a goal with their physician in a consultation (which will be tracked in subsequent consultations with the patient) • Positive change in health behaviour: 19.7% state that, overall, they live a healthier life than before joining Healthy Kinzigtal (with 0.4% stating the contrary and 79.9% stating no change) • Amongst insured with an agreed health-related goal 45.4% state they live a healthier life (compared to 0.6% stating the contrary and 54% stating no change, $p > 0.001$) /entry>
Improving the health of the population	• Analysis of routinely available claim data • Controlled quasi-experimental study comparing the intervention population to a random sample of ca 500,000 members of the same SHI, but that are not from the Kinzigtal region • 6 indicators of overuse and 10 indicators of underuse of health services	• Overuse of health services: • Five out of the six indicators demonstrate an improvement compared to control group (prescription of anxiolytics, antibiotics for higher respiratory tract infections, non-steroidal anti-rheumatics, non-recommended prescription for vascular dementia, non-recommended prescription for Alzheimer dementia), one no difference (% avoidable hospitalisation) • Underuse of health services: • 4 indicators demonstrated an improvement compared to the control group (patients with chronic coronary heart disease (CHD) on antiplatelet drugs, CHD patients on statins, acute myocardial infarct (AMI) patients on statins, heart insufficiency patients with cardiology contact), 4 indicators suggest no difference (CHD patients on beta blockers, heart insufficiency patients with indicated medication, diabetes patients with

(continued)

Table 69.1 (continued)

Triple aim	Method	Result
		ophthalmologist contact, diabetes patients with CHD and statins), and 2 indicators suggest a deterioration (AMI patients on beta blockers, osteoporosis patients with indicated therapy)
Reducing the per capita cost of health care	• Calculation of the contribution margin: the differences between the risk-adjusted expected costs for the insured, compared to the actual incurred costs (high-cost cases are winsorised) • Note: the calculation is based on all inhabitants of the region (based on the postcode of residence), and not restricted to GK members from that region	• Positive development of the contribution margin • i.e. the costs for the AOK + LKK insured in the GK postcodes lie 5.613 million € under the morbidity-adjusted expected costs of 75.353 million € • i.e. for every AOK/LKK insured person living in the region, the costs are on average 150€ lower than expected • The incurred costs amongst AOK-BW and LKK-BW insured in Kinzigtal consistently lay below the risk-adjusted expected costs. This difference is expected to further increase in the coming years as some of the health programmes will only start paying off years after the initial intervention

In order to successfully transfer and scale up this model elsewhere, a number of experiences should be taken into consideration. Their relevance may differ depending on the health system context and the organisational model applied, but in HK the following issues proved relevant

- First, a key component of the triple aim model is the role of the "integrator". In our experience, this should be a regionally based organisation, partly owned by local providers, which is familiar with local (health) services issues, plans and delivers local intervention and maintains the communications with all stakeholders. The "integrator" needs to be supported by an organisation capable of providing investments, engaging in negotiations with high-level decision-makers, and of providing advanced health data analytics while at the same time (supported by shareholders) pursuing long-reaching value development instead of short-term profits.
- Second, during the first years, considerable start-up investment is needed to set up the organisational structures, integrate stakeholders and design interventions, which in turn means that appropriate funding has to be ensured for at least three years until income can generate a return-on-investment. This is because of two

types of delay: (a) the time lag between intervention onset and successful health improvements (at least one year) plus (b) the time lag in obtaining the data reflecting such improvements (which often amounts to another year).

- Third, a vision to go beyond traditional institutional boundaries in the planning of health interventions is needed, in particular in the form of interventions that place a focus on improving population health. This competence may not be readily available a priori in existing structures.
- Fourth, the size of the population needs to be appropriate to ensure networking amongst providers, the identification of local solutions and the exchange of ideas amongst all stakeholders. Population sizes smaller than 100,000 appear ideal (assuming the number of stakeholders that can be managed should not exceed 100). While it may be tempting to establish much larger regions, it is unlikely that the local "kit" (a common culture, mental models, mutual understanding of local issues and trust) needed to motivate stakeholders towards a common goal can be easily established.
- Fifth, a comprehensive information technology package (including shared patient records) and competencies for advanced health data analytics to inform intervention planning, feedback reports to providers and internal evaluation are crucial in order to ensure seamless care and monitor performance.
- Sixth, an approach focusing on "coopetition" (a portmanteau of cooperation and competition) through transparency and benchmarking and based on management theory is needed to support the continuous strive towards improvement and to facilitate effective knowledge sharing in cross-functional teams (Ghobadi 2012).
- Seventh, a balanced payment system oriented towards achieving the triple aim which is incorporated in the shared savings approach is needed. This level of accountability which allows providers to make decisions on how cost savings are (re-)invested is an important governing factor supporting regional autonomy. In HK, the majority of these savings are used to reinvest in the population health management strategy, for example, by constructing a new comprehensive health centre (partly supported by the cost savings), by distributing tokens to citizens that can be used to support local entities (such as schools, sports club or church entities) or by providing some additional financial incentives for good performance.
- Eight, in order to have long-term success, both an innovative culture and friendly interactions are essential to harness value from the relationships with all stakeholders.
- And finally, a long-term (10 year) contract with the purchasers is required to provide stability for the planning of health interventions.

Bearing in mind the scientific evidence base underlying the HK experience and considering the nine implementation prerequisites above, we argue that the results from the HK can be successfully transferred and achieved elsewhere, including in regions that are different in population structure and health service organisation. The existence of a stable physician network previous to the set-up of Healthy Kinzigtal Ltd was certainly a factor that facilitated the implementation. Likewise, purchasers willing to share long-term savings and a robust method to monitor costs and quality over time are a qualifying condition. However, of greater importance is that the conditions reflected in the nine prerequisites can (to some extent) be created by the integrator.

Programme expansions are currently being discussed with various regions in Germany (and abroad), taking into consideration the lessons learned in HK. For example, from January 2017 to December 2019 we implemented in collaboration with a physician network a population-based integrated care contract in the borough of Billstedt-Horn of the city of Hamburg (Heinrich et al. 2018). Motivation of the project was on the one hand a high level of deprivation and on the other hand a low density of physician coverage, leading to worse health outcomes and excess healthcare costs. The project was funded by the German Innovation Fund for a three-year period, established the first German healthcare kiosk (a low threshold access point for health education and social/medical referral) and implemented many of the pillars of population health management as described for HK. Since 2020, the project has received financial support from four of the major statutory health insurance companies to extend the work into the future. In 2019, we initiated a third regional integrated care project in the state of Hesse in the west of Germany ("Gesunder Werra-Meissner Kreis"). Here, we extended on the health kiosk function but expanded its scope by training healthcare navigators which can provide health assessments, motivational counselling and referral to appropriate medical and non-medical services. A key aspect of the integrator care project is also to improve health literacy in the general population and to use the power of digital transformation to provide access to health information, health coaching and patient empowerment (Hildebrandt et al 2020).

For the next stage of expansion, we are building on the EU-funded Joint Action on Digitally Enabled, Person-Centred Integrated Care, which is planned to start on 1 October 2020. The Joint Action builds on best European best practice models of integrated care, including the OptiMedis model on population-based integrated care, and aims to transfer the learnings to many other European Member States.

We anticipate a much faster learning curve in additional new regions, bearing in mind that various prerequisites and interventions are ready to scale up, such as quality indicators, evaluation protocols, programme outlines, incentive systems, management guidelines, data warehouse and reporting systems. Ideally, if multiple regions could be set up and implemented simultaneously, that would generate a unique source of data for advanced health analytics to further evaluate the impact of integrated, population health management systems, and moreover, to allow a systematic process evaluation of how the model could be further scaled up nationally and abroad (Ovretveit and Klazinga 2012).

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Case Study Finland, South Karelia Social and Healthcare District, EKSOTE

70

Merja Tepponen and Pentti Itkonen

70.1 Background

In Finland, autonomous municipalities are responsible for almost all social and health services where the local and regional authorities are the main service providers. The 18 regional hospital districts are responsible for the specialized care. The role and significance of decentralized social and health services outside the hospitals have increased.

Also the private sector provides some health and social services and a large number of third sector/ voluntary organizations. The public budget, i.e., tax income, mainly funds the Finnish social and healthcare system and covers the whole population. Although the Social Insurance Institution afterward reimburses the private sector's costs for the client for some part, it is cheaper for patients to choose services provided by public services.

The Ministry of Social Affairs and Health prepares legislation and guides its implementation. As a result of the decentralization and issued demands of efficiency, integration of services has become a fundamental topic. The health, social services and regional government reform include national recommendations (including strategies and legislative framework) that encourage integration (Health and Social services reform 2020). Regarding to ageing policy, services and prevention, Finland has passed an Act on Supporting the Functional Capacity of the Ageing Population and on Social and Health Care Services for elderly people (980/2012; the elderly care act), which came into force in July 1, 2013. In this act, there quite a few tasks listed to organize and ensure prevention and increase wellbeing of the

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older population, i.e., those over 64 years old or older or who are retired, even in younger ages (https://finlex.fi/en/laki/kaannokset/2012/en20120980).

70.1.1 Population

Finland's population is approx. 5.53 million (in 31.12.2018). The biggest change in the demographic structure is aging. The over-65′s is accounted for 20.9% of the population in 2016 (see Table 1). The life expectancy at birth is 78.4 years for men and 84.1 years for women. South Karelia's population was 130.506 in 2016, and GDP per capita was 99 (whole country = 100 as relative value) in 2014. The biggest city in South Karelia is Lappeenranta with population approx. 73.000 (the over-64′s 22.1%).

Finland's population is aging fast, of the total population one in ten is 75 five years old in 2018, but in 2030 already 14%. The fact that people are living longer can be seen as a success story. However, the challenge is: If and when older people are staying more healthier and independent in the oldest age, how can we monitor it?

The main striving policy in Finland has been to ensure that older people can live in their homes as long as possible with the support of home-based services. Of those 75 years old about 91% are living at home and 81% of the 85 years old or older, respectively. The trends in use of services indicate decrease in long-term institutional care but increase in service housing with 24/7 h services available. There is an increase in informal care, also in terms of Foster care for older people, which is still a newcomer in healthcare services.

Service type/ 75 + year-old population (%)					
Year	2010	2015	2016	2017	2018
Living at their own home, %	89.5	90.6	90.9	91.1	-
Support for informal care, %	4.2	4.7	4.7	4.8	4.9
Regular home care, %	11.8	11.8	11.3	11.3	11
Service housing with 24-h assistance for older people, %	5.6	7.1	7.3	7.5	7,0
Care in residential homes or long-term institutional care in health centers, %	4.7	2.1	1.7	1.3	2,0
Foster care of older people (number of people)	*79*	*343*	*456*	*729*	*1155*
- not yet available					
©*THL, Statistics and Indicator Sotkanet.fi 2010–2019*					

The share of health costs in Finland's GNP is 9%, which is less than the average in the OECD. Social and health services account for about 53% of the municipal expenditure.

70.1.2 Social and Healthcare Reform in Finland

At present, the responsibility for organizing health and social services in Finland rests with 310 municipalities, either alone or by forming joint municipal authorities. In addition to the public sector, services are available from various private companies, and the third sector healthcare and social welfare organisations who all play a major role in the provision of services that supplement public services. Organizations provide services both free of charge and paid. The resources that municipalities have for organising these services vary considerably. The objective of providing people with equal access to services is not currently realized. Both differences between population groups and regional differences have increased, which is reflected as inequalities in health and wellbeing. Finland's population is aging and will need more services than previously. At the same time, the birth rate is declining and the dependency ratio is changing. Finland will need a health and social services structure that will be able to respond to these changes.

Studies indicate that larger organizers of health care and social welfare are better able to secure the equal availability of services as well as efficient operations and administration.

According to the government's reform plan 2020–2023, healthcare and social services including long-term care will be transferred to counties that are larger than municipalities. Social welfare and healthcare services will be combined at all levels to meet these objectives. The aim is to create seamless service chains for the provision of key social welfare and healthcare services. Because of more effective services, the reform is expected to stop cost expansion (Health and Social Services Reform 2020).

The reform will shift the responsibility for organising health and social services and rescue services from the local government level (municipalities) to the regional government level (22 social and healthcare counties). After the reform, the public administration in Finland will be organized at three levels: state, counties and municipalities. The counties will be responsible for arranging all public social welfare and healthcare services, and the decisions will be made by elected county councils. Initially, the funding of the counties, which will now be established, will principally be based on central government funding. The funding system for health and social services will be reformed and be based on needs-based standardised criteria. The right of counties to levy taxes will be examined in a parliamentary process.

The administrative structure will be reformed to ensure that wellbeing can be guaranteed in Finland in the coming decades. The counties will produce services predominantly as public services. Private sector actors and the third sector will supplement these. Municipalities will continue to be responsible for promoting health and wellbeing. Day care, teaching, schools, physical activity and culture will remain the responsibility of the municipalities. The objective of Finland's health and social services reform is to ensure that everyone in Finland has equal access to high-quality health and social services. The reform will develop healthcare and social welfare services and reorganize their structure. Basic public services and preventive work will be strengthened. Healthcare and social welfare structures will be reformed to ensure the equal availability of services throughout Finland. The preparations for the legislative work have started in autumn 2019. The government's draft of laws on social and health care and rescue reform went for a round of opinions in June 2020. The aim is that the Sote counties election is to be held in January 23, 2020, with the term of office of the council starting in the beginning of March 2022. Responsibility for organizing and service provision would begin 1.1.2023 (Health and Social Services Reform 2020).

70.2 South Karelia Social and Healthcare District EKSOTE

South Karelia Social and Healthcare District EKSOTE was established on the voluntary bases in 2008. All nine municipalities in the regions made a political decision to handover their social and healthcare services to a joint municipal federation called EKSOTE. After the reorganization of all social and healthcare services was finalized, EKSOTE became responsible for all social and healthcare services in the region in the beginning of 2010. This means that EKSOTE is a vertically and horizontally integrated social- and healthcare organization from the acute care to whole way to the homecare. EKSOTE has carried out social and healthcare reform in the past, and in the future South Karelia (EKSOTE) will be one of the 22 counties mentioned in the social and healthcare reform.

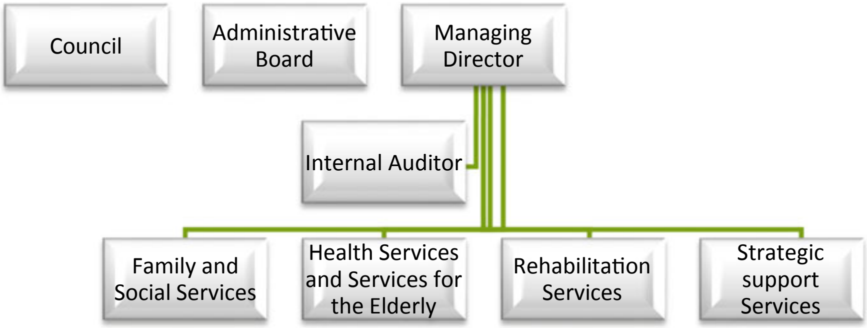
The political decisions in EKSOTE are made in the council where every municipality sends its own representatives. The county elects the board for the operational decision making.

EKSOTE is an entity to hold the whole population budget about 550 M€ having one regional management system and direct management relationships to all services provided. EKSOTE makes contracts with every nine local municipalities, and in these contracts, the number of services as well as financial details is agreed. EKSOTE also has contracts of service provision with some private companies mainly in housing services for elderly people. The local municipalities pay EKSOTE monthly a fixed sum, and EKSOTE the municipal federation has no right to ask more money over this sum. If these financial assets are not enough, it means deficit in EKSOTE`s book keeping.

70.2.1 EKSOTE’s Organization Chart

EKSOTE’s organization includes Council, Administrative Board and Divisions, Auditing Committee, Advisory Board of municipality managers and different levels of Areas of Responsibility of Services (see Picture 1).

The Council is the highest decision-making power in EKSOTE. Municipal councils of the participating municipalities appoint members to the Council for the duration of their term in the office-based on the population of the municipality. The



Picture 1 EKSOTE's Organization Chart (at the beginning of 2020)

council's tasks include appointing the administrative board, auditing committee, and managing director of EKSOTE and approving the rules of procedure, financial statement, budget, and financial plan. As the administrative board manages EKSOTE's operations, the Managing Director is responsible for EKSOTE's operative management. The Managing Director is supported by the committee of municipality managers, particularly in relations to planning of the financial operational conditions of the joint authority.

The EKSOTE Council has confirmed the following **Areas of Responsibility**:

- Family Services and Social Services
- Health Services and Services for the Elderly
- Rehabilitation Services
- Strategic-related Support Services

The Areas of Responsibility are divided into divisions confirmed by administrative board:

- Family Services, Social welfare and Mental Services for Adults, Special Services for the Disabled
- Primary Health Care, Acute Hospital, Care
- Leadership and Management-related Support and Development-related Support Services.

The services produced by EKSOTE include outpatient care, oral healthcare, mental healthcare and substance abuse services, laboratory and imaging examination services, medicinal care, rehabilitation services, hospital services, family services, and social services for adults, special services for the disabled, and flexible services for the elderly that are adaptable to the needs and age structure of the population.

The EKSOTE region has a common client and patient records system and a common follow-up system of all services with use of AI. The following examples will include a description how EKSOTE as joint municipal federation uses evidence in steering and following-up service providers and clients. Furthermore, they provide insights on the process of discussing and negotiating with older population and service users in planning and evaluating services on the region. It will also include how the benchmarking with RAI system is working in a local level.

70.3 Examples of Integrated Service

70.3.1 Low-Threshold Services

EKSOTE's network places a high priority on assessing service needs and on providing advisory and instructional services. Evaluation of patients must take place 24/7 in order to avoid unnecessary hospitalizing of patients. Assessing the need for services is also an important part of the work of low-threshold service centers. The mental health and evaluation clinic is open for adults 24 h a day, 7 days a week. The special unit for children and young people provides psychosocial services during normal office hours without ques. The "Iso Apu" service center brings together EKSOTE district's social services and advisory and instructional services relating to care of the elderly and the disabled under one roof. The hospitals are able to discharge patients sooner through electronic services and light service options, without compromising patient safety and sense of security. Furthermore, services like telemonitoring and health coaching have been shown to suit, for example, for persons having diabetes two (Karhula et al. 2015).

70.3.2 Rehabilitative Home Care

The holistic service need assessment takes place in elderly person's home. It is done on the basis of common criteria. There are several ways to measure one's performance and need of assistance. Indicators used in EKSOTE are Mini-Mental Sate Examination (MMSE), Geriatric Depression Scale (GDS-15), Alcohol Use Disorders Identification Test (AUDIT) and, for example, test for nutrition. In home rehabilitation, multidisciplinary interventions are not separated physical training programs, but they concentrate more on practicing everyday-life functioning with the help of all the professionals that visit the customer. This way, independent living and participation are supported. In EKSOTE area, only 5.6% of elderly over 75 years are in long-term care outside their own homes. Finnish Ministry of Social Affairs and Health recommendation is 8–9%. There are more physiotherapists and occupational therapists in home rehabilitation than in other public social or healthcare actors in Finland. By dissembling institutional care and putting resources to rehabilitation, EKSOTE has succeeded in cutting down expenses in elderly care (Soukkio et al 2020).

70.3.3 Mobile Services by Car (Mallu and Malla)

In EKSOTE, new kinds of flexible, customer-oriented service models are innovated and developed continuously. Mobile laboratory unit called Malla and a clinic van called Mallu support the operation of the wellbeing centers and low threshold service centers. This mobility and flexibility are especially useful for people living in remote areas ensuring them equal access to services.

Mobile clinic van Mallu provides nurse and oral health services. While parking at the day care center, school or sheltered accommodation for the elderly, Mallu gives preventive oral care there. On nurse service day, Mallu follows a scheduled route with appointed stops around the region.

Mobile laboratory unit Malla provides basic laboratory services such as blood tests and EKG. Malla also provides specialized multi-professional services for the unemployed provided by Labour Force Services Centre. Both Mallu and Malla vans serve as well during influenza vaccination campaigns (Eksote, Malla 2020a, 2020b; Tepponen and Heiskanen 2012).

70.3.4 Emergency Services (ER) in Your Living Room, Stand-by Urgent Care at Home

The ER in Your Livingroom project delivers a new model of service, where paramedical nurses don’t just treat acute events, but support other professionals by offering evaluation, examination, medications and procedures 24/7, outside the hospital where and when needed to enable citizen to live and function better at home (we call this model “Stand-by urgent care”). So, there is usually no need for transporting them to the emergency department and people don’t have to wait at the hospital emergency room.

The requirement for the implementation of the new acute care model was the improvement of the know-how of the paramedical staff. In Finland, the first paramedical nurses graduated with the double degree after a four-year education in 2002. This started the development of paramedical care into the service structure of health care. Now almost all staff members of ambulances are paramedic nurses. This has enabled much broader use of paramedics in the patient’s chain of services. It’s not effective or optimized use of resources or neither customer friendly to transport patients to the hospitals. Over forty per cent of all the interventions in EKSOTE’s ambulance service are evaluated and treated at the scene (Tepponen et al. 2017, Tepponen 2018).

Mobile paramedical evaluation and care units provide flexible evaluation of patients including need analysis of care and other services. Nurses are able to do procedures, medications, examinations and advanced point of care based on a physician’s consultation, general guidelines and wider variety of point of care diagnostics. The professionals are additionally trained to the acute hospital and intensive home nursing procedures. Consulted physicians can write an electronic prescription that patients can get straight from a pharmacy. Furthermore, when needed, the unit is able to reserve a doctor's appointment to primary care or to psychosocial services or to reserve a multidisciplinary assessment for the need of service (Tepponen et al. 2017, Tepponen 2018).

EKSOTE's intensive home care nursing units provide hospital services to living rooms, thereby present an incremental part of the stand-by urgent care unit. Specialized nurses give short-term care: medications, wound care, take care of, for example, PEG, tracheostomy, and cystofix catheters. Nurses in intensive home nursing also dispense palliative care and home hospice. With the, Stand-by urgent care EKSOTE has been able to avoid unnecessary visits to hospital and optimize releasing patient from the hospital (Tepponen et al. 2017, Tepponen 2018).

70.3.5 Coordination

There are more and more aged citizens who require multidisciplinary assistance and care. It is harder than before to get the overall picture of customers' needs and possibilities of the service system. Moreover, if the customer can't connect with the professional fast and easy way around the clock, it produces insecurity and weakens confidence to the service system. At the same time, patients and relative caregivers are raised to the center of the service processes by giving them more freedom of choice and responsibility of the care and social conditions. The goal is to involve patient´s relatives to participate and to reduce unnecessary concern.

To manage service processes outside the hospitals, all professionals must have the identical real-time patient information system, identical situational awareness and knowledge of service system's resources and service delivery options. All professionals must have information and knowledge that ensures value provision to the processes and patients. Information must be at hand quickly and collectively making evaluation and estimation of situations more comprehensive. The customer itself owns the service process and the data concerning his/her health and wellbeing. So, the data must be visible to the customer anytime.

In EKSOTE, all these requirements are combined into the role of special coordinator. With the help of this e coordinator, human resources outside the hospital can be managed and fitted to the needs of the clients. The coordinator role improves the utilization of different professionals. The coordinator can also monitor home safety technology, bio-signals and other devices placed in the home of the clients.

The healthcare service structure changes from centralized and "inter-hospital" to decentralized, preventive and customer oriented. Every encounter, regardless of service channel, demands comprehensive information, evaluation, coordination and cooperation (Tepponen et al. 2017).

70.3.6 Measurement of Health Outcomes and Social Services

One of the greatest demands across managers, politicians and providers is establishing common objectives and new ways to measure performance. All are attempting to overcome the disincentives in current payment mechanisms only to controlling costs. We need to consider new financial rewards or penalties to motivate new kind of performance to avoid hospital admissions and avoid using other social services.

In response to the failure of traditional methods for controlling only costs, the experience in EKSOTE is improving value by evaluating well-defined patient outcomes against treatment costs. This means that healthcare systems and their management practices ought to provide contested information about the ways how to perform more efficiently and how to perform better in terms of citizen-driven wellbeing models aiming at a systemic change in the field of health. This is due to the fact that putting more financial resources into the health systems do not necessarily enhance health at population level.

One of the key issues is the systematic measurement of health outcomes by disease, procedure or segment of the population. The systematic collection of detailed information on health outcomes makes it possible to identify variations in outcomes across clinical sites, analyze the root causes of those variations and codify best practices.

Outcomes must be measured over the full cycle of service system not separately for each intervention. Outcomes of service system are inherently multidimensional, including not only health outcomes but also the connections to social services like the degree of income support, unemployment or the degree of children in institutional care. It is possible to investigate weather investing in preventive care in order to avoid higher treatment costs at later points in value chain. The model allows closer linkages between primary and secondary care, social and wellbeing services and more integrated action pathways for patients. In practice, this means for example to invest more in home rehabilitation to keep patients in a good condition and then have less service needs in other parts of the pathway. The other example is to invest in a new kind of emergency care model to avoid patient transportation to emergency room services.

The measurement is possible to implement especially in Finland and in EKSOTE because every Finnish resident has a personal identity code. This means that the measuring system has unique personal identifiers to link multiple sources of data, such as episodes of care, visits to doctor or expert nurse, visits to emergency room services, labor input and compensation that currently exists in multiple databases. The possibility of linking the various data sets in this fashion has the potential for creating a holistic view of outcomes and system costs, both direct and indirect, across the entire care-delivery pathway.

In practice, it is possible to form different patient/customer groups (diabetes, asthma, blood pressure, mental disorders etc.) and then follow what happens to these customers after the treatment or service. It is possible to follow if the customers come back to other services or where they are after certain period of time. Also following questions have answers:

- What is the service utilization (and costs) of different customer groups and are there any changes?
- How the customer groups care/service pathways have gone (processes)?
- How the customer groups mortality, performance (or quality of life) have developed?
- Aid in decision making: What are the options and what are the effects (to customer and costs) on longer term.

70.3.7 Reimbursement System

As well as setting new objectives, we need to make substantial changes to payment systems to develop financial incentives to support having agreed social and health outcomes. Today all service providers are paid for activity to provide more services. This means that they cannot expect any additional funding if they treat less patients. No part of the system benefits financially if it keeps more people out of social and healthcare services. That is why the system should be based on an out-of-service model.

We need to have reimbursement system to bear operational risks that might better sit with providers—for example, the costs of avoidable hospital admissions or children being to institutional care outside their homes. The payment scheme of care need to be two-folded. The providers receive an upside payment if they make improvements such as reducing admissions or having less social contacts but they also receive a downside penalty if they allow admissions or social problems to rise.

Once health and outcomes are tracked systematically and care is integrated around specific patient groups and medical conditions, a health system is in position to develop meaningful value-based incentives on the basis of accurate measurement of outcomes and system costs. Determining the most appropriate incentives—for example, assessing whether reimbursement should be based on capitation, bundled payments, or some other mechanism—will depend in large part on specific disease or condition. The underlying principle is however to orient competition among providers around value, creating an alignment in which those providers that deliver high value care are rewarded. The shift from producer-oriented model to customer-oriented means that the unit of analysis must be the regional ecosystem gets the value, not the single service provider. Social and healthcare need a reimbursement system that aligns everyone's interests around improving value for patients. Reimbursement must move to single-bundled payments covering the entire cycle of care for a medical condition and social needs including all providers and services. Bundled payments will shift the focus to restoring and maintaining health, providing a mix of services that optimizes outcomes, and reorganizing care into integrated practice structures. For chronic conditions, bundled payments should cover extended periods of care and include responsibility for evaluating and addressing complications. EKSOTE is a national pilot for testing bundled payment or package prizing reimbursement model on the basis of clinically defined episodes of care or services. All this makes it possible to continue and create more specialized and efficient models around value for patients (Klemola 2015, Korpela et al. 2012, Sote-tietopaketit 2018).

70.3.8 Digitalization

Many countries and governments are currently trying to adapt themselves to digitalization which is one of the most important megatrends just now going very strongly forward. Traditional arguments to integrate acute hospitals, primary-care settings and social wellbeing services have centered around better co-ordination in political decision-making and strategy management, financing, ICT and estate investments, common use and recruitment of staff, and sharing other resources in new ways. These arguments were also relevant when the South Karelia Social and Healthcare District in Finland was established. Although these arguments and progress have been important as such, costs are still rising strongly especially in caring for elderly people. We need to understand that we cannot solve this issue only by adding new human resources and building new hospitals and housing facilities.

As regard to technology, in many countries we're still in the development phase, where workers are searching patient and customer data from different data sources. In spite of long period of development, the workers are still bound to the system and pretty far from the autonomy of work where the systems release workers to use independently their education, knowledge and skills. To use data as data gives only limited added value to working processes and the individual workers cannot see data as a service. To develop simple browsing algorithms is the first phase to move to artificial intelligence in social and healthcare working patter.

South Karelia district is facing challenges in health care in the near future as the age structure is changing and the number of elderly is increasing. Simultaneously, fewer professionals are available for employment, and therefore, an extensive cooperation between the third-sector organizations is needed. Solutions to meet the forthcoming challenges require goal-oriented activities to achieve common visions. EKSOTE is organizing a large number of activities in cooperation with volunteers, the municipalities, the third-sector organizations, regional operating networks such as diverse associations and congregations.

As mentioned earlier, one of the most important reasons to create integrated frameworks in social and healthcare is to find such models that can prevent hospital admissions and as a result only those patients go to the hospital who really benefit the hospital care. Hospitals will have a vital role in the care also of the elderly but in the future they are seen more as one part of the system because the largest cost savings resulting the fact that hospitals will have fewer patients. All professionals need to rethink where they perform their role to minimize the pressure to hospitals and maximize the effective use or alternative facilities which run at lower costs and exploit the whole potential of technology. It is important to realize that we cannot solve the forthcoming financial crises only by adding new human resources and building new hospitals and housing facilities.

In concrete, this means to predict diseases at population level, personalize treatment by customizing treatment workflows, prevent adverse events like hospital admissions and readmissions, manage outcomes and measure values instead of volumes.

The first experiences to implement e-services and artificial intelligence in social and healthcare indicates that especially the medical establishment will demand a rigorous proof of concept before taking these solutions into use in their daily work. The mystic artificial intelligence including independent and inhumane creativity and social skills form the basis of media hype and myths about these systems. We all accept that in the future, the machines will take over tasks, but it will take a long time before they will take entire jobs (Chen 2019, Itkonen 2019a; b).

70.4 Examples

70.4.1 The Smart Assessment of Service Need

The RAI system (Resident Assessment Instrument) is a standardized data collection and observation tool designed to assess the service needs of an elderly or disabled customer and to develop a treatment, rehabilitation, and service plan. The abbreviation RAI stands for Resident Assessment Instrument.

RAI tools are uniform in substance in all countries where RAI is used. Some evaluation questions, such as those related to the service system, may vary from one national version to another. It is also possible to add issues of national importance to the versions.

Evaluation forms and manuals are available on the extranet for RAI participating organizations.

The RAI system consists of customer evaluation tools designed for different applications and different target groups.

In Finland, the Ministry of Social Affairs and Health has made a proposal for the Parliament that inter-RAI system must be used by law to do the assessment of care and clarify the functional ability of elderly people.

Smart assessment of care in housing means that the artificial intelligence can help to find the right form for housing while the functional capacity is changing. Also what is the best and most suitable form for services and how much they need resources and what kind of resources and how you can predict these changes.

From the technology point of view, this assessment process must include also the assessment of suitable technology considering the functional ability of the customer and the who is responsible to purchase the suitable devices and where is the help desk for the customer (Itkonen 2019a, THL 2020).

70.4.2 Smart Home

Already for many years, it has been possible to install different sensors and microchips to measure, monitor and scan different bio-signals of your body and organ functions. In the same way, it has been possible to install microchips to alarm if there are deviations or functional failures in the building where you are living. In addition, it is also possible to have different kind of data from your living environment for instance traffic, weather conditions and climate.

These kind of measuring and self-care possibilities have increased and followed the development of technology. Because the variety of different possibilities in measuring and scanning is almost unlimited, it is very important to pay attention to national requirements to ensure the credibility, safety, efficiency, usability, compatibility and interoperability. If the data is documented by the customers themselves, it is very challenging to transfer this data from different systems to the use of professionals. There is not much benefits to invest in different separated and scattered sensors and alarms if you cannot modify and transfer the data at national or at regional service. If every individual need to have a wristband to follow the huge amount of scattered data, it is not cost effective.

That is why the first implementations should be done very carefully in low risky processes where the mistakes and errors are not fatal. If the machine makes a fatal mistake, the attitudes turn more and more against the reforms and it is more difficult to continue AI projects. Low-risky processes exist especially in the inquiries of different test results and changes in booking times. Also in the assessment of service need in elderly care and in the processes to grant social benefits (Nordic Welfare Center 2017, Tepponen et al. 2017, STM 2018).

70.4.3 Speech and Voice Recognition

Currently, many new innovations in speech and voice recognition have resulted in widespread deployments of such solutions that can identify words and phrases in spoken language. The major advance has been the development of software that can understand, recognize and engage in voice interactions. They can do a variety of simple and complicated tasks; later, they can improve their intelligence with machine learning capabilities or apps with training features, they can be dedicated to specific functions and they have a sociability component and can be a virtual pal or front-end knowledgeable contact.

By using only parts of these new phone services, each social and healthcare provider could save a great number of person-years and use them to benefit the patients and customers. But these benefits do not come without consequences (European commission 2020).

All stakeholders will benefit from speech recognition and interactive voice-assisted services which can re-engineer the processes and improve the customer's experience when contacting the social and healthcare professionals in a new way. But providers also need to manage the impact of the potential unlimited volume of issues and requests for service that smart workflow systems operating on a 24/7 basis could generate. On the other hand, these systems can collect user- and machine-generated data that can be used to save hours of work that previously required layers of time-consuming activities, keystrokes and human participants. As a result, smart workflows and seeing data as a service will reduce contacts to social and healthcare professionals and can help them to work more effectively with patients in acute need for help (European commission 2020).

70.5 Conclusion

The long period of time to wait the social and healthcare reform in Finland only to find the administrative framework which is suitable from the constitution point of view has meant that the actual content to development of the system has retarded. The first initial model is already under a hard debate in Finland, and the government will have a lot of work to pass the Parliament during this year as they have said.

All this have meant, i.e., that at the moment social and healthcare is using new technology to automate current and inefficient structures and that is why they are all the time adding human resources and building new housing facilities.

Integration itself is not enough. To achieve real results from integrated settings, big changes inside the integration are needed. The examples in this article are only the first short steps to move toward real benefits of integration.

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Ireland Case Study

71

Áine Carroll and P. J. Harnett

71.1 Introduction

Ireland is an island situated in the North Atlantic Ocean. It is separated from Great Britain to the east by the North Channel, the Irish Sea, and St George's Channel. The Republic of Ireland, Éire, comprises the southern four-fifths of Ireland, Northern Ireland being part of the UK.

The Census of 2016 showed that Ireland's population stood at 4,761,865 in April 2016, an increase of 173,613 (3.8%) since April 2011 (Office 2016) (Fig. 71.1).

Historically, the Irish health system has been considered a Beveridge-type model of healthcare provision. In reality, the situation is more complex, and funding and provision is more akin to a mixed system. Although 45% of the population have private health insurance, this only contributes 15% to the overall health budget (Burke et al. 2018). Overall responsibility for the health and social care system lies with the government, exercised through the Department of Health, under the direction of the Minister of Health. The original design for the modern Irish healthcare system was set out in the Health Act 1970, which established eight Regional Health Boards (RHBs). These were population-based and shifted responsibility from the local authorities to the Department of Health (DoH) for the development and implementation of health policy. These boards became the main providers of health and personal social services through three core programmes:

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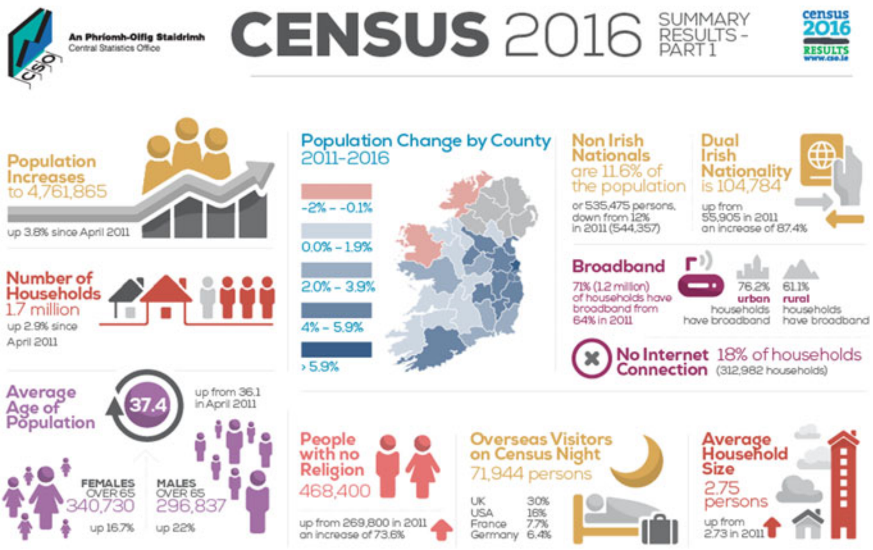


Fig. 71.1 Summary results census 2016 CSO Ireland (Office2016, 2017)

general hospitals, specialist hospitals, and community care programmes. In 2000, the Eastern Health Board was replaced with three new Health Boards. Then, opinion moved away from the decentralised RHB model with increased interest in the development of more centralised national structures. In 2003, in response to a number of significant healthcare scandals, three government commissioned reports (Hanly, Prospectus and Brennan) (Hanly 2003; Management et al. 2003; Worldwide 2003) were published. These reports were highly critical of the regional boards and recommended a more centralised accountable system. This ultimately led to the creation of a single national body, the Health Services Executive (HSE) in 2005. Government allocated funding to the HSE each year and agreed a service plan with the Health Service Executive that set out the quantum and nature of services to be provided.

The new national structure, however, failed to restore trust in the Irish healthcare system, and there was further restructuring with the establishment of Hospital Groups and Community Healthcare Organisations in the mid-2010s (Higgins 2013; HSE 2014).

The latest policy document is the 2017 report of the All-Party Oireachtas Committee on the Future of Healthcare, the Sláintecare Report (Committee 2017). This report sets out a vision for the future of healthcare over a ten-year period to deliver whole-system reforms and a universal single-tier health and social care system. Its reforms centre on health promotion and disease prevention, eligibility, expansion of primary and community services and the funding of health and social care in Ireland into the future.

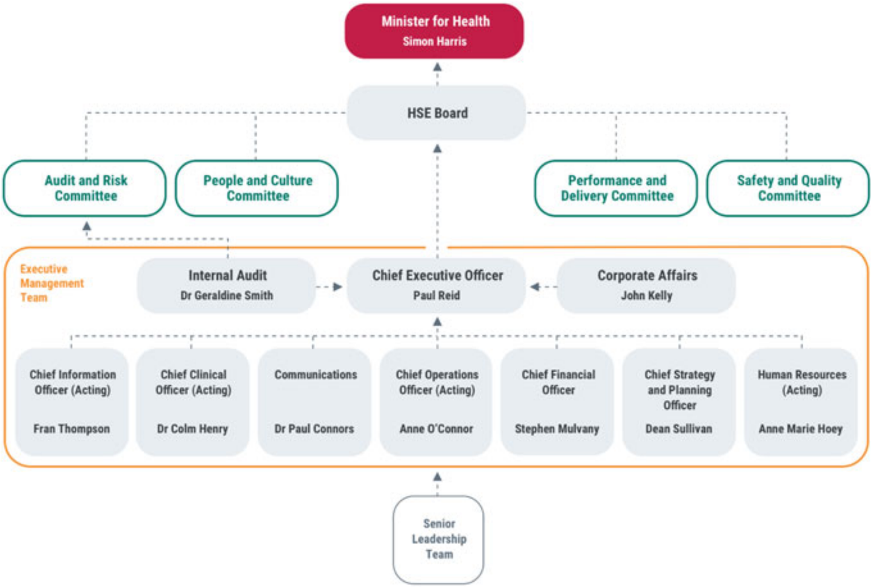


Fig. 71.2 Organisational structure of the HSE 2020

In response to the Sláintecare Report, the Government approved the Sláintecare Implementation Strategy in July of 2018. Towards the end of 2018 and into 2019, the Sláintecare Programme Implementation Office (SPIO) in the DoH further developed and refined the implementation strategy document into the Sláintecare Action Plan 2019 which outlined key areas of focus for the first full year of Sláintecare implementation.

It did this under four workstreams:

1. Service Redesign and Supporting Infrastructure
2. Safe Care, Co-ordinated Governance and Value for Money
3. Teams of the Future
4. Sharing Progress.

Each workstream consists of five main programmes made up of 137 projects in total.

Key reforms included the establishment of the HSE Board (current organisational structure shown in Fig. 71.2), the development of Regional Integrated Care Organisations and an emphasis on integrated care.

It should be noted, however, that many of these reforms were already in train prior to the launch of the report.

71.2 Integrated Care in Ireland

71.2.1 Health of the Nation

According to CSO figures, the greatest change in population structure over the last 10 years has been the growth in both the proportion and the number of people aged 65 years and over. The number of people aged 65 years and over has increased by 35% since 2009, which is considerably higher that the European Union (EU) average of 16% over the same period. This growth is thought to be due to good public health policy, medical innovations, enhanced treatments, and improved lifestyles.

Many people living in Ireland and their families are affected by chronic diseases and activity limitations and participation restrictions due to poor diet, smoking, alcohol misuse and physical inactivity. The prevalence of chronic conditions is strongly influenced by socio-economic status, levels of education, employment and housing (Balanda et al. 2010). In response to these figures, in 2013, the government launched Healthy Ireland, a government-led initiative aimed at improving the health and wellbeing of everyone living in Ireland.

71.2.2 The HSE National Clinical Programmes

In 2009, as part of the HSE Transformation Programme 2007–2010 (Drumm 2006), The Quality and Clinical Care Division was established. This was subsequently divided into the Quality and patient safety Division and Clinical Strategy and Programmes Division (CSPD). CSPDs' strategic role was to develop a national, strategic, and coordinated approach for the design of clinical service improvements to deliver improved patient care, improved access, and better use of resources. The Division was responsible to the Director General of the HSE, who was in turn accountable to the Secretary General of the Department of Health. National Clinical Programmes (NCPs) were agreed, scoped, and resourced under the remit of the CSPD and reported to that Division on their deliverables via the respective National Clinical Leads.

CSPD's role was to improve the patient experience and quality of care through the design of standardised models of care throughout the healthcare system by bringing together clinical and management disciplines and enabling them to share innovative solutions to deliver greater benefits to every user of our health services. This was achieved by designing and specifying standardised models of care, guidelines, pathways, and associate strategies for the delivery of evidence-based integrated clinical and social care. The implementation of these strategies was outside the scope of the NCPs, although the programmes provided clinical leadership to support local implementation where needed.

The first phase of NCPs was based around developing excellence in individual specialties, specific diseases and stages of care, such as acute medicine and elective surgery and were instrumental in driving improvements in clinical care in Ireland

(Committee 2011; McElwaine et al. 2016; McHugh et al. 2015; Lang 2017; Flynn 2017; Smyth 2017).

Although the approach to achievement of the goals was at the discretion of each individual programme, common aspects across the programmes included: (1) a defined governance structure, (2) detailed description of how cost savings would be made, (3) development of care pathways and models of care, and (4) emphasis on measuring success based on metrics. Each programme had a governance structure involving the HSE, the professional body and clinicians. A Clinical Advisory Group (CAG) consisting of a diverse group of clinicians in the relevant specialty/s was appointed by the professional body and a National Clinical Lead. The CAG provided clinical strategic planning and direction, reviewed, and agreed practice guidelines and models of care and supported and facilitated the implementation of the nationally agreed model of the programmes. In addition, each programme had a National Programme Manager, Regional Clinical Leads and a Multidisciplinary Working Group established to support the implementation of the work of the programme locally. The NCPs were supported by a professional Diploma in Quality Improvement in association with the Royal College of Physicians of Ireland. Many of the national clinical leads of the NCPs undertook the diploma along with key members of their clinical and management teams. Part of the emphasis within the diploma and in the NCPs was on standardisation as an element of quality improvement.

The adoption of the NCPs coincided with a profoundly challenging period for the Irish economy and consequently for publicly funded health services. Significant funding and staffing cuts were imposed on the Irish health system in 2009. Despite this, however, evidence from several quality metrics indicated that services were maintained or enhanced despite the cuts. Nevertheless, after 3 years, despite the improvements indicated above, there was clear recognition that the desired outcome of nationalising best practice and achieving whole system change had not been achieved. To inform the next phase of the programmes, a series of multi-stakeholder engagement world café events were held to assess the challenges that had been experienced by the programmes and co-design the next steps.

71.2.3 The National Integrated Care Programmes

In November 2012, the Department of Health issued Future Health: A Strategic Framework for Reform of the Health Service 2012–2015 (Health 2012). Future Health stated that ‘The current hospital-centric model of care cannot deliver the quality of care required by our people at a price which the country can afford. For this reason, the Government is determined to create a new integrated model of care that treats patients at the lowest level of complexity that is safe, timely, efficient, and as close to home as possible. The aim of increasing integration is consistent with initiatives in other countries that seek to shift the emphasis from episodic reactive care to care based on needs which is evaluated as to its impact on outcomes.’

To best meet the recommendations set out in Future Health CSPD reformed to position itself as the Clinical Design Authority, building and incorporating the NCPs and established the National Integrated Care Programmes (ICPs) to enable the delivery of integrated models of care in Ireland. CSPD in partnership with the operational divisions within the HSE identified an initial five ICPs, which met defined principles of an ICP.

The ICPs were established on a phased basis and were as follows:

1. Integrated Care Programme for Patient Flow
2. Integrated Care Programme for Older People
3. Integrated Care Programme for the prevention and management of Chronic Disease
4. Integrated Care Programme for Children
5. Integrated Care Programme for Maternity.

These ICPs sought to work in partnership with the existing clinical programmes and other key enablers such as Finance, Human Resources, and ICT to ensure that they were aligned and could support the delivery of seamless patient-centric services.

The agreed working definition of an Integrated Care Programme was one which outlined a framework for the management and delivery of health services which ensure that patients receive a continuum for preventative, diagnostic, care and support services, according to their needs over time and across different levels of the health system. The supporting models of Care would be incorporated cross service, multi-disciplinary care and support which would facilitate the maintenance of health and the delivery of appropriate high quality, evidence-based care, delivered in a coordinated manner which feels seamless to the user. The ICPs would be underpinned by proactive management of interfaces between stakeholders to reduce barriers to integration and allows for cohesive care provision across a continuum of services.

The following principles were developed to help identify potential ICPs:

- Disease or condition that currently affects a significant population.
- Potential to reduce burden of illness is high.
- Potential to alleviate service pressure points/waiting lists/delays is significant.
- Vulnerable groups (socially deprived/young/old/those with disabilities) that are greatly affected by their condition.
- Outputs will result in appropriate care delivered closer to preferred location and at an appropriate level of acuity.
- The model should result in better quality of care.
- The theme is considered appropriate by patient advocacy representatives.
- Potential to obtain better value for money within health budget is high.
- The services delivered by at least three Operating Divisions would feature in the associated Model/Framework.
- The programme would require multi-disciplinary care planning; and

- Benefits would be tangible and measurable.

Each ICP was underpinned by the principles of illness prevention, patient empowerment, multi-disciplinary cross service care planning and delivery and supported by specifically commissioned systematic literature reviews (Programme charter and literature reviews available here: https://www.hse.ie/eng/about/who/cspd/resources/files/).

It was recognised that supporting integration did not mean that everything had to be integrated into one package. Instead services could work together to provide a flexible network of care responsive to the changing needs of patients and their families.

71.2.3.1 Key Features of Establishing the Integrated Care Programmes

The following key features of the Integrated Care Programmes were identified to promote the vision of developing the health service of the future for Ireland:

- Designed by clinicians, with formal structures agreed with the Medical Colleges for input and sign-off; and developing similar structures with Nursing & Midwifery and with Health and Social Care Professionals
- Take a cross-organisational view—basing the models and pathways around the needs of the patient rather that organisational structures
- Each Integrated Care Programme would be chaired by an executive with deep knowledge and experience of the challenges of implementation of integrated services
- Each programme would utilise best available evidence for the design of models of care; within each programme specific workstreams will be prioritised for immediate work.

The vision for each Integrated Care Programme was set out in a programme charter that was agreed by all parties.

71.2.3.2 Governance

It was recognised that good governance would be key to successful implementation and appropriate governance arrangements were put in place at all levels of the portfolio of programmes and projects.

Building upon the principles of the HSE System Reform Governance, the governance included the following key levels:

- CSPD Reform Steering Group, accountable for the successful reform of the Clinical Strategy and Programmes Division
- Clinical Design Authority, providing assurance of the clinical design for implementation of the ICP's
- Core CSPD Reform team, responsible for the day-to-day management and delivery of reform within the CSPD

- Programme Management Office to provide guidance and control for the Integrated Care Programmes and national clinical programmes
- Integrated Care Programme teams to deliver implementable integrated models of care supported by:
  - Integrated Care Programmes Working Group (multidisciplinary group providing expertise from across the health system)
  - Stakeholder Advisory Groups to assist with the formal structures for input and sign-off with the Medical Colleges and similar structures within Nursing and Midwifery and with Health & Social Care Professionals and patient representatives.

71.3 The Patient Voice in Integrated Care

71.3.1 Patient Narrative Project

In early 2017, the Patient Narrative Project was launched, and a study commissioned to elicit the essential aspects of people's expectations of the health service in Ireland. Applying the principles of public and patient engagement, the study was led by the Irish Platform of Patient Organisations, Science and Technology (IPPOSI), whose mission is to put patients at the centre of healthcare and innovation. This focus on stakeholder engagement reflected a global priority and has resulted in increased satisfaction with healthcare and cost effectiveness. A set of regional workshops was organised around the country to, for the first time in Ireland, deliver the patient/service user perspective on what should be expected from person-centred coordinated care in the Irish Health Service.

IPPOSI through the their Patient Narrative Steering Group (IPPOSI Members) led an evidence-based, narrative enquiry methodology to hear and collate experiences of service users and patients in Ireland who need care over time from multiple services, as well as their carers and families relating to their experiences. Dr Amanda Phelan, UCD School of Nursing, Midwifery and Health Systems, and her research team facilitated three focus groups at each regional workshop. The research was funded by the HSE (Phelan et al. 2017). The report can be found here: https://www.ipposi.ie/wp-content/uploads/2017/09/Patient-Narrative-Project-Phase-1-report-FINAL-.pdf.

To complement the work of the focus groups, an online survey was set up to gain the views and experiences of the wider IPPOSI patient membership.

The experiences from both the focus groups and the online survey were translated into descriptors, and a definition of person-centred coordinated care was developed for all, not just for experts, but for patients, people, families and carers. The goal was that the descriptors and definition of what good integrated care and support looks and feels like for people would be adopted nationally and used to guide policy, strategy and design, and as a guide to what teams at local levels should be aiming to achieve practically, in their efforts to integrate services around patient, family and carer needs.

Definition:

'*Person centred coordinated care provides me with access to and continuity in the services I need when and where I need them. It is underpinned by a complete assessment of my life and my world combined with the information and support I need. It respects my choices, building care around me and those involved in my care'*.

The report also contains 18 statements written from the perspective of people needing care over time from multiple health services. The statements and definition emphasised that people want to be empowered in a seamless journey through the health services; they want to take an active, informed role in their care and to be treated as people, not health conditions. In addition, they expect staff to live the values of the Health Service Executive (HSE); care, compassion, trust, and learning, as they go about their work.

The narrative was designed for the people who use health services and all staff working in them to:

- Empower patients, service users and families by enabling person centredness to become a real experience for them.
- Prompt staff to view health care from the perspective of service users and what matters most to them.
- Facilitate partnership approaches to healthcare design and delivery from individual care planning to local and national healthcare improvements.

The patient narrative was to be the cornerstone of the Integrated Care Programmes, with co-production as an essential component.

The National Integrated Care Programme for Older People (ICP OP), is now in implementation and scale up phase, and the others are at different stages of implementation. We will now look at ICP OP in more detail as an exemplar.

71.4 The National Integrated Care Programme for Older People (ICP OP)

The National Integrated Care Programme, Older Persons (ICP OP) was developed to support older people to live in their own community by providing timely access to health and social care that enabled them to receive the right level of care, in the right place by the right team. ICP OP had four key objectives:

1. Supporting Older Persons to live well
2. Enabling Older Persons to remain in their place of residence by providing secondary care in the community
3. Providing integrated Intermediate Care (Hospital/Community Care)

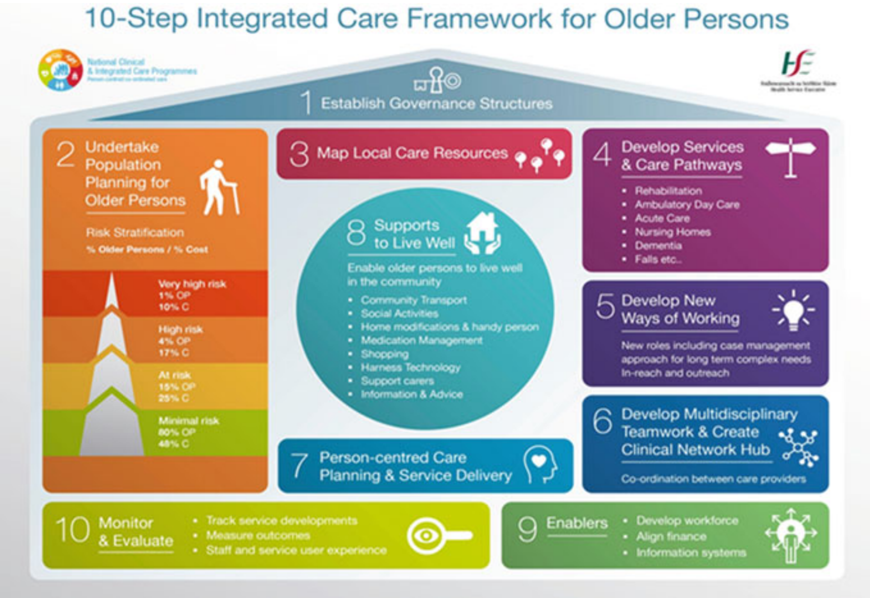


Fig. 71.3 ICP OP 10-step framework (Harnett et al. 2019)

4. Supporting Older Persons in residential Care.

In addition, the learning from the design, development, and implementation of ICP OP was to help in the development of the other ICPs.

The ICP OP evidence informed 10-step framework was developed to describe a series steps to implement integrated care (Harnett et al. 2019; Harnett 2018) (Fig. 71.3).

This framework enabled local and national change agents to share a common conceptual map of what 'good looked like' thus facilitating a shared understanding of roles and responsibilities. It could also be interpreted locally and adapted depending on the local context.

Guidance on the use and application of the framework was developed and launched in 2017, 'Making a start in Integrated Care for Older Persons' (Group 2013). This methodology recognised that there are some key elements necessary to facilitate integrated care;

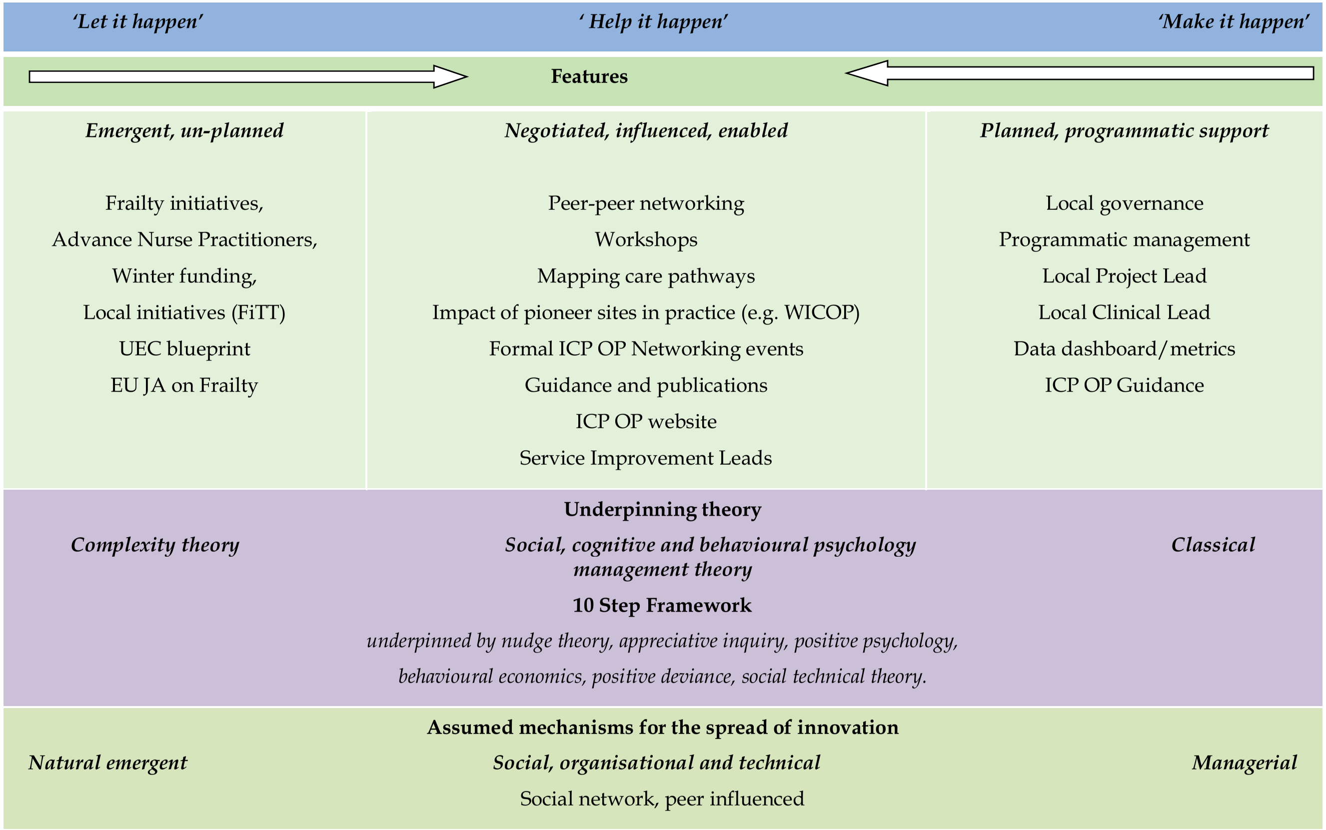
1. Case management approach for Older Persons with long-term complex care needs.
2. A multidisciplinary, community approach.
3. Clearly defined pathways allowing more patients to stay at home or get back home more speedily.

ICP OP undertook a ‘design and test’ phase over 2 years. This culminated in a case study account of ‘lessons learned’ during implementation (HSE 2018). The impact in pioneer sites has been transformative in terms of hard metrics and softer measures of success. Pioneer sites grew from 6 to 15 sites with 3 years providing integrated care across an >65 years population of 234,000. This represents approximately 37% of the >65 years population. The adoption of the approach, propagated by networking days, creating an appetite for a rapid growth in areas wishing to adopt the model. ICP OP subsequently formed a central tenet of the Sláintecare Implementation plan which sought to invest heavily in accelerating integrated care for older people nationally (Slaintecare 2018). This was founded on impressive results from pioneer sites despite modest investment (HSE 2018) and a widespread interest in the approach set out by ICP OP. By the end of June 2019, 51% of all Consultant Geriatricians nationally ($n = 53$) were directly participating in the programme. This finding is suggestive of the importance of supporting leadership within professional social networks.

A key implementation paper by Greenhalgh and colleagues in 2004 indicated that organisational forces pull in opposite directions (Greenhalgh et al. 2004). ICP OP overlaid their experience onto this model as shown in Fig. 71.4 which shows that the tension between traditional managerial approach (make it happen) and a more emergent approach (let it happen) can be positively harnessed. A detailed discussion of this process is beyond the scope of this chapter. This approach contrasts with traditional health system change where there is a greater emphasis on command and control. This shift in emphasis focuses the organisation on the work of clinical and managerial leaders rather focusing clinical and managerial leaders on the work of the organisation. As a result, the influence of professional social networks has a multiplier effect when it comes to implementation (Horton et al. 2018). The combination of diffusion (emergent, opportunistic modes of spread) and dissemination (planned and programmatic) in the spread of ICP OP reflected many of Greenhalgh and colleagues early observations on the nature of change in health systems. This includes accommodating the emergent nature of implementation in complex systems as well as harnessing positive deviants (Sternin and Choo 2000). The creation of this adaptive space was facilitated through the ICP OP networking days.

71.4.1 Insights into Implementation

Implementation is a dynamic, multi-faceted process. Whilst the 10-step framework provided a conceptual map, implementation involved the simultaneous mobilisation of several moving parts by the programme though the service improvement leads. Whilst previous models of care for Older Persons were described by the National Clinical Programme for Older people (NCP OP) (HSE 2012), the means of achieving implementation were not articulated prior to the work undertaken by ICP OP. As integrated care represents a fundamental shift in care delivery, it calls for many interdependent components to progress simultaneously. This included



'Let it happen'	*' Help it happen'*	*'Make it happen'*
	Features	
Emergent, un-planned	*Negotiated, influenced, enabled*	*Planned, programmatic support*
Frailty initiatives, Advance Nurse Practitioners, Winter funding, Local initiatives (FiTT) UEC blueprint EU JA on Frailty	Peer-peer networking Workshops Mapping care pathways Impact of pioneer sites in practice (e.g. WICOP) Formal ICP OP Networking events Guidance and publications ICP OP website Service Improvement Leads	Local governance Programmatic management Local Project Lead Local Clinical Lead Data dashboard/metrics ICP OP Guidance
	Underpinning theory	
Complexity theory	***Social, cognitive and behavioural psychology management theory*** **10 Step Framework** *underpinned by nudge theory, appreciative inquiry, positive psychology, behavioural economics, positive deviance, social technical theory.*	*Classical*
	Assumed mechanisms for the spread of innovation	
Natural emergent	*Social, organisational and technical* Social network, peer influenced	*Managerial*

Fig. 71.4 Implementation of 10-step framework overlaid on Greenhalgh et al. (2004) framework

guidance, a structured engagement process, enablers (ICT, data, Workforce) within an overall service architecture. A detailed account of these discrete elements is beyond the scope of this chapter.

As ICP OP evolved, the key ingredients that were deemed essential are as follows:

1. Good local governance.

   This allowed for the emergence of new 'structures' that focused on a population need rather than an institutional agenda. The development of governance locally and nationally meant that emergent initiatives (frailty at front door, policy, technology), could be harnessed. This allowed local entrepreneurship to flourish but combined it with a national mandate, resources, and linkages to a broader improvement network. Likewise, when significant workforce changes such as the candidate Advanced Nurse Practitioners initiative were announced, having ICP OP pioneer site status allowed these developments to be integrated into a local service design more seamlessly.
2. Context-specific, incremental guidance:
   This provided clear guidance and practical exemplars of good practice which were more easily identifiable with by local teams. This avoided the interpretation of change as 'external' and a more practical knowing that takes place the messy and complex reality of practitioners and managers organisational life.
3. Local interpretation:
   Local pioneer sites were given latitude to determine immediate priorities. This included how they would spend resources provided by ICP OP. This was a very different approach to established, centralised, programmatic (corporate) decision making which traditionally resulted in clinical and managerial leaders were told what resources they were getting and how they should be used.
4. Psychological and Practical Support by Service Improvement Leads (SIL):
   SILs provided practical enablers (ICT, collection of data) and psychological support to sites. This ensured programmatic rigour but equally allowed each site to put a local flavour on their strategy, thus promoting a feeling of ownership and control. This co-production approach required a tolerance on the part of ICP OP and the local sites for some ambiguity and thus enabled emergence.
5. Leverage existing resources as well as introducing new roles and functions:
   ICP OP worked closely with pioneer sites to map the journey of the Older Person through the 'current state' service and envision a 'future state'. Each site started this process based on local opportunity and perceived priorities. The act of mapping the complete Older Person's journey adopted an appreciative inquiry approach (Whitney and Cooperrider 2011). This allowed ICP OP, acting as a neutral, independent (from the local context) agent to challenge current practice and assumptions. ICP OP, operating in an insider/outsider capacity, could raise issues that were potentially uncomfortable to discuss locally (Bartunek et al. 1992; Bartunek 2008). This typically involved challenging hospital centric thought processes and/or where services could be delivered. This process

involved empowered service users, clinicians and managers and used patient narrative data to prompt an exchange of ideas and innovation. The development of bespoke care pathways was a foundational component of ICP OP, and the growth in number of discrete care pathways is testimony to the ripple effect of ICP OP. The process of mapping in itself represented an opportunity for local leaders to publicly articulate a common shared vision of the future state service model for older people. This dispensed with silos where attribution of blame was supplanted by solution focused objectives. The public commitment to a shared common vision, developed with service users, was usually the first time this had been undertaken locally.

71.4.2 Impact of ICP OP

Measuring the ‘impact’ of investment is hugely problematic given the complex and interdependent nature of health and social care. The indications are that it may take at least three years to show impact on service use indicators such as hospital admissions, but this is dependent on integrated service components being in place right across social care as well as healthcare domains (Baxter et al. 2018; Miller 2016; Miller and Stein 2020; Nolte and Pitchforth 2014). The evidence and presumption internationally is that whilst integrated care does not provide a ‘magic bullet’ in terms of ‘bending the cost curve’, instead it yields longer-term benefits in terms of individual patient experience and outcomes and better staff experience.

The impact in ICP OP pioneer sites has been transformative in terms of hard metrics and softer measures of success. The evidence to date points to significant return on investment when local leaders (clinicians and managers) have the autonomy to redesign services. Pioneer sites grew from 6 to 15 sites with 3 years providing integrated care across an >65 years population of 234,000. This represents approximately 37% of the >65 years population. The adoption of the approach, propagated by networking days, creating an appetite for a rapid growth in areas wishing to adopt the model. By the end of June 2019, 51% of all Consultant Geriatricians nationally ($n = 53$) were directly participating in the programme. ICP OP subsequently formed a central tenet of the Sláintecare Implementation Plan (action 4.5) (Slaintecare 2018) which sought to invest heavily in accelerating integrated care for older people nationally. This was founded on impressive results from pioneer sites despite modest investment (HSE 2018) and a widespread interest in the approach set out by ICP OP. For example, a sample of data from a pioneer site with a functioning Ambulatory Hub had 5.3 Emergency Department (ED) self-referrals per day (representing 26.1% of overall ED referrals) in contrast to a site without a Hub which had 31 self-referrals per day (representing 59.8% of overall ED referrals). This is important in avoiding default to ED as a point of service access. In addition, Average Length of Stay was reduced in pioneer sites with bespoke inpatient pathways by 2.1% (or 0.3 of a day) (Dec 2016- Dec 2017) and remained high relative to other equivalent hospitals.

71.4.3 Summary of Findings

The use of and contents of the 10-step framework as a concept map reinforce the need for an agile mixture of emergent, negotiated, and planned approach. The 10-step framework became a national conceptual shorthand for integrated care for Older Persons and helped confer institutional authority to endorse and support local initiatives. This reflects some of the lessons from implementation of systemic change (Braithwaite et al. 2018; Dixon-Woods et al. 2011) and also attends to the need for professional peer networks to influence one another and not only socially construct 'what good looks like' but has utility in the 'messy' reality of people responsible for doing the implementation (Schön 1995).

71.4.4 Dissemination

The Integrated Care Programmes are the result of co-production between people and families, clinicians, managers, and policy-makers. Many stakeholder events have taken place locally regionally and nationally to both inform but also learn from local experiences. These have taken the form of world cafes, workshops, fora, seminars and learning events. This approach helped develop a new perception of engagement and knowledge generation. Such engagement also helps to build or rebuild interpersonal relationships, and to foster collaborative learning. The work of CSPD and the ICPs have also been presented at many national and international conferences and also published in a variety of journals (Carroll and Cooney 2017; Carroll and Twomey 2015; Carroll et al. 2018; Carroll et al. 2017; Collins 2019; Darker et al. 2018; Morrow and Carroll 2019; Power 2017; Ryan 2014; Shaw 2020; Byrne 2012; Darker et al. 2017; Jeffers 2020; Power et al. 2017).

71.5 Lessons Learned and Outlook

71.5.1 We Have Learned that Integrated Care Is a Journey and not a Destination

Health care is a complex adaptive system and mechanistic linear reductionist thinking is insufficient for systemic change. Creating the conditions for change, an adaptive space and some simple rules have been successful in our experience. All integration is local, and attending to relationships and history is important to be successful. You ignore history at your peril. Creating rich connections especially locally is vital. Improvement is iterative, dynamic, and organic. It takes time to build trust and confidence, and patience by policy-makers is required. The relentless restructuring within the Irish healthcare system has made implementation challenging, but the Sláintecare policy is perhaps an opportunity for full implementation.

Good governance structures are important at micro-, meso-, and macro-level, with macro providing the mandate and resources and facilitating adaptation.

There must be recognition that whole system change takes time. We must also develop good research and evaluation methodologies that allow a deep, rich understanding of the health and social care ecosystem and remembering that what really matters is what matters to the person being served.

Acknowledgements The authors would like to thank all the people who have been involved in the Integrated Care Programmes at local regional and national level and in particular IPPOSI. Without you, none of this would have happened.

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Disease Management Programs in The Netherlands; Do They Really Work?

72

Using the Chronic Care Model to Thoroughly Evaluate the Long-Term Effects of Dutch Disease Management Programs

Jane Murray Cramm and Anna Petra Nieboer

72.1 Using the Chronic Care Model to Evaluate the Long-Term Effects of Disease Management Programs in The Netherlands

Healthcare systems and providers are currently not equipped to deal with the complexities of aging populations and the high prevalence of chronic diseases that come with it. Clearly, rapid increase of people with chronic diseases is expected to lead to increased healthcare, social care and social security costs. However, evidence also indicates that carefully planning ahead and making evidence-based choices will enable countries and their primary care systems to successfully manage the situation. According to Ed Wagner, care processes must be redesigned and supportive of productive patient–professional interactions, which in turn leads to better outcomes (Wagner et al. 1996a, b, 2001; Coleman et al. 2009) which resulted in the chronic care model (Fig. 72.1). This model provides a multidimensional framework guiding disease management programs (DMPs) aiming to replace their current system which are usually based on acute and reactive care, with planned, population-based care delivery to patients with chronic diseases (Wagner et al. 2001; Coleman et al. 2009; Norris et al. 2003).

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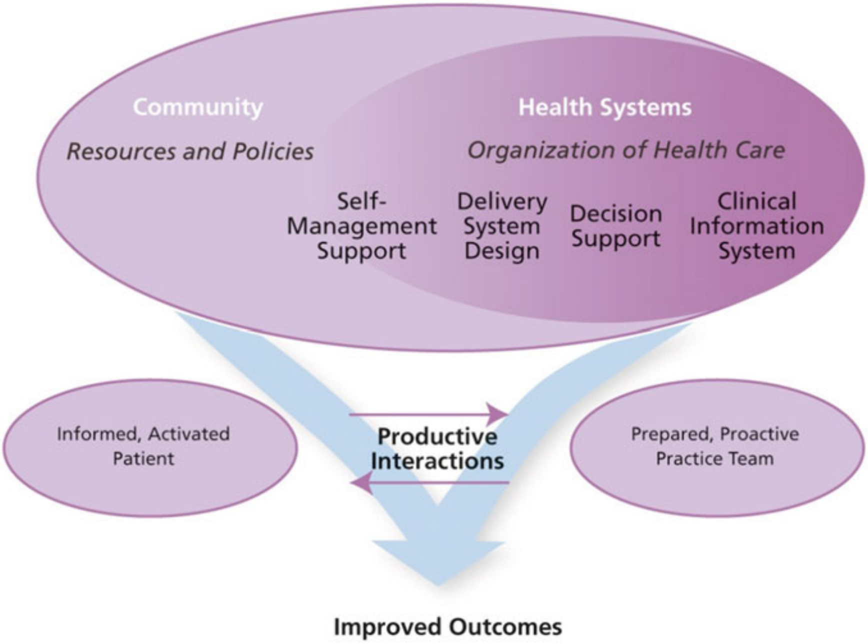


Fig. 72.1 Chronic care model developed by Ed Wagner

The CCM includes six interrelated components of the quality of care for the chronically ill:

1. Self-management support (i.e., empowering patients to self-manage their own care through education, lifestyle programs, skills building, planning, goal setting and problem solving);
2. Delivery system design (i.e., redesign the way that care is delivered to chronically ill patients by redefining healthcare team members' roles);
3. Decision support (i.e., implement and use of care standards and clinical guidelines, use the latest evidence when decisions are made with patients);
4. Clinical information systems (i.e., implement information systems, providing timely reminders and feedback for patients and health professionals, planning and coordinating care for individual patients, monitoring healthcare team performance and effectiveness of individual care);
5. Healthcare systems (i.e., promoting effective strategies at all levels to comprehensively change the care system, developing agreements to coordinate care and address quality issues, provide (financial) incentives to improve the quality of chronic care delivery); and
6. Community linkages (i.e., developing partnerships with community organizations to support interventions that complement health services, advocating for policy changes that improve patient care) (Cramm and Nieboer 2015a, b, c; Wagner et al. 1996a, b, 2001; Coleman et al. 2009).

Although it is known that DMPs based on the chronic care model prevent disease complications among patients with chronic obstructive pulmonary disease (COPD) (Adams et al. 2007) and are related to better outcomes indicated by measures of care processes and clinical outcomes (Tsai et al. 2005) and their *long-term* benefits have not been established thoroughly. Furthermore, the Chronic Care Model is not static but incorporates flexibility in the implementation of interventions, resulting in a mixture of DMPs (Cramm et al. 2013). Thus, different DMPs may incorporate the six components of the Chronic Care Model to various extents using diverse constellations of interventions. To understand the design and effects of DMPs based on the Chronic Care Model, it is important to (1) know which interventions were actually implemented within the Dutch DMPs, (2) assess if implementation of interventions led to better quality of chronic care, (3) investigate if (improvements in) quality of chronic care resulted in more productive patient–professional interactions and (4) assess long-term effects on patient outcomes (healthier lifestyles, better self-management abilities, quality of life). These four questions will be answered in this chapter.

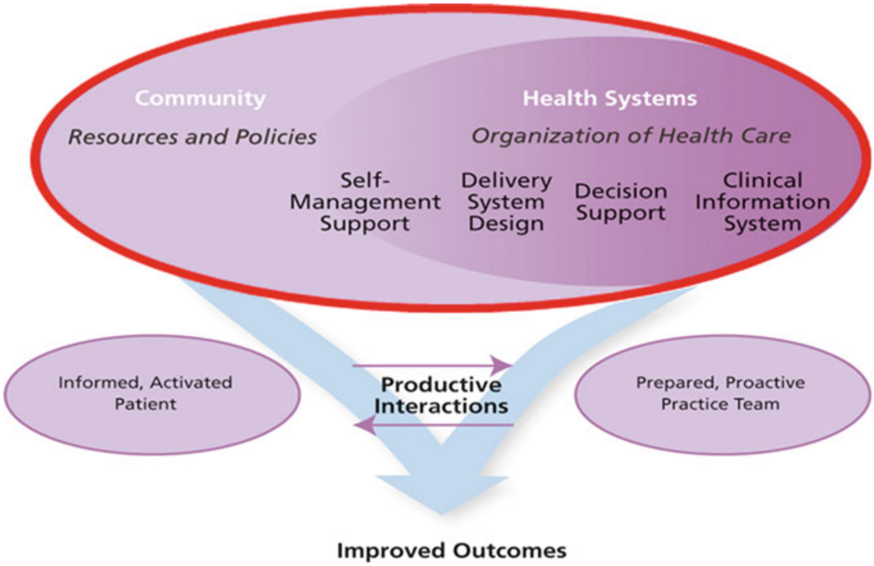
This study included patients and professionals participating in 18/22 disease management programs based on the Chronic Care Model that were implemented in various regions of the Netherlands that were followed for at least two years (Lemmens et al. 2011; Cramm et al. 2014a, b). For this chapter, four DMPs were excluded due to (i) a sample size smaller than 15 patients; (ii) incomplete data availability caused by delayed questionnaire distribution; (iii) DMPs aimed at hospitalized patients instead of those still living on their own and (iv) slightly different questionnaire content to address a specific mental health condition (e.g., eating disorders and depression). The 18 included DMPs were aimed at patients with CVDs ($n = 9$), COPD ($n = 4$), heart failure ($n = 1$), comorbidity ($n = 1$) and diabetes ($n = 3$) (Cramm et al. 2014a, b).

72.2 Question 1: Which Interventions Mapped to the Chronic Care Model Were Actually Implemented Within the Dutch DMPs?

In order to answer this research question, we developed a template based on the Chronic Care Model. All project leaders of the 18 DMPs were asked about the implementation of all interventions within their DMP. After finalizing, the template was sent back to the project leaders for final corrections (Cramm and Nieboer 2015a, b, c).

Each disease management program successfully implemented a constellation of interventions within each of the six dimensions of the Chronic Care Model (see Table 72.1). Care standards/clinical guidelines, training and independence of practice assistants, professional education and training for care providers and hospital or practice information system were implemented within all the DMPs, whereas organizing a health market, use of cognitive behavioral therapy, use of care protocols for immigrants specifically and having an electronic patient records system with a working patient portal were implemented in a single DMP only. DMPs clearly vary in the interventions they implemented within each DMP.

72.3 Question 2: Did the Quality of Chronic Care Delivery Measured with the CCM Dimensions Improve Over Time?



An important question is the implementation of the interventions listed in Table 72.1 resulted in better quality of chronic care. Looking at the results of professionals' experiences with quality of chronic care delivery over a two-year time frame, all six dimensions of the CCM as well as the overall score improved significantly (Table 72.2). Two years after implementation of the DMPs, all CCM areas were indicated as advanced support for chronic illness care (Bonomi et al. 2002; Cramm and Nieboer 2014; Cramm et al. 2014a, b).

In addition to investigating quality of care as experienced by professionals, we were also interested in assessing patients' experiences. These results indicated DMPs implementation which also led to more positive experiences among chronically ill patients (Cramm and Nieboer 2013a, b).

Furthermore, results clearly showed that quality of chronic care delivery at *T*0 ($p < 0.001$) and quality changes in the first ($p < 0.001$) and second ($p < 0.01$) years predicted program sustainability (Cramm and Nieboer 2014).

Table 72.1 Overview of interventions implemented within DMPs in The Netherlands

CCM dimension	Intervention	Number of programs	%
Healthcare organization	Integrated financing of disease management	9	50
	Specific policies and subsidies for immigrant population	5	28
	Sustainable DMP financing agreements with health insurers	10	56
Community	Communication platform between stakeholders about patients	2	11
	Health market	1	6
	Cooperation with external community partners	15	83
	Multidisciplinary and transmural collaboration	14	78
	Role model in the area	8	44
	Regional collaboration for DMP expansion	8	44
	Treatment and care pathways in out and inpatient care	15	83
	Involvement of patient groups and panels in care design	9	50
	Regional training course	13	72
	Family participation	3	17
Self-management	Promotion of disease-specific information	14	78
	Individual care plan	13	72
	Lifestyle interventions (e.g., physical activity, diet, smoking)	16	89
	Support of self-management (e.g., Internet, email, SMS)	2	11
	Tele-monitoring	0	0
	Personal coaching	15	83
	Motivational interviewing	16	89
	Informational meetings	6	33
	Diagnosis and treatment of mental health issues	7	39
	Reflection interviews	0	0
	Group sessions for patient and family	5	28
	Cognitive behavioral therapy	1	6
Decision support	Care standards/clinical guidelines	18	100
	Uniform treatment protocol in out and inpatient care	10	56
	Training and independence of practice assistants	18	100
	Professional education and training for care providers	18	100

(continued)

Table 72.1 (continued)

CCM dimension	Intervention	Number of programs	%
	Automatic measurement of process/outcome indicators	16	89
	Use of care protocols for immigrants	1	6
	Audit and feedback	10	56
	Periodic evaluation of interventions and goal achievement	6	33
	Structural participation in knowledge exchange/best practices	11	61
	Quality of life questionnaire	7	39
	Evaluation of health care via focus groups with patients	4	22
	Measurement of patient satisfaction	9	50
Delivery system design	Delegation of care from specialist to nurse/care practitioner	16	89
	Substitution of inpatient with outpatient care	11	61
	Systematic follow-up of patients	16	89
	One-stop outpatient clinic	3	17
	Specific plan for immigrant population	3	17
	Expansion of chain of care to the secondary care setting	6	33
	Joint consultation hours	3	17
	Meetings of different disciplines for exchanging information	17	94
	Monitoring of high-risk patients	13	72
	Board of clients	4	22
	Periodic discussions between care professionals (and patients)	11	61
	Stepped care method	6	33
Clinical information systems	Electronic patient records system with patient portal	1	6
	Hospital or practice information system	18	100
	Integrated chain information system	10	56
	Use of ICT for internal and/or regional benchmarking	14	78
	Creation of a safe environment for data exchange	8	44
	Systematic registration by every caregiver	15	83
	Exchange of information among care disciplines	12	67

CCM chronic care model, *DMP* disease management program, *SMS* short message service, *ICT* information and communication technologies. Ref Population Health Management. Table was published in Cramm and Nieboer (2015a, b, c)

Table 72.2 Two-year changes in the quality of chronic care delivery, as measured by Assessment of Chronic Illness Care Short Version (ACIC-S) Scores

	Baseline (T0) assessment	Follow-up (T2) assessment	Change
	M(sd)	M(sd)	*p*
Organization of health care	7.11 (1.20)	7.72 (1.84)	<0.001
Community linkages	6.51 (1.78)	7.54 (1.69)	<0.001
Self-management support	6.10 (2.19)	7.19 (1.86)	<0.001
Decision support	6.73 (1.76)	7.50 (1.51)	<0.001
Delivery system design	7.36 (1.57)	8.67 (1.38)	<0.001
Clinical information systems	6.16 (1.93)	7.34 (1.64)	<0.001
Overall score	6.66 (1.50)	7.66 (1.29)	<0.001

M mean, *SD* standard deviation. Results are based on paired *t*-test, *T*0 versus *T*2. Scores indicate 0–2 (little or no support for chronic illness care), 3–5 (basic or intermediate support), 6–8 (advanced support) and 9–11 (optimal or comprehensive integrated care for chronic illness). These analyses included respondents who completed questionnaires at measurement points *T*1 and *T*2 only ($n = 170$). Results are published in Cramm and Nieboer (2013a, b)

72.4 Question 3: Did Quality of Chronic Care Delivery Result in Productive Interactions Between Patients and Healthcare Professionals?

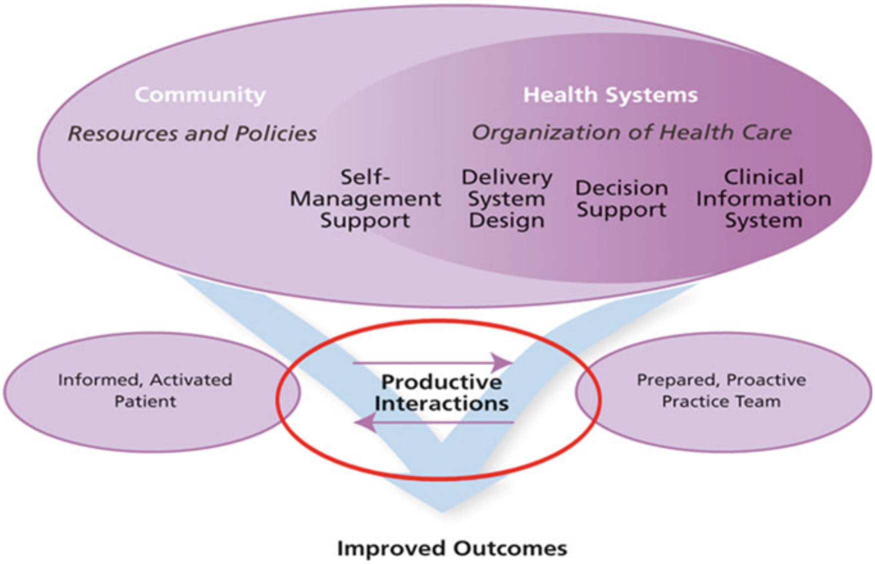


Table 72.3 Predictors of productive interactions between patients and (teams of) healthcare professionals as assessed by multilevel regression analyses (random intercepts model)

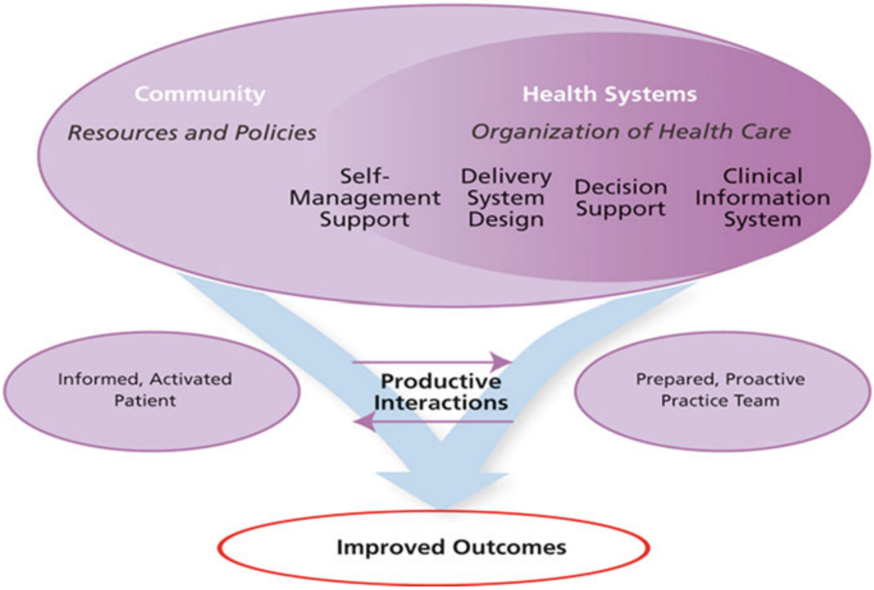
	β	SE
Constant	2.90***	0.03
Age (*T*0)	−0.00	0.03
Marital status (single) (*T*0)	−0.01	0.02
Low educational level (*T*0)	−0.06*	0.03
Gender (female) (*T*0)	−0.02	0.03
Quality of chronic care (*T*0)	0.38***	0.03
First-year changes in quality of chronic care (*T*1–*T*0)	0.30***	0.04
Second-year changes in quality of chronic care (*T*2–*T*1)[a]	0.25***	0.03

$^{***}p \leq 0.001$, $^{**}p \leq 0.01$, $^{*}p \leq 0.05$ (two-tailed)

[a] Based on implemented interventions in the disease management programs. Multilevel analyses included only respondents who filled in questionnaires at all three time points (n = 981; n = 716 after list wise deletion of missing cases). [Table published in Cramm and Nieboer (2014)]

While theoretically it is expected that improvement in the six components of the Chronic Care Model increases productive patient–professional interaction, empirical evidence is lacking. We, therefore, aimed to assess the influence of (improvement in) the six components of the Chronic Care Model on productive patient–professional interaction. The results presented in Table 72.3 clearly show that after controlling for main characteristics of patients, quality of care delivery at baseline, as well as first- and second-year changes therein predicted productive interactions between patients and professionals (Cramm and Nieboer 2013a, b).

72.5 Question 4: Did DMP Implementation Lead to Better Patient Outcomes?



Finally, we aimed to determine experiences of DMPs and their long-term effects on the following outcomes (i) health behaviors (smoking and physical exercise), (ii) self-management abilities (self-efficacy, investment behavior, and initiative taking), and (iii) physical and mental quality of life among chronically ill patients. Analyses showed DMP implementation improved patients' physical quality of life and their health behaviors; they smoked less and are more physically active (Cramm and Nieboer 2015a, b, c). However, they struggled with patients' mental quality of life and their self-management abilities to maintain well-being (Cramm and Nieboer 2015a, b, c). Self-management abilities to maintain well-being as well as mental quality of life decreased over time, despite improvements in quality of care and more productive patient–professional interactions. These findings suggest that the Chronic Care Model and DMPs based on it focus primarily on clinical and functional outcomes rather than overall quality of life and well-being (Barr et al. 2003; Cramm and Nieboer 2015a, b, c; Cramm and Nieboer 2012).

72.6 Conclusion

The long-term benefits of DMPs based on the Chronic Care Model in the Netherlands resulted in (i) the successful improvement of quality of chronic care as perceived by chronically ill patients and professionals, (ii) more productive interaction between chronically ill patients and their healthcare professionals (iii) and improvements in chronically ill patients' health behaviors and physical quality of life. However, these programs did not successfully improve or even maintain broader self-management abilities or mental quality of life, which declined over time. These findings highlight the need to broaden the scope of DMPs not aimed at functional health and self-management of a chronic disease only but also at broader self-management abilities and overall well-being. DMPs have failed to address important difficulties chronically patients are dealing with such as the effects of pain and fatigue on the ability to maintain a job, hobby and social life. Patients' ability to maintain engagement in stimulating activities related to work and one's social life may be even more important than aspects of disease self-management such as glycemic control or blood pressure. This calls for a person-centered approach aimed at their physical, social and mental well-being (Cramm and Nieboer 2012).

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