4 *Achieving person-centred health systems: levers and strategies*

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Introduction

Traveller, there is no path. The path is made by walking.
Antonio Machado

As we have seen in Chapter 2 of this book, the terminology and interpretations of person-centredness vary across disciplines, professionals and stakeholders. A common theme underlying the diverse understandings is the ethical premise that people as patients and service users, and, by extension, family members, members of the community and citizens more broadly, should be treated as persons, with respect and dignity, and that care should take into account their needs, wants and preferences. However, expectations regarding the outcomes of enhanced person-centred care vary among stakeholders. Thus, managers and decision-makers might anticipate increased efficiency and wider system level effects, while others emphasize more effective engagement at the interpersonal level. Different understandings and perspectives will significantly impact on the translation of principles into practice, and on the perceived or demonstrated effectiveness of relevant initiatives and strategies. This is especially relevant since person-centred policies and strategies involve trade-offs and the implementation of policies will be heavily influenced by how stakeholders balance goals and trade-offs, and, ultimately, existing power relations.

Based on our exploratory review of the evolution of person-centredness (Chapter 2) we can distinguish three perspectives; the interpersonal level of care (micro level), quality of care more broadly (meso level) and health systems (macro level). The micro-level perspective sees person-centredness as a concept or a framework that helps inform the (interpersonal) delivery of care, a view that is most likely held by health professionals. The meso-level perspective interprets person-centred care as a means to enhance the quality of care more

https://doi.org/10.1017/9781108855464.007 Published online by Cambridge University Press

broadly, as reflected in the seminal 2001 report *Crossing the Quality Chasm* by the Institute of Medicine (Institute of Medicine, 2001). This is a view most likely held by managers and decision-makers. Conversely, as Gillespie, Florin & Gillam (2004) showed, lay groups tend to view person-centredness in the context of a social or whole person model of health that occurs at the level of people involvement in the planning and delivery of services rather than within the individual clinical encounter, although this perspective may vary among people (*see also* Box 4.1). This broader view is more closely linked to those perspectives that see person-centredness as a principle that guides the design of what some have referred to as people-centred health systems (World Health Organization, 2016; World Health Organization Regional Office for Europe, 2015).

This chapter summarizes the key insights from individual chapters in this book. We conclude that contemporary approaches to organizing and governing health services and systems have largely failed to deliver person-centred care, although some progress has been made. We note that there is a need for policies to strengthen the capabilities for engagement across all stakeholders concerned, and we discuss some of these options, including the challenges that need to be overcome in order to move to more person-centred health systems.

Why different understandings and interpretations of person-centredness matter

Depending on the perspective, person-centredness will be understood and interpreted in different ways, and the implications for the further development of health services and systems will differ. Importantly, those that view person-centredness as a means to inform service delivery and to enhance care quality more broadly tend to be narrower in their approach as they rest on the assumption, or indeed postulate, that service providers play an important role in people's lives. Yet this is not necessarily the case from an individual service user (or carer) perspective, even among those who use services more frequently because of chronic health problems. For example, Foss et al. (2016) highlighted that, among people with type 2 diabetes, encounters with health care are often experienced as "yet another demand in their lives" (p. 681). Indeed, the need to navigate services and clinical appointments, interact with different health and care professionals and engage in self-management

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and other treatment activities creates a 'treatment burden', as the work of managing ill health ('patient work' – Shippee et al., 2012) has shifted as part of a wider agenda of increased patient responsibility for their own health and care (May et al., 2014). Treatment burden has been associated with poor adherence and unfavourable outcomes. Demain et al. (2015) also highlighted that among people with a range of conditions, treatments may lead to physical symptoms and side-effects (such as pain and nausea), yet it is often not the severity of symptoms that people struggle with but the impacts arising from those symptoms and side-effects, such as on identity, independence and interaction with others. While the interaction and the nature of the relationship with health professionals can help address and reduce these impacts (May, Montori & Mair, 2009), much of the adaptive work people undertake to "psychologically normalise treatments to their lives and their lives to the treatment" (p. 11) takes place without formal care providers' involvement (Vassilev et al., 2016). It could thus be argued that interpreting person-centredness in the context of the current mode of service delivery only reinforces existing structures. A move to 'truly' person-centred systems requires the redesign of services and systems more broadly.

This conclusion is corroborated throughout the individual contributions to this book (*see also* Chapter 3). For example, Draper and Rifkin (Chapter 5) and Beresford and Russo (Chapter 6), looking respectively at user engagement in health service and system development and in research, find that relevant strategies have been and appear to remain dominated by professional and service-led motives, which might explain the lack of measurable impact on outcomes. Similar observations are noted by Nolte and Anell (Chapter 12), citing evidence that contemporary approaches to self-management support tend to focus on managing people's conditions in terms of biomedical outcomes or disease control. This focus is driven largely by professional perceptions of self-management when instead there is a need to support people to manage well (or live well) with their conditions within the wider context within which they live. The reviews by Fotaki, Van Ginneken et al. and Verhaeghe in Chapters 8–10, which explore the role of the individual as a consumer in making decisions about purchasers or providers of individual care packages and services, all find that enabling people to exercise choice requires appropriate support structures at the different tiers of the system. Yet what is available has tended to be designed

https://doi.org/10.1017/9781108855464.007 Published online by Cambridge University Press

without user input. Indeed, as Verhaeghe argues, the nature and scope of what people actually would want in terms of information and support remains poorly understood. Overall, there is a more general lack of understanding of whether and how people want to be involved in decision-making at the different tiers of the system (Box 4.1).

Box 4.1 What do we know about whether people want to engage in health care decision-making at individual and collective levels?

Fredriksson, Eriksson & Tritter (2017) examined preferences for involvement in health care decisions at individual and collective levels among adults in Sweden and the UK. Using a general population survey (people aged 15 years and older) in 2014, they explored (i) the extent to which individuals wanted to make the final decision about their treatment, and (ii) whether they wished to be involved in decision-making about local health services. They also asked whether people believed that they can influence decisions about the health service more broadly. The survey found that, overall, two-thirds of respondents preferred that a health professional makes the decision about their treatment (Sweden: 70%; UK: 66%), and only a minority wanted to make this decision themselves (10% vs. 13%). The finding that people in both countries preferred their health professional to make the treatment decision may perhaps seem surprising, although it is important to note that the question was about the *final* treatment decision. The authors acknowledged that their finding did not imply that people do not wish to be involved in the process overall. Indeed, Coulter & Jenkinson (2005), in a 2002 survey of people aged 16 and over in eight European countries (including Sweden and the UK) about treatment decisions found that about one-quarter of respondents wanted to make the decision themselves (albeit after consultation with their doctor). However, the majority favoured a shared decision-making model, in which the doctor and patient are jointly responsible for making treatment decisions. Predictors for desiring a shared role include familiarity with a clinical condition, while level of trust in the physician, age and education also influence whether individuals prefer an active over

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Box 4.1 (cont.)

a more passive role in the decision-making process (Kraetschmer et al., 2004; Deber et al., 2007).

Concerning decisions about local health care organization and delivery, Fredriksson, Eriksson & Tritter (2017) found that 44% of respondents wanted to be involved, and this was more common among people in Sweden compared to the UK (55% vs. 33%). Respondents from Sweden were also somewhat more likely to believe that their involvement in decision-making could improve services (39% vs. 36%), although a considerable minority did not believe this to be the case (30% vs. 24%). Those who wanted to be involved in decisions about their own care were more likely to also want to be involved in health care decision-making in either country. The higher propensity among Swedish respondents for wanting to be involved was explained by relative levels of dissatisfaction with the health system overall, which was found to be higher in Sweden, and this might prompt people to want to influence decision-making to improve services. However, there are various reasons for people's willingness to actively engage (Martin, 2008), reflecting a combination of individual beliefs, interests and knowledge, as well as wider contextual factors and norms, and effective involvement will need to take account of this complexity.

There has been more progress in the understanding of how people view the quality of services, with recent moves to the collection of patient-reported experiences and outcomes measures (PREMs and PROMs). Yet as Coulter, Paparella & McCullough note in Chapter 7, lay involvement in the development of such measures remains inadequate, and this observation is confirmed by a scoping review of patient involvement in the development of PROMs (Wiering, De Boer & Delnoij, 2017). More importantly, there is very limited use of such data and understanding of how people view the quality of services to support redesign of services. Overall, as Légaré et al. summarize in Chapter 11, there is a need to move to a more complex model of engagement that systematically considers people's values and preferences at all tiers of the system, from the individual patient–professional relationship to the organizational, the governance and finance, and

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wider societal levels in order to systematically implement person-centred strategies.

The question, then, is about how to get there. It is conceivable that progress has to be thought of as incremental, considering the various strategies that have been reviewed in this volume. Each chapter has provided useful pointers of what is needed to move towards a more person-centred approach in a given area. However, given the nature and pace of challenges facing health systems today, as discussed in the introduction to this book, and the impact this will have on people's lives, more fundamental and, by implication, more difficult change may be needed. As noted, a health system that is focused on the person at the centre is expected to address the varied challenges by ensuring accessible health care that is of high quality, responsive, affordable and financially sustainable. Yet the review of the evidence of a diverse range of strategies in this book raises a number of critical questions about the readiness of decision-makers at the various tiers of the system to truly wish to move towards more person-centred strategies. Doing so will require confronting established relationships and a rethink of some of the more fundamental processes that have traditionally governed the provider-centric and expert-based organization and financing of health services and systems. This chapter explores some of these critical questions. While not providing answers to how to solve these questions, it aims to help the various stakeholders to reflect on what person-centredness will mean in their individual system context and consider the options that may be available to them.

Are decision-makers ready to support people to actively engage at the different tiers of the system?

We have suggested that a continued focus on conceptualizing person-centredness from a professional or service delivery perspective only is likely to reinforce existing structures, thus undermining the central idea of person-centredness as a design principle. Indeed, it could even be argued that contemporary narrow strategies or approaches cater to 'dysfunctional' systems. This is exemplified by a continued focus on the traditional approach to health care organization and financing that emphasizes a biomedical model of service delivery that centres on managing and measuring biomedical indicators, such as blood sugar levels in people with diabetes, or intermediate indicators such as behaviour

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change that will lead to changes in the biomedical indicator. This focus is perhaps not surprising given that much of the available literature on person-centredness addresses the interpersonal level between the care provider and the patient or service user more broadly, while the organizational and system contexts are rarely discussed (Chapter 2). Yet, this 'narrow' or biomedical focus tends to be unnecessarily reinforced at the meso and macro levels, too. Examples include contemporary pay-for-performance schemes in primary care such as those implemented in the UK or France, or disease-management programmes in various European countries that incentivize control of mainly biomedical indicators (Nolte, Knai & Saltman, 2014). While such vertical, disease-oriented indicators are of course perfectly valid as a means to monitor the progress of a given disease, complementary horizontal measures that focus on outcomes that matter to people may be more important at the organizational and systems level.

This discussion raises a number of more fundamental questions. One relates to power relationships between different actors and stakeholders, most prominently perhaps at the individual level between the service user and the health professional (Box 4.2).

Box 4.2 The role of 'power' in the physician–patient interaction

Much of the work around the doctor–patient relationship has focused on the role of power, knowledge and status, dating to the work of Parsons (1951) and the notion of the 'sick role', where the patient is a passive recipient of care who responds to medical authority. Freidson (1970) pointed to the principal 'conflict' in the relationship, with doctors and patients having different agendas and formal medical knowledge competing with the patient's lay or 'folk' knowledge. Improvements in medical technology further reinforce the power imbalance between physicians and patients. Parsons' work has been challenged, inter alia, on the grounds of its medico-centric approach and the limited applicability of the 'sick role' to chronic illness. However, contemporary debate has reinterpreted Parsons' work as remaining fundamental to the understanding of the interaction between the patient and the health professional (Shilling, 2002).

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Box 4.2 (cont.)

Related work has explored the role of the physician with the emergence of a 'new professionalism' against a rapidly changing context within which health care is being provided and a changing society more widely (Irvine, 1999). This has involved the redefinition of what it means to be a medical professional, such as within the US/European Charter on Medical Professionalism. This builds on three principles: those of the primacy of patient welfare, of patient autonomy and of social justice (Medical Professionalism Project, 2002). The Charter sets out professional responsibilities. These include, inter alia, a commitment to honesty whereby patients "must be empowered to decide on the course of therapy"; patient confidentiality; maintaining appropriate relations with patients; improving quality of and access to care; a just distribution of finite resources; and maintaining trust by managing conflicts of interest. This change is reflected by evidence that doctors generally seem to support shifts away from paternalism towards a new type of relationship with the patient that emphasizes partnership (Hilton, 2008). However, as the various contributions in this volume have shown, it remains challenging to translate this notion into daily practice (*see also* Chapters 11 and 12).

The move to more person-centred strategies is seen as a way to overcome these challenges, with a desire to shift from a paternalistic approach to a (more) equal partnership, but this remains difficult to realize in practice. For example, as highlighted by Légaré et al. in their review of shared decision-making (Chapter 11), and Nolte and Anell in relation to self-management (Chapter 12), numerous tensions arise, for example, where the service user wishes to pursue a course of action that costs more or may even be harmful for patients or others. The evidence about the extent to which this is happening in practice is, however, largely absent. Similar challenges related to individuals' capabilities of making good decisions have been highlighted by van Ginneken et al. (Chapter 9) in relation to insurance choice, pointing to instances where individuals have made choices of insurer that may not be in their own best interest, a challenge also highlighted by Verhaeghe in the context of personal budgets (Chapter 10).

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Whose expertise 'counts'?

This then raises the question about professional authority, 'expertise' and whose experience and knowledge counts in judging whether a given decision is 'good' or appropriate. This question is not limited to the individual service user and professional interaction (Hamilton et al., 2017), but also extends to the organizational and macro or system levels. While a 'poor' decision at the individual service user level may impact the individual and their immediate carers, a 'poor' decision at the organizational or systems level may have negative consequences for populations more widely. In the context of individual service users, Renedo, Komporozos & Marston (2017) and others have highlighted the role of evidence-based medicine as a central principle of clinical practice, which can create tensions for health professionals who are asked to tailor their practice to individual service user's needs and preferences. Yet individual tailoring of services may run counter to standardized approaches, which are underpinned by ideas about hierarchies of evidence and where scientific and technical evidence is ranked above clinicians' practical or experiential evidence (Pope, 2003) and above patient or carer experience (Greenhalgh et al., 2015).

Fundamental here is the role and status of lay experience and expertise within the clinical encounter specifically and in the health service and system more broadly. This issue comprises different layers of complexity. These include the degree to which service user experiences might be ignored or excluded, because individuals are unable to articulate these, or health professionals are unable or unwilling to accept the patients' expertise as a legitimate input, as they might override the clinician's perspective on a given issue and requires them to reflect on their role as 'experts' (Carr et al., 2014). It also concerns the systematic collection of patient experience data to evaluate the quality of services (Chapter 7), information which, as Coulter, Paparella & McCulloch observed, is often not acted upon to improve services. This is despite evidence showing that among the key enablers for successful learning from service user experience to improve care quality is their active engagement. Renedo, Komporozos & Marston (2017) warned about a possible 'commodification' of patient experiences for other commercial purposes, which in turn raises ethical questions about how patient experiences are used and re-articulated by others. Importantly, it

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concerns questions about the nature and conceptualizations of evidence as such, what is considered to be a legitimate source of evidence and who decides on this in the context of participatory initiatives (*see* Box 4.3 for an illustrative example).

The question about what evidence counts, and whether it counts at all, has been shown to be of particular relevance in the context of patient and public involvement in research (Chapter 6). The research process, infrastructure and evaluation of public involvement remain dominated by professional expertise, and this is also reflected in research priorities (Crowe et al., 2015). This imbalance may risk undermining and devaluing participation and the systematic incorporation of experiential knowledge generated from lived experiences of users in the research process and it will be particularly problematic where vulnerable populations are concerned.

Box 4.3 Whose experience counts? Patient involvement in health technology assessment decisions in Australia

Lopes, Carter & Street (2015) examined patient involvement in health technology assessment decisions in Australia, based on 12 semi-structured interviews with patient organization representatives and members of Advisory Committees that provide advice to the Australian Department of Health. This found that participants viewed the involvement processes to be inadequate, but for different reasons that were linked to how different stakeholders conceptualized evidence. Thus, Advisory Committee members viewed evidence as encompassing clinical outcomes and patient preferences, while patient organizations focused on aspects not directly related to a given health condition but instead on "the social and emotional aspects of patients' experiences in living with illness" (p. 84). The study further highlighted that patient representatives reported having interacted with other stakeholders (in particular industry) to advocate for their conception of evidence on decision-making, illustrating existing power differentials within the decision-making process, an issue that would need to be addressed if the public is to be involved meaningfully.

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The role of wider developments outside the immediate grasp of the health system

A further challenge for contemporary health systems lies in the role of new and innovative practices that are beyond the immediate control of care providers, and that role is only beginning to be understood. This applies in particular to the rapidly changing digital world, ranging from innovative devices, e- and m-health tools and technologies (mobile communication and network technologies) (Iribarren et al., 2017) to social networking sites (Rozenblum, Greaves & Bates, 2017), including online health fora and peer-to-peer support networks. These are already reshaping the way individuals and citizens are engaging with health care and systems more widely, with online resources now established as a primary route to health information. For example, a 2014 Eurobarometer study found that about 60% of adult Europeans go online when looking for health information (TNS Political & Social, 2014). Seeking health information online can improve the relationship between service users and providers, although the degree to which this is happening in practice will depend to a great degree on the willingness of the health professional to engage with the patient and the nature of their prior relationship (McMullan, 2006; O'Connor et al., 2016; Tan & Goonawardene, 2017). Online communities have become an increasingly important source and platform for finding and exchanging information and experiences around health and for providing a space for building relationships and support (Ziebland & Wyke, 2012). Social ties established online were shown to provide people living with chronic health problems with ready access to support to help self-manage their conditions and address aspects of self-management that are particularly difficult to meet offline (Allen et al., 2016). We will return to the potential of digital technology in supporting and enabling person-centred services and systems below.

Where to go from here?

The preceding sections have highlighted how contemporary approaches to organizing and governing health care and health systems largely fail to deliver person-centred care at the different tiers of the system. This is not to say that no progress has been made since the 1978 Alma Ata

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declaration, which advocated for the "right and duty to participate individually and collectively in the planning and implementation of their health care". Indeed, as this book has illustrated, countries have engaged and are engaging in a range of activities that aim to strengthen person-centredness at the different tiers of the system, but approaches tend to be disjointed, often focusing on the micro-level of the individual service user–professional relationship while neglecting the need to embed such approaches within the organizational and system context more broadly. More importantly perhaps, person-centred strategies, where implemented, often tend to take a professional, or service provider perspective, which may take service user views into consideration, but more often than not without involving people in the actual design of involvement processes, support and measurement tools that are meant to benefit the service user. Overall, such narrow approaches heavily constrain any true development towards person-centredness. Services are provided more or less as before, while support at organizational or system levels tends to remain haphazard. Inconsistent or poorly aligned policy frameworks at meso and macro levels are likely to further undermine the successful redesign of services that take user experiences and preferences into account.

We have highlighted that there is a need to move to a more complex model of engagement that considers people's values and preferences at each level of the system; from the individual patient–professional relationship (micro level) to the organizational (meso) and the governance, finance and wider societal (macro) levels in order to systematically implement person-centred strategies (Chapter 3). This means that we have to challenge the traditional approach to organizing and governing health care and systems by moving away from the profession- and expert-led approach towards enabling and participatory strategies which emphasize respectful and enabling partnership working. Thus, if we accept this challenge and are committed to taking a broader perspective that recognizes people's social context within which they live and make decisions, we need to reconsider the 'boundaries' between service providers and service users and people more broadly. This includes giving due consideration to the experiences of (or, more specifically, experiential evidence generated by) individuals as patients, carers, taxpayers and citizens, and ensure that these are being used strategically to inform the redesign of services at the different tiers of the system.

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To achieve this, there will be a need for more general policies that seek to strengthen the capabilities for engagement across all stakeholders concerned, along with a need to make better use of existing levers, such as digital technologies. This needs to be accompanied by more supply-side oriented strategies that include investment in education and training along with measurement and monitoring to understand what matters to people and how this can be used strategically in the (re)design of service organization and delivery at the different tiers of the system. As noted earlier, we here discuss some of these options, highlighting the opportunities while also considering the barriers that need to be overcome in order to move to more person-centred health systems.

Strengthening and enabling capabilities of people at the different tiers of the system

Making sure that people are able to access information about health and health care that they can understand is seen to be key in supporting them to be involved in decisions and to make choices that benefit their health and well-being and the system more broadly (Kickbusch et al., 2013; Nutbeam, 2000). The inability to do so has been linked to poorer health outcomes among older people, increased service use such as hospitalizations and emergency care, and lower use of disease prevention services (Berkman et al., 2011), and it is viewed as an important determinant of health inequalities (Kickbusch et al., 2013).

The concept of 'health literacy' has been gaining increasing traction among policy-makers, practitioners and researchers alike. Better understanding of the potential that enhancing related skills and competencies can have on improving the health and well-being of individuals and populations and on reducing inequities in health has contributed to its inclusion as an important dimension in national and international health strategies, such as the Health 2020 health policy framework for the World Health Organization European Region (World Health Organization Regional Office for Europe, 2013). At the same time, among countries in the European Union, health literacy is only beginning to be addressed through relevant policies and initiatives, and the available evidence does not yet allow drawing firm conclusions about their impacts (Heijmans et al., 2015).

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Health literacy has been, and continues to be, variously defined. A widely used understanding refers to the knowledge, motivation and competencies of accessing, understanding, appraising and applying health-related information within health care, disease prevention and health promotion settings (Sørensen et al., 2012), with Dodson, Good & Osborne (2015) emphasizing the social resources needed to enable people realizing this vision in practice. These interpretations place health literacy in a broader public health model that highlights the complex interdependencies between health understanding, health attitudes and behaviours. They also consider the social determinants of health, such as income, education, the material environment and gender, as well as the design and delivery of health services, in turn highlighting the requirement for a system-wide response to meet individual needs (Greenhalgh, 2015) (*see also* Box 4.4). The importance of the broader context has been conceptualized as health literacy responsiveness, which describes "the way in which services, environments and products make health information and support available and accessible to people with different health literacy strengths and limitations" (Dodson, Good & Osborne, 2015, p. 12). This wider interpretation implies that interventions that rely solely on educational programmes to advance health literacy are likely to fail (Greenhalgh, 2015); instead a strategic response will be needed that not only takes account of individuals' and communities'

Box 4.4 Health literacy levels in European countries

The first European comparative survey on health literacy was conducted in 2011 in eight European countries (Austria, Bulgaria, Germany, Greece, Ireland, the Netherlands, Poland and Spain) (Sørensen et al., 2015). It found that across all eight countries, almost half of all respondents showed very low ('inadequate') or low ('problematic') levels of health literacy, ranging from just under 29% in the Netherlands to around 60% in Spain and Bulgaria. The strongest predictor for low levels of health literacy across all countries was financial deprivation, followed by low social status, low educational attainment and older age. Similar findings were reported for the adult working-age population in England, highlighting that people most in need for health information appear to have least access to it (Rowlands et al., 2015).

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strengths and the constraints that influence how effectively they engage with health information and services, but also introduces change in ways that reduce health inequalities.

There is a persuasive argument that addressing health literacy at the community level holds great potential for improving health knowledge, skills and behaviours, which in turn is expected to lead to better health outcomes (Beauchamp et al., 2017). Yet it remains unclear, for now, what a health literate population should look like and the approaches that would be suitable for its measurement (Guzys et al., 2015). More importantly perhaps, it remains unclear how 'the public' thinks about the idea of health literacy and there appears to be a suspicious absence of the public voice in contemporary conceptualizations of health literacy. By the same token, it is important to recognize that in order to be effective, strategies to strengthen and further advance health literacy should go beyond the individual as a (potential) service user and communities. Effective strategies also need to incorporate professionals and providers, as well as managers and decision-makers at organizational and national levels. This is an emergent field although work is ongoing that can provide useful guidance.

Rowlands et al. (2017) noted that among the health workforce, health literacy appropriate skills, knowledge and attitudes tend to be low, often reflecting the lack of inclusion of health literacy in education and training (Groene et al., 2017). Initiatives to build such skills and competencies among professionals are emerging, but more work needs to be done to better understand the impacts of a more skilled workforce in health literacy on quality of care and service efficiency more broadly (Rowlands et al., 2017).

To help operationalize the shift to a systems perspective, members of the US National Academies of Sciences, Engineering, Medicine Roundtable on Health Literacy defined 10 attributes of a health literate health care organization (Brach et al., 2012). These recognize that health literacy improvement is increasingly being viewed as a systems issue and that action is required on multiple levels. While developed in the context of the USA, the attributes have been adapted in other system contexts, including Australia and New Zealand. Trezona, Dodson & Osborne (2017) advanced the idea of health literate organizations further by developing the Organisational Health Literacy Responsiveness (Org-HLR) framework. Involving professionals from across the health

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and social services sectors in Australia using a series of workshops, the authors identified seven domains of health literacy responsiveness:

(i) *External policy and funding environment*: relates to the role of governments and other relevant bodies in providing adequate funding for programmes, flexible services agreements, incentives and health literacy-specific policy frameworks and standards.
(ii) *Leadership and culture*: describes "the necessary ethos, philosophy and values of a health literacy responsive organisation, which includes being inclusive, person-centred and equity driven" (p. 7) and which recognizes health literacy as an organizational priority.
(iii) *Systems, processes and policies*: refers to intraorganizational measures such as data collection and needs assessment, performance monitoring and evaluation, service planning and quality improvement, communication systems and processes, and internal policies and procedures that are required to provide responsive services.
(iv) *Access to services and programmes*: reflects the need for organizations to ensure that services are accessible to all people, with access defined in terms of geography, physical access, financial access and cultural access. It incorporates the need for providing support for people to navigate the system and outreach.
(v) *Community engagement and partnerships*: describes the need for organizations to "undertake meaningful consultation" and involve individuals and communities in all aspects of service planning, delivery and evaluation. It further stresses the need for organizations to engage in and develop partnerships with other organizations across the health and social care sectors to promote the design and delivery of coordinated services.
(vi) *Communication practices and standards*: refers to the range of strategies and approaches that organizations would need to develop and implement to ensure effective communication across all levels of the organization. These include communication principles, the provision of health information, use of media and technology, and health education programmes.
(vii) *Workforce*: describes the responsibility of organizations to ensure a skilled, competent and motivated workforce through appropriate recruitment and retention policies and the provision of a supportive working environment, practice resources and professional development opportunities.

The Org-HLR framework includes a range of domains that have been identified elsewhere as characteristics of organizations with a

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reputation of improving patient experience (e.g. Luxford, Safran & Delbanco, 2011). The key defining feature is that all domains consider health literacy as a priority and that the framework recognizes the role of the macro-level – that is, the external and funding environment – as a core element that can enable or constrain organizations in their efforts to become more responsive to local population needs. Indeed, as we have illustrated in the context of self-management support specifically (Chapter 12) and care coordination efforts more broadly (Nolte, Knai & Saltman, 2014), available evidence points to the challenges organizations can face when implementing local improvement strategies that are not appropriately resourced or that run counter to the demands placed upon them by the wider system context.

The Org-HLR framework may provide useful guidance for policymakers, managers and practitioners seeking to strategically embed advancing the engagement of people at all levels within the system. Examples of system-wide approaches to embedding health literacy are provided by Austria (Box 4.5) and Scotland (NHS Scotland, 2017), which may usefully inform policy development elsewhere.

Box 4.5 A national strategy to strengthen health literacy at all levels in Austria

Austria included strengthening health literacy among its 2012 ten national health targets (Bundesministerium für Gesundheit und Frauen, 2017) and introduced, in 2013, the 'Österreichische Plattform Gesundheitskompetenz (ÖPG)' (Austrian Platform Health Literacy), which is tasked with the coordination, further development and support of implementation of this target by means of three strategic goals (Österreichische Plattform Gesundheitskompetenz, 2017):

1. *To strengthen the health literacy of the health system*
   This goal focuses mostly on (i) improving the quality of communication and information on health care, prevention and health promotion and (ii) embedding health literacy in the form of health-in-all-policies across all organizations and institutions that impact health.

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Box 4.5 (cont.)

2. *To strengthen individual health literacy with particular consideration of vulnerable groups*
   This goal includes a range of measures seeking to impact the health literacy of individuals both directly and indirectly through measures that aim to strengthen a health literate environment through health-in-all-policies and equal opportunities in health.
3. *To embed health literacy in service provision*
   Measures are yet to be defined.

   An evaluation of the ÖPG in 2016 found that it had established itself as a 'learning platform' that successfully embedded the notion of health literacy across stakeholders, with active engagement of its members (a wide range of national and state governmental institutions and non-governmental organizations across sectors) (Gutknecht-Gmeiner & Capellaro, 2016). The platform was credited with great potential to systematically develop and embed health literacy in Austria and to lead to lasting changes.

Digital technologies to support person-centred care: potential and challenges

Digital health technologies have become increasingly important and they are at times claimed to be the main route into person-centred health services and systems through strengthening empowerment (European Commission, 2012). The available evidence on the benefits of many innovative technologies remains somewhat patchy, however (Castle-Clarke & Imison, 2016). We have seen earlier that the majority of people in Europe uses the internet for health-related information, but only about one-fifth have as yet used health and care services that are provided online, such as getting a prescription or an online consultation (TNS Opinion & Social, 2017). In 2017 the share of those using online health services varied substantially across EU Member States, with people in Estonia, Finland and Denmark most likely to have done so (between 40% and 50%), compared to fewer than 10% in Malta, Germany and Hungary. This variation is likely to reflect, at least in part, the actual availability of online health and care services, along with knowledge about their existence in a given setting, although there are few robust data on this issue. The same study also showed that just over half of

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Box 4.6 Access to and use of e-health portals in Australia, Denmark and Estonia

Nøhr et al. (2017) examined access to e-health portals for residents in Denmark, Estonia and Australia, three countries that have implemented nationwide access to people's health records online. Looking at data for 2015 they found the proportion of those actually logging into the system to be rather low, ranging from less than 1% in Australia and 1–2% in Estonia to about 3–5% in Denmark. Younger people were more likely to access the portal in all countries, as were women in Denmark and Australia, but the proportions varied. For example, in Estonia the highest usage was among men and women aged 20–49, at around 5–7%, with the share steadily declining as people are older. In Denmark the highest levels of usage were seen among women aged 20–69, at around 5%, while among men the share was around 3%, and in both cases the share fell rapidly among those aged 70 and older. Overall usage levels tended to be low, raising questions about the degree to which investment in e-portals that provide residents access to personal health data alone contributes to patient empowerment.

respondents would like to have online access to their medical and health records, with those in Estonia, Denmark and Finland most likely to say so (72–82%), compared to respondents in Hungary, Germany and Austria (32–38%) (*but see* Box 4.6).

A crucial challenge remains the continued digital divide, ranging from principal access to the internet (primary divide) and its use (secondary divide) to comprehension of information on health (tertiary divide) (Latulippe, Hamel & Giroux, 2017). Principal access to the internet has increased across the EU, with, in 2014, about 70% of homes in Member States having a fixed broadband subscription (62% in rural areas) (European Parliament, 2015). The share was highest in the Netherlands and Luxembourg, at over 90%, and lowest in Bulgaria and Romania, at under 60%. About three-quarters of the population reported using the internet on a regular basis (43% almost daily) but some 58 million people did not use it; these were mostly older people and those with disabilities (*see also* Figure 4.1). Some 70% of those who lack basic digital skills were over the age of 55 and the proportion

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of 55–74-year-olds who reported to have never used the internet was highest in Bulgaria, Cyprus, Greece and Romania, at around 70%, and lowest in Denmark, Luxembourg, the Netherlands and Sweden, at around 10%. The latter set of countries are also those which, in 2017, scored highest on the Digital Economy and Society Index in the EU, while Bulgaria, Greece and Romania, along with Italy, scored lowest (European Commission, 2017).

This matters because those who are least likely to use the internet tend to be most vulnerable in terms of health risks and chronic illness, and vice versa. This means that e-health strategies could exacerbate social inequalities in health if not carefully designed (Latulippe, Hamel

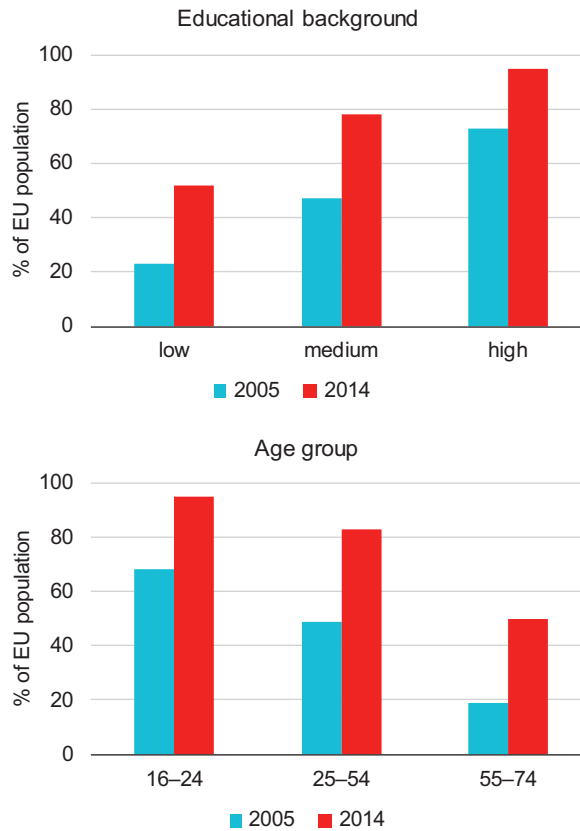

Figure 4.1 Regular internet use among EU citizens, 2005 and 2014

Source: adapted from European Parliament, 2015

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& Giroux, 2017), especially where policies envisage online communities as one way for people to engage in self-management for example. Older people increasingly engage in social media and networks (Anderson & Perrin, 2017), and data from Europe suggest that this is particularly common in the Nordic countries and the Netherlands. Some evidence points to a positive association between use of social networking sites and well-being among older people (Nef et al., 2013; Sims, Reed & Carr, 2017), although others have noted that as their health declines, older people tend to engage less with technology, especially those with new-onset dementia, low physical performance or who have relocated to a nursing home (Levine, Lipsitz & Linder, 2017). Better understanding of the patterns of use may help target digital technology-based solutions, although context remains important (Peek et al., 2017). Thus, as Levine, Lipsitz & Linder (2017) cautioned, "complex everyday and digital health technology reaches few seniors in general" (p. 4).

The implementation and scaling-up of e-health technologies remains challenging

A 2012 review of reviews of the evidence of the implementation of e-health systems found that the 37 included studies that had been published between 1995 and 2009 had largely focused on organizational factors that would enable or hinder implementation (Mair et al., 2012). Studies neglected the wider social framework that should be considered when introducing new technologies. These include the purpose and benefits of e-health systems, along with their anticipated value to users; factors promoting or inhibiting engagement and participation; the impacts of e-health technologies on roles and responsibilities; risk management; and "ways in which implementation processes might be reconfigured by user-produced knowledge" (Mair et al., 2012, p. 357).

Lack of attention to the wider context within which digital health technologies are being introduced was also found to be a major impediment to the implementation of a national digital health innovation programme in the United Kingdom (Lennon et al., 2017). The programme aimed to stimulate a consumer market for person-centred digital technologies, which involved a wide range of products and services (apps, personal health records, telecare, telehealth, wearable activity trackers, etc.) to enable preventive care, self-care and independent living at scale.

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Capturing the experiences of a wide range of stakeholders and over time, an evaluation of the programme found that while there was a general receptiveness to digital health, there remained numerous barriers to routinization of technologies into daily practice at all tiers of the system. Identified barriers included lack of IT infrastructure, uncertainty around information governance, lack of incentives to prioritize interoperability, lack of precedence on accountability within the commercial sector, and a market perceived as difficult to navigate by consumers. These findings highlight a need for greater investment in national and local infrastructure, the implementation of guidelines for the safe and transparent use and assessment of digital health, incentivization of interoperability, and investment in training of professionals and the public.

These observations were broadly confirmed in a subsequent update of the above-mentioned 2012 review (Ross et al., 2016). It highlighted that successful implementation of e-health systems requires multiple factors to be present, including the need for supportive legislation, and recognized standards, as well as the 'fit' of e-health systems with current organizational workflow. The review further noted that although e-health is a rapidly moving field, many factors that are relevant for effective implementation remain fairly consistent over time. These include the need for adequate resources, in particular financial and policy support, as well as standards and interoperability. Based on these findings, Ross et al. (2016) formulated a set of recommendations for the implementation of e-health systems, which are summarized in Box 4.7.

Box 4.7 Recommendations for implementation of e-health systems based on a systematic review of systematic reviews

Updating and re-analysing the systematic review of the e-health implementation literature by Mair et al. (2012), Ross et al. (2016) identified a set of recommendations to help guide more successful implementation of e-health systems. The recommendations are:

- Select an appropriate e-health system, taking into account:
  - Complexity
  - Adaptability
  - Compatibility with existing systems and work practices
  - Cost

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Box 4.7 (cont.)

- Include key stakeholders and implementation champions as early as possible in the implementation process.
- Make available sufficient financial and legislative support to support implementation.
- Establish standards for technology which address interoperability, security and privacy to improve acceptability and implementation.
- Plan implementation, ensuring that organizations are in a state of readiness.
- Provide training and education to all those involved with implementation.
- Implementation does not stop with 'go-live': ensure ongoing monitoring, evaluation and adaptation of systems so that intended goals are being met and benefits realized. This also requires ongoing identification of barriers to effective use, along with strategies to overcome these barriers.

Strengthening and enabling the redesign of services at the different tiers of the system

In order to move to a person-centred system that takes a broad approach we need to better understand what matters to people and whether and how they would like to be involved at the different tiers of decision-making. A first step is to support the development and advancement of health literacy responsive organizations, as discussed above, but this needs to be informed by the systematic assessment of people's experiences, goals and preferences. We also need to better understand and develop further how those who are meant to organize, finance, govern and deliver services have to be supported if we want them to take people's views seriously and incorporate these into service (re)design and delivery. We briefly discuss these issues in turn.

Measuring what matters to people

Arguably, the science of measuring patient-centred outcomes is growing, yet metrics of 'success' continue to be defined by providers and payers

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(Batalden et al., 2016). Coulter, Paparella & McCulloch in Chapter 7 have highlighted the need, at the level of the clinical encounter, for measurement to go beyond individual episodes or services and the prevailing biomedical paradigm. Instead, what is required is the development of measurement tools that reveal people's experiences across clinical pathways and service boundaries, as well as broader indicators that better reflect service users' goals and outcome preferences, along with better measures of concepts such as empowerment, autonomy, care coordination and self-management capabilities. In short, there is a need for novel or adapted measures that recognize the role of the person at the centre and reflect 'what matters to people'. Narrative accounts that describe encounters with clinicians in patients' own words can usefully complement statistical reports of survey data by providing insights into why current practices may not be working well, so informing quality improvement strategies (Schlesinger, Grob & Shaller, 2015).

At the meso and macro levels, new social media platforms have been proposed as a way to share information and narratives about health experiences and public views more broadly, adapting methods used in commercial sectors to better understand and respond to consumers (Rozenblum, Greaves & Bates, 2017). Monitoring social media may give providers insight into the drivers of a service user's assessment of their experience during an encounter with the service. Rozenblum, Greaves & Bates (2017) further highlighted the potential of social media to engage service users in ways that can directly impact behaviours and promote positive health outcomes, patient satisfaction, care delivery efficiency and improved quality of care. They also offer providers with a 'new set of information' suitable to inform the design and improve the delivery and evaluation of care. However, wider use of social media for the purpose of monitoring people's experiences and engaging them in the health service needs to carefully consider population groups that are least likely to use this format but whose voices may be most important to be heard; thus there remains a continued bias towards the young, wealthy and technologically savvy. There also remain concerns regarding privacy, stigma and patient consent, along with broader ethical concerns around online monitoring of social media platforms by providers (Rozenblum, Greaves & Bates, 2017), requiring careful attention to be given ways to protect privacy.

Importantly, as Coulter, Paparella & McCulloch note, if people's views and experiences are to be usefully incorporated into efforts to

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improve equitable and responsive delivery of health care, those measuring and monitoring these perspectives will need to be clear about the purpose of collecting related data. For example, whether data are being used for external reasons such as the provision of information for consumer choice, public accountability or pay-for-performance, or for internal use by providers as part of quality improvement schemes (Box 4.8). Each goal may be legitimate but requires the design of approaches that are appropriate for this purpose. Crucially, any such measurement will require service user and wider public input to ensure that we capture what matters to people. There is considerable potential for countries to collaborate and develop and test methods for ensuring that people's views and experiences are taken seriously and inform the (re)design of service organization and delivery at the different tiers of the system.

Box 4.8 Measuring and reporting the performance of institutions and practitioners in health care

The public release of information on the quality of health (and social) care delivered by identified providers can be seen to be located within broader concerns about accountability of health and social care systems. Reporting on provider performance aims to help hold the various actors in a given system to account by informing stakeholders and so enable them to make decisions, to facilitate the selection and choice of providers by service users and purchasers of care, to influence provider behaviour to enhance the quality of care, and to strengthen transparency of the system as a whole (Smith et al., 2009). Much of the published work on public reporting centres on the reporting of performance data of hospitals (Cacace et al., 2010), including, in the USA and the UK, individual surgeons (Behrendt & Groene, 2016), and, more recently, long-term care, while similar efforts within primary care are only emerging (Rechel et al., 2016).

One of the key objectives of public reporting systems is to support service user choice, yet available evidence suggests that people rarely search out information about the quality of care delivered by providers (Hussey et al., 2015). Low uptake of published information suggests that the available data do not sufficiently meet patients' information needs (Damman et al., 2009). Public reports

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Box 4.8 (cont.)

vary widely in their accessibility, data transparency, appropriateness and timeliness. Variability of results can be confusing for users searching more than one website and it provides a potential source of bias and unfairness towards providers when used by regulators, purchasers or, indeed, service users (Austin et al., 2015). Further, few systems systematically involve service users or the wider public in the design of systems, including the selection of information to be reported on.

Lack of evidence does not imply lack of impact, however. There remains a shortage of rigorous evaluations of many major public reporting systems and there are also serious measurement problems. The effects of information systems on quality of care are difficult to isolate as these are frequently part of broader quality initiatives. Several authors have highlighted the risk of unintended consequences of the systematic reporting of information on quality of care delivered by identified providers. One example includes providers avoiding high-risk cases in an attempt to improve their quality ranking. Also, public reporting may result in providers focusing on improving those indicators that are reported on, such as waiting times, while diverting attention away from other, non-reported areas (Smith et al., 2009).

Investing in education and training

The move to person-centred care has considerable implications for the training of health and care professionals and how this needs to be adapted to enable professionals, organizations and systems engaging in a true partnership with individuals as service users and the wider public to provide the support appropriate to their preferences and needs. The delivery of person-centred care will require a new range of knowledge, skills and competences for professionals, managers and decision-makers but, as we noted in the context of health literacy above, our understanding of how to develop the workforce to put person-centred approaches into practice remains patchy (Box 4.9).

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Box 4.9 Skills education and training framework for person-centred care in England

In England the national agency responsible for coordinating education and training within the health and public health workforce, Health Education England, published a skills education and training framework for person-centred care in 2017 (Health Education England, 2017). The framework is aimed at workforce leads to help them understand the knowledge, skills and capabilities of a person-centred workforce. It places communication and relationship-building skills at the core, setting out the underlying values and behaviours, juxtaposing desirable (what people receiving care and their carers would like to see in practice) and undesirable practices, along with learning outcomes that would be expected from education and training for staff to realize person-centred approaches. Importantly, the framework recognizes that developing new skills and knowledge on their own will not be sufficient to realize person-centred approaches and it highlights the need for a supportive system and culture within organizations that encourages and fosters behaviour change. It considers system levers for embedding person-centred communication and support in daily practice, including leaders and managers in organizations, human resources and organizational development, commissioners of services, education and training providers and the wider system, including regulators and professional bodies.

Managers need to consider approaches of how to best support their staff in implementing person-centred approaches. This will involve making relevant activities a priority, which in turn requires the ability of organizations to do so against the background of demands placed upon them by the wider system context. This also highlights the need for the wider policy framework to be alert to the potential tensions and unintended consequences of policies, and to create a policy environment that provides the means for those who are asked to implement change to acquire the actual capacity and competence to do so.

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Health(care) system redesign

Our exploratory review of the evolution of person-centredness (Chapter 2) highlighted that much of the evidence on person-centredness has tended to focus on the interpersonal level between the care provider and the individual service user, while wider contextual issues at organizational level, let alone the systems level, have only rarely been addressed explicitly. These are heavily influenced by the relationships between different actors and institutions, and the wider regulatory, economic and cultural framework within which organizations and systems are embedded. This will make it difficult to identify specific levers and strategies for how to support and enable redesign that will fit all contexts. However, the available evidence does provide some important pointers that should be useful for all stakeholders involved, irrespective of health system characteristics. One source of evidence is Liberati et al. (2015), who reported a narrative review of studies examining organizational facilitators and barriers for achieving person-centred care. We summarize the findings of selected studies included in the review in Table 4.1. Identified levers for the implementation of person-centred care include a committed senior leadership as well as engagement of staff, service users and the wider community at all levels. This requires systematic measurement and feedback to continuously monitor people's experiences and a culture supportive of change and learning. Such an approach needs to be embedded in a wider policy framework, which ensures that there are clear incentives and lines of accountability that are supportive and aligned with the strategic vision of person-centredness.

The organizational levers described in these and related studies (e.g. Frampton et al., 2008) resemble in many ways the mechanisms and processes that were identified as the key drivers of large-system transformation in health care more broadly (Best et al., 2012) (Box 4.10).

Similar observations were reported by Hobbs (2009) in her review of concepts of patient-centred care. This highlighted the importance of the organizational and institutional context, with the distribution of authority and interaction of systems found to be of particular relevance. Thus, organizations that relied primarily on a command-and-control style of leadership were less likely to provide person-centred care compared to those with shared governance.

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Table 4.1 *Levers for the implementation of person-centred care innovations in health care organizations*

	Shaller (2007)	Luxford, Sanfran & Delbanco (2011)	Hernandez et al. (2013)
Levers identified	– senior leadership, sufficiently committed and engaged to unify and sustain the organization in a common mission – strategic vision that is clearly and constantly communicated to every member of the organization – involvement of patients and families throughout the organization – supportive and respectful work environment that engages employees in all aspects of process design – systematic measurement and feedback to continuously monitor the impact of specific interventions and change strategies – built environment providing supportive and nurturing physical space and design for patients, families and employees alike – supportive technology that facilitates information access and communication between patients and caregivers	– strong, committed senior leadership – clear communication of strategic vision – active engagement of patient and families throughout the institution – sustained focus on staff satisfaction – active measurement and feedback reporting of patient experiences – adequate resourcing of care delivery redesign – staff capacity building – accountability and incentives – a culture strongly supportive of change and learning	– effective leadership, with the necessary technical and professional expertise and creative skills – strong internal and external motivation to change – clear and internally consistent organizational mission – aligned organizational strategy – robust organizational capability – continuous feedback and organizational learning

Box 4.10 Key factors that are likely to enhance the success of large-system transformation initiatives in health care

Best et al. (2012), in a realist review of examples of successful and less successful large-system transformations initiatives in health care, identified five factors or 'simple rules' that are likely to enhance the success of large-system transformation initiatives in health care:

- *Engage individuals at all levels in leading the change effort* through an explicit alignment of the formal vision and goals by top and middle-managers; an active management of the change strategy; small-scale pilot projects (to demonstrate to actors that change is worthwhile and possible); and assurance that people will not be penalized for taking actions that are part of the transformation.
- *Establish feedback loops* through active participation of all relevant stakeholder groups to determine the nature and range of measures to be used; ensuring actors' confidence in the validity of the measures, their understanding of what these mean and their ability to influence and revise the measures; and the inclusion of incentives (or penalties) for (not) acting upon feedback from reported measures.
- *Attend to history* through educating the leadership throughout the system about previous change efforts and their outcomes, along with factors that influenced outcomes in those efforts; and building on familiar and valued ideas and activities.
- *Engage physicians* through the alignment of professional and regulatory drivers; of the incentive structure; facilitation and guidance through the process; and professional examples through engaging physician leaders.
- *Involve patients and families* through increasing awareness among policy-makers and change agents of people's perspectives and priorities; increasing awareness that metrics reflect users' priorities; and increasing sense of equity that changes are inclusive and equitable.

Hernandez et al. (2013), in their assessment of person-centred innovation in health care organizations, highlighted the role of internal hierarchies in shaping person-centred care. They drew attention to the importance of external financial incentives and government regulations.

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The role of incentive schemes in driving more person-centred care has been emphasized by a number of commentators. It has been argued that incentive schemes that focus on vertical, disease-specific biomedical outcome measures are likely to hinder the implementation of more horizontal and person-centred strategies that take account of the wider context within which people live (Heath et al., 2009) and which, as we have shown, will be important to support people living with their conditions (Reidy et al., 2016). Furthermore, as Schlesinger, Grob & Shaller (2015) have pointed out, strong financial incentives for biomedical or clinical outcomes risk undermining valued aspects of the service user–provider relationship. This implies that unless public policies, which have historically undervalued service user experience, are attentive to people's views more broadly, strong financial incentives for clinicians can threaten aspects of care that users most value. This in turn suggests that integrating user feedback with financial incentives and implementing these in ways that recognize the importance of non-financial incentives for quality improvement may help protect and promote user-valued outcomes. As with any scheme that involves financial incentives, the development and implementation would require a coherent strategic vision (Schlesinger, Grob & Shaller, 2015).

We have also noted earlier that person-centred approaches inevitably challenge standardization, with the latter having played an important role in reducing unintended variation in health services and contributed to improved quality and safety (Batalden et al., 2016). This too would caution any financial incentives linked directly to treatment measures. What is needed is flexibility to allow for 'intended' variation, with service providers responding to the needs and preferences of individuals and communities through active engagement and partnership while also offering the option of not being involved or not needing to choose if people prefer not to. As mentioned by Luxford, Safran & Delbanco (2011), such flexibility also stresses the importance of time needed for transforming service delivery towards person-centred care.

While financial and non-financial incentives that incorporate person-centredness may support incremental change, more efforts by those who organize, finance and govern health care are likely needed to support more fundamental redesign of service delivery. This view was recognized by Luxford, Safran & Delbanco (2011), who identified adequate resourcing of care delivery redesign as a lever for implementation of person-centred care. More fundamental or radical changes will likely need to be developed separately and tested against

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regular care before they are implemented more generally. Although such steps and practices are perhaps novel at the organizational and systems levels, they are fully accepted at the clinical level. This also suggests that adoption of similar steps and a systematic approach of exploration, evaluation and organizational learning may be an important lever towards real change. However, core to any of these moves will be the systematic and serious inclusion of the perspective of 'the public', as service user, carer, community, taxpayer or citizen, in the redesign of services at the different tiers. While it is encouraging to see that person-centredness has become a key priority for policy-makers nationally and internationally, those involved in service and system design would do well to recognize that the public voice still remains pretty much absent in many of the local strategies that are being considered to achieve this. This is a fundamental shortcoming and should be addressed by leaders at the organizational and system levels as a matter of priority. We hope that this book will help to support this process.

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