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Person-centred health systems: strategies, drivers and impacts

ELLEN NOLTE, ANDERS ANELL

Introduction

Patient/citizen participation should be an integral part of health care systems and, as such, an indispensable component in current health care reforms.

Council of Europe, 2000

As the notion of person-centredness of health services and systems is becoming more established in national and international policy declarations and commitments, there is a need to better understand and clarify the use and usefulness of relevant strategies and approaches that seek to improve the position of individuals, their families and communities in the health system.

This book takes as a starting point the various roles people take in health systems, while recognizing that these roles overlap and may be performed simultaneously (*see* Chapter 1). Indeed, as Coulter (2002) suggested, the 21st-century health service user is at once “a decision-maker, a care manager, a co-producer of health, an evaluator, a potential change agent, a taxpayer and an active citizen whose voice must be heard by decision-makers” (p. 6). Viewed through this lens, a greater person focus can contribute to advancing equity, efficiency and the responsiveness of health systems. For example, service user choice of provider may increase satisfaction because individuals choose the provider they prefer; it may increase efficiency because people are using their voice (and, where possible, exit) to express dissatisfaction, which then may lead to enhanced service quality to better meet individuals’ needs; and it may decrease inequity because more knowledgeable service users may be better equipped to exercise choice. Likewise, involving people in health care planning and decision-making may positively impact service user satisfaction as it might increase the likelihood that their views are taken seriously; it may also impact on equity if lay

involvement is representative of the views of the local population in provider governance and service delivery.

However, the degree to which any of these aspirations will be met will depend, to a great extent, on how relevant strategies and policies are designed and implemented, and by whom. Inevitably there will be trade-offs and there may be unintended consequences. Thus, it is conceivable that policies that seek to involve people in health care decision-making but where the decision-making space is driven by policy and clinical priorities, rather than by patients or the public, may be perceived as tokenistic or not making a difference, and so lead to disengagement (Peckham et al., 2014). This is likely to weaken rather than strengthen the individual's role in the system. Likewise, where lay involvement is not representative of the wider population, those participating might constrain their contributions and so inadvertently reduce, rather than enhance, public influence on health service decisions (Martin, Carter & Dent, 2017).

Building on the principal framework of voice, choice and co-production as described in Chapter 1, Chapters 5–13 explore these issues further. They examine the different roles people take in health systems, from engaging in and leading on health service and system development (Chapter 5) and research (Chapter 6), evaluating the quality of health services and systems (Chapter 7), and making decisions about purchasers or providers of individual care packages and specific services (or choosing not to do so) (Chapters 8–10), to participating in their own care (Chapters 11 and 12), along with legal frameworks seeking to ensure that people can exercise their rights as taxpayers and citizens (Chapter 13). Each chapter contributes a different perspective on person-centred strategies and describes the outcomes, both positive as well as unintended.

This chapter synthesizes the main insights and lessons that emerge from the in-depth analyses presented in Chapters 5–13. Inevitably there will be overlap between the individual chapters that are being presented here. This is intended: this chapter is aimed at extracting the main messages for readers who wish to gain an instant overview of the key issues that are being discussed in the detailed syntheses in the second part of the book. In examining the different perspectives we identify a number of common themes which we then summarize and analyse in further detail in Chapter 4.

The person at the centre of the health system: insights from different roles individuals can take

Engaging in health service and system development and research

In Chapter 5 Draper & Rifkin explore the contribution of community participation to health systems and to people's health, and highlight the core role that has been ascribed to participation both as a means to improve service provision and utilization and to achieve greater equity in health care, a main driver behind the Alma Ata Declaration of 1978 (World Health Organization, 1978). Yet the authors caution that while the evidence to support policies addressing equity has successively strengthened, policies to promote community participation have struggled to find strong supporting evidence and direction. One major reason for the relative lack of robust evidence around the contribution of community participation to health improvements is that relevant strategies often fail to account for a number of factors. These include defining realistic outcomes of what could be achieved, considering the complex reasons why people do or do not wish to participate, and understanding the degree to which a given strategy empowers people to actively engage and to engage in ways that lead to the desired outcomes (Rifkin, 2012). Policies advocating community participation tend to combine different rationales. They often simultaneously seek to achieve more effective (and potentially more efficient) health services by incorporating public or community views while also recognizing that people have the right to be involved in those decisions that affect them. However, this can lead to tensions inherent in the underlying political and societal values, representing utilitarian or consumerist views on one hand, and a democratic or rights-based perspective on the other. Furthermore, the extent to which power should be devolved to community members remains contested.

Draper & Rifkin highlight the renewed interest in community participation internationally, and by exploring a range of experiences in European settings they find that community participation in the context of health service design and delivery is very variable in terms of who is engaged, for what, how and why. They highlight that the reasons for people to get involved, and the subjective benefits gained, are complex, ranging from personal benefits (e.g. achieving a sense

of purposeful action) to considerations of contributing to the ‘public good’. Yet there is also evidence of unintended negative consequences, such as stress and fatigue caused by demands placed upon people. This underlines the need for community participation programmes to be realistic and take account of the ability of marginalized people in particular to participate. Importantly, the authors show that community participation can make a difference, but not always. Factors that have been associated with positive outcomes include appropriate financing of the initiative, logistics and systems of communication, and partnerships with relevant organizations (Tempfer & Nowak, 2011). Overall, the evidence of impact of involving people in health service planning and development, and health care decision-making more broadly, remains difficult to establish. At the same time, the authors emphasize that while there is a lack of clear empirical evidence on the outcomes, the process of participation in itself can have its own benefits and intrinsic value.

Moving forward, it will be important for all stakeholders involved in the development of community participation in health services and systems to agree what it is they seek to achieve and how. Central to any such effort will be ownership by the community, with power-sharing identified as key to enable transformation of community action that is sustainable (Marston et al., 2016). Participation should be conceptualized as a *process* that facilitates a given intervention or strategy, rather than as an intervention in itself that can then be studied in terms of its effects on health outcomes. This would enable reflection on how intended beneficiaries view their role in the process. There is a need to take account of the wider context within which communities operate and function and this should be core to any evaluation to strengthen the evidence base for community participation in health systems development, with successes as well as failures to be shared widely to inform learning.

The rationales identified as key drivers for community participation can also be seen to have shaped much of the emergence of patient and public involvement (PPI) in research, although, as Beresford & Russo note in Chapter 6, this evolution needs to be interpreted in the context of broader social and political developments. Focusing on the UK initially, the authors contrast the influence of the emancipatory disability research emerging in the 1970s, which sought, among other things, to equalize the relationships of research production between researcher

and the researched, with more recent researcher and service system-led initiatives. It is, however, the latter that has tended to dominate contemporary approaches to user involvement in research nationally and internationally, and the authors illustrate this with a small number of examples of PPI initiatives in research, such as INVOLVE within the UK National Institute for Health Research (National Institute for Health Research, 2017).

PPI in health and social care research takes place at different levels and intensities, from no involvement to consultation, contribution, and collaboration, through to user control. PPI also takes place at different stages within the research process (from identifying the research topic and designing the research to writing-up findings and dissemination), as well as the wider research infrastructure (from identifying and setting research agendas and research priorities to editorial roles in research journals and speaking on research platforms). However, as Beresford & Russo clarify, while there are isolated examples for each of these, PPI in research still has some way to go towards becoming an accepted feature in the research landscape. Importantly, the authors highlight that the research process and infrastructure remain dominated by professional expertise. This is confirmed in an analysis by Nasser et al. (2017) of efforts by 11 research funding organizations in seven countries to reduce waste in research. It found that grant-awarding committees continued to be dominated by academics and clinicians.

Evidence of the impact of PPI in research suggests that involving patients and the wider public can have beneficial effects on service users, researchers and communities (Brett et al., 2014b), as well as on the quality and appropriateness of the research itself (Brett et al., 2014a). However, it will be important to understand whose perspective is being measured, as this will determine the criteria used for assessment and what will eventually be referred to as 'evidence'. The quality of research is traditionally assessed on grounds of scientific criteria (from applications for funding to academic dissemination of findings). This approach may risk undermining and devaluing participation and the systematic incorporation of experiential knowledge generated from lived experiences of users in the research process. This, the authors highlight, is increasingly seen as problematic, especially with regard to the engagement (or lack thereof) of vulnerable populations such as older people, people from minority backgrounds, refugees and asylum seekers, and others.

Thus, as Beresford & Russo conclude, if PPI in research is to develop effectively as part of the mainstream, there is a need for a series of strategies that systematically address identified tensions. Similar to what we have learned from the review of community participation in health service and system development (Chapter 5), there is a need for strengthening the theoretical underpinnings of research with patient and public involvement, and of the evidence base more broadly. This process requires the comprehensive evaluation of user involvement in research, taking due account of the context within which any such approach is being implemented and improving the sharing of learning from PPI in research. Ensuring greater PPI in research structures will be of particular importance, as will be adequate resourcing if PPI in research is seen as a means to improve the appropriateness and relevance of health research. This includes building capacity to support the development of PPI and user-controlled research, improving access to PPI in research especially for vulnerable or marginalized populations, and supporting user-controlled organizations.

Evaluating the quality of health services and systems

Coulter, Paparella & McCulloch in Chapter 7 focus on the role of the individual (as a patient, a service user, member of the public or citizen more broadly) in the evaluation of the degree to which a given health system is person-centred. People's views on the quality of care and their experiences of care constitute key indicators of person-centred care (*see also* Chapter 2). The authors highlight that measuring people's views and experiences is important for both intrinsic reasons (person-centred care is a dimension of quality in its own right, i.e. the philosophical argument) and extrinsic motivations (person-centred care is a means to improve the quality of care, i.e. the performance-based argument) (Berwick, 2009).

Person-centred care includes both functional aspects, such as access to care, waiting times, physical environment and amenities, and interpersonal or relational aspects, especially communication between service users and professional staff. The authors note that while both are important, relational aspects are likely to have the greatest influence on the way people evaluate the care they receive (Entwistle et al., 2012). It is these aspects that are more closely linked to positive outcomes, such

as self-rated health, adherence to recommended treatments, and lower health care resource use such as hospitalizations and primary care visits, among others (Doyle, Lennox & Bell, 2013). Yet despite their key role, interpersonal characteristics such as the quality of care relationships do not tend to be covered by existing health care quality frameworks (Entwistle et al., 2012).

Coulter, Paparella & McCulloch further highlight that capturing public and patients' perspectives on health care is becoming increasingly important as systems strive to be more responsive to the needs of those using their services. Many European countries now have implemented related measurement programmes and policies on the public release of quality data at national or regional levels. They illustrate these approaches with a number of country examples, finding that the publication of data on patient satisfaction, patient-reported experience and patient-reported outcomes (PROMs) (Box 3.1) is widely seen as an important way to hold providers to account for the quality of care they deliver ('voice') and for providing patients with information to act as 'discerning consumers' ('choice'). The evidence of whether or not these aspirations are being met remains scant, however (Roland & Dudley, 2015; Schlesinger et al., 2014) (*see also* Chapters 8 and 9).

Box 3.1 Approaches to collect data on people's views and experiences of care

Approaches to collect data on people's views and experiences are often focused on measuring satisfaction, that is the extent to which health care fulfils people's expectations (e.g. by answering the question, 'how satisfied were you with your care in hospital x?'). Yet, as Coulter, Paparella & McCulloch caution, such assessments are unlikely to reliably capture the complexities of modern health care and the diversity of patients' expectations and experiences. There is increasing interest in gathering factual reports on what actually happened to people during, for example, a particular service or an episode of care, such as through surveys of patient-reported experience measures (PREMs). Alongside these, patient-reported outcome measures (PROMs) are receiving attention as a potential means to improve process and outcomes of care, and to reduce

Box 3.1 (cont.)

inappropriate care (High Level Reflection Group on the Future of Health Statistics, 2017). PROMs measure patients' perceptions of their health status, clinical outcomes, mobility and quality of life, using standardized questionnaires. They are currently mostly used for clinical research and to facilitate shared decision-making between clinicians and patients to improve clinical practice; their wider use for performance measurement or to inform decision-making is not yet common.

A key challenge that remains concerns the timeliness of survey data to inform improvement activity, given the time that is required to collect experience data that are representative and reliable. This has led to a search for briefer, easy to implement measures, such as the collection of real-time feedback during routine clinical activities. These ask patients (or their carers) about their experiences while they are still in a given service setting (hospital, clinic, GP practice, etc.) or shortly thereafter. However, such methods remain problematic because of their unsystematic approach to data collection, which reduces their reliability as a performance indicator (Coulter, 2016; Sizmur, Graham & Walsh, 2015).

An increasingly important source of data on people's experiences of health care is social media. As Coulter, Paparella & McCulloch highlight, there is an increasing number of websites that collect unstructured feedback from patients about their experiences, such as PatientsLikeMe (patientslikeme, 2017), while health care providers have been setting up social network pages such as through Facebook inviting their patients to review the care they have been receiving. There is some evidence of a positive association between objective quality measures and Facebook reviews of hospitals, with Lagu & Greaves (2015) proposing that hospitals that are active on social media and that "encourage patients to provide ratings and feedback are the hospitals that are most concerned with patient-centeredness" (p. 1397). However, they also caution that patient-generated ratings on social media face the same limitations as real-time feedback data in terms of unsystematic elicitation which reduces generalizability and reliability of data, at least if these are to be used to compare performance across providers.

It is against this background that the authors argue that it is unethical to not act upon information derived from asking people to report their health care experiences. Promising examples of local initiatives that have made systematic use of large-scale surveys of user experiences to improve quality do exist (Haugum et al., 2014), as does the understanding of the key enablers for rolling-out this learning across whole health systems. These, as Coulter, Paparella & McCulloch highlight, include, among other factors, the active engagement of patients and families and workforce policies that embed quality improvement skills in training and staff development, along with adequate resourcing and effective institutional support.

Reflecting on their insights, the authors outline a set of key lessons to be taken forward if the collection of data on people's views on and experiences of care is to effectively inform service and system improvement. They emphasize a number of key principles for establishing national systems of patient experience measurement, if measurement is expected to lead to actual, measurable improvements in the quality of health care. These include, among other things, that measurement should be patient-based, with relevant instruments developed with patient input. Further, the goals of measurement should be clear. For example, is the goal to provide information for consumer choice, for public accountability or pay-for-performance, or for internal use by providers as part of quality improvement schemes or even research? The actual measurement and analyses of patient experiences should be standardized and reproducible, and reporting methods of experience data should be carefully designed and tested. Coulter, Paparella & McCulloch emphasize that national systems for the measurement of patient experiences should be supported by appropriate infrastructure and they call for countries to work together to develop and test methods for ensuring that survey findings are taken seriously and incorporated into quality improvement initiatives.

Making decisions about purchasers or providers of individual care packages and services

Chapters 8–10 look at person-centredness from the perspective of service users as 'customers' who make decisions about purchasers or providers of care packages and individual services (or choose not to do so). Fotaki in Chapter 8 begins by setting the wider context for the

'choice' debate, drawing on the theoretical underpinnings and empirical evidence to understand the rationale for and objectives of choice policies more broadly, along with their impacts. Focusing on choice of health care provider, the author then identifies the likely tensions between choice and the other values that societies (wish to) pursue and some of the practical challenges of implementing any such strategy.

Similar to public involvement policies discussed above, and the more general discussion about arguments to support person-centredness presented in Chapter 1, the introduction of choice policies in the health context can be seen to have both intrinsic value, that is, choice is a 'good thing' that speaks to philosophical principles of individual autonomy and user empowerment, while the utilitarian or performance-based motive views choice as a means to achieving desirable goals such as improving efficiency and quality of care. The former recognizes the need for health systems to respond to the demands of user groups for greater control of health care resources that are available to them, while the utilitarian argument is based on the assumption that service users rationally select high-quality providers based on their needs and preferences. Fotaki traces the evolution of choice of provider policies in a small number of single-payer health systems in northern Europe, highlighting that both arguments permeated relevant approaches. Yet it is perhaps fair to say that the strive for greater quality and efficiency of health services was the key driver in most settings. Thus, in Denmark, England and Sweden choice policies were driven, at least initially, by policy concerns about waiting times in accessing specialist care, with improving access to primary care becoming a greater focus from the 2000s onwards, dominating the choice agenda in Norway and Sweden in particular.

Fotaki then examines the evidence base on the degree to which choice policies have achieved desired impacts. This analysis finds that the majority of people value having the possibility of choice. However, perceptions of choice are influenced by individuals' characteristics and circumstances such as age, gender and health status, and these factors also determine whether they exercise choice at all. For example, evidence from Sweden suggests that highly educated young people, especially women, both exercise and favour choice more when compared to other population groups (Rosén, Anell & Hjortsberg, 2001). Access to information is equally important, and this tends to be worse for people with low educational attainment. This latter point will be particularly

pertinent for policies that introduce or strengthen choice of provider as a means to improve equity in access. Fotaki cites evidence from England, Norway and Sweden that choice can lead to improved access to certain services for some populations and in some settings, but warns about potentially negative impacts for those who are less able to exercise choice, a finding confirmed in a systematic review by Aggarwal et al. (2017). Thus, choice policies may exacerbate existing inequalities if they are not designed carefully with the appropriate structures in place to support vulnerable population groups in particular.

Robust evidence of whether choice of provider improves the quality or efficiency of care remains scant. Overall, it remains difficult to attribute observed outcomes to choice policies as such, given that these tend to be introduced as part of a larger set of reforms. For example, limited work from Sweden and Norway points to increases in patient satisfaction and trust in primary care services, although it is unclear whether this reflects increased choice, or greater capacity and access, or both. The evidence that patient choice of provider leads to greater efficiency is also weak, and it will be important to interpret observed findings in the context in which they were generated (Goddard, 2015).

Based on these observations, Fotaki emphasizes that policy-makers should consider the suitability of provider choice for promoting the goals of health systems and for supporting person-centred care. There is so far no evidence to support that choice policies have increased efficiency or welfare at population level. There is also a need to better understand the information needs of people to help inform choices, and their preferences for choice, including the option of choosing not to choose.

Similar conclusions are drawn by van Ginneken et al. in Chapter 9, which focuses on choice of payer, and more specifically, choice of health insurance. Again noting that choice is generally valued by people, the authors find that the evidence of whether insurance choice leads to higher quality care remains weak. However, it is this latter feature that has largely driven the introduction of choice and competition between insurers in a number of health systems. Reviewing the experiences in Germany, Israel, the Netherlands, Slovakia, Switzerland and the USA, the authors describe considerable variation in the types of choice offered to individuals, highlighting the difficulty people face in making informed insurance choices.

As with provider choice, a core question is whether people exercise choice and their motivations for doing so, or choosing not to. Here

the authors cite empirical evidence from Germany, the Netherlands, Switzerland and the USA that finds that people who change between insurers tend to be young, male, healthy and well-educated. However, as van Ginneken et al. highlight, reasons for moving ('switching') between insurers vary and, importantly, switching does not appear to be motivated by the quality of contracted care providers, or by costs, two of the key assumptions underpinning insurer choice and competition policies. This may be because of the complexity of the information that people have to comprehend in order to make choices, in particular where there are multiple options of what is covered. For example, the authors cite data from Switzerland showing that in 2013 there were 58 insurers offering some 287 000 different policies. Countries have put in place strategies and tools to support people through providing comparative information. Yet the provision of meaningful data that would allow people to make inferences about the quality of care of providers contracted by insurers remains a challenge, as does their presentation in a transparent and easy-to-understand manner.

Concerning the impact of insurance choice and competition, it may thus not seem surprising to find that evidence of improvements in the quality of care is largely absent. This is in part because of the lack of robust empirical research. More importantly perhaps, and similar to what we have seen for choice policies more broadly, it remains challenging to attribute a specific outcome to a specific policy, with the latter typically forming part of a wider reform package. However, the authors point to some evidence suggesting that insurance choice may have led to increased satisfaction with insurance services and, possibly, insurance policies that are better tailored to the needs of individuals in terms of benefits and services. It remains equally uncertain to determine the degree to which insurance choice may have led to more person-centred care. Here the authors point to conflicting impacts, with evidence from the Netherlands and Slovakia suggesting that some insurers have pursued strategies to attract more 'profitable' individuals such as young professionals; contracting for more person-centred care approaches may not be financially attractive to insurers. Many countries are experimenting with new ways of organizing and delivering care to better meet the needs in particular of those with (multiple) chronic conditions. But these strategies are typically driven by motivations other than insurance choice. Risk-adjustment schemes may provide an opportunity to incentivize insurers to focus their attention on those population groups

that would benefit the most from more integrated, person-centred care arrangements, such as those with chronic conditions and vulnerable groups more broadly.

Like Fotaki in Chapter 8, van Ginneken et al. conclude that if insurer choice and competition are to lead to the expected outcomes of improved care quality and person-centred care, there is a need for more strategic consideration of the needs of those who are meant to choose through involving them in the governance, design, operations, learning and purchasing decisions of insurers. In addition, their review suggests that there is also a need to better understand the nature of the information and its presentation that most appropriately meet individuals' needs, by involving people in the design and operation of relevant tools such as comparison websites. The authors further highlight the need for regularly improving and updating the risk-adjustment system to minimize gaming and optimize incentives for contracting for person-centred services. Overall, however, it will be important for decision-makers to be considerate of the wider implications of insurer choice for health systems, including the administrative burden, incentives that may undervalue public health, and possible further system fragmentation, which is likely to undermine rather than promote more person-centred systems.

Finally, Verhaeghe in Chapter 10 explores the evidence around personal budgets and similar schemes that are viewed as an alternative way of purchasing elements of health and social care services. Somewhat in contrast to wider choice policies, and similar to what we have learned about the evolution of public and patient involvement in research (Chapter 6), the origins of personal budgets are closely linked to the independent living and disability rights movement in western countries during the 1970s. This movement argued for greater self-determination and the right of people with disabilities to make decisions about the services that affect their lives. It was only more recently that personal budget schemes gained greater attention as part of a move towards personalization of care to promote choice, with an expectation that greater choice will lead to greater independence and autonomy, which, it is assumed, will then result in improved outcomes that are achieved at lower costs (Gadsby et al., 2013).

Reviewing experiences in Australia, Belgium, England, the Netherlands, Scotland, Sweden and the USA, Verhaeghe finds wide variation regarding the nature and scope of related schemes (Box 3.2), as well as in the drivers behind these. While all seek to place the individual

‘at the centre’ of the process of identifying needs and making choices about the services they expect to best meet their health and/or social care needs, there is also a range of other policy goals. These include cost savings (Australia), reducing care home admissions (Belgium), or strengthening the private sector and diversification in the care market, so increasing service options (the Netherlands).

Box 3.2 Personal budgets and related schemes: an overview

The terminology used under the broad heading of personal budgets varies widely. It includes ‘direct payments’ (England), ‘cash and counseling’ (United States), ‘personal assistance budgets’ (Belgium), ‘assistance allowances’ (Sweden), and ‘consumer directed care’ (Australia), among others. Based on the commonalities between schemes, Verhaeghe uses ‘personal budgets’ as an overarching concept, defining it as ‘an amount of money to be spent by individuals to purchase services to tailor care to meet specific needs’.

Verhaeghe identifies four principal approaches to the way personal budgets are managed. These are:

- direct payment models, in which the individual as the budget holder receives a cash payment or vouchers to purchase services or support;
- third-party payment models in which a third party holds the budget (e.g. a professional, care worker, ‘broker’) who will then assist the individual to access funding; service provision is monitored according to an approved care plan;
- notional budget models in which commissioners are responsible for purchasing services, but the individual is aware of the treatment or service options and the corresponding costs; and
- a combination of one or more features of the above models.

Among the countries reviewed, Verhaeghe finds that most operate direct payments and third-party payment models (England, the Netherlands, Scotland, Sweden, USA), while Belgium uses direct payments and notional budgets. In Australia the self-directed care scheme operates on a model in which the provider holds the budget.

Box 3.2 (cont.)

Schemes in place in different countries also vary in terms of the populations targeted. These differ by age range ('older people' in Australia, USA; 'youth' in the Netherlands) or the nature of needs (e.g. 'long-term care needs' in Belgium, England, the Netherlands, USA; 'physical or mental disabilities' in Sweden; 'psychiatric problems' in the Netherlands). Most schemes are located in the social care or long-term care sectors, with more recent moves also introducing health-related support in the form of personal health budgets. For example, in England people who are eligible for NHS Continuing Healthcare had the right to have a personal health budget from October 2014 onwards (NHS England, 2017b).

Personal budgets and related schemes permit individuals to determine how to spend an allocated budget on care and support services that best meet their needs, such as therapies, personal care and equipment, and so offer individuals more choice and control. Whether this is realized in practice will, however, depend on a number of factors. As Verhaeghe points out, while personal budgets can enhance an individual's sense of control and allow for flexibility in terms of selecting services thought to best meet their needs, there is a risk that people choose services that are not in their own best interest. Also, greater choice brings with it greater personal responsibility, which may disadvantage those who are less able to act upon this without appropriate support, for example older people with complex health and care needs. Family members or third parties can provide this support for those lacking the capacity to manage budgets themselves, but there are concerns about potential financial exploitation by family members or aggressive marketing tactics by third party organizations. Importantly, personal budgets may challenge established ways of working, in particular in the health sector. An inquiry into personal budgets in the UK noted that health care staff can find it difficult to support service users in experimenting with novel ways to meet their health needs, in particular where these counter their own experiences (House of Commons Committee of Public Accounts, 2016) or where these require additional capacity that is not available.

Similar to what we have seen for choice of provider and insurance, access to comprehensive information will be crucial to help inform choices but countries vary in terms of the data that are made available (Gadsby et al., 2013). Overall, as Verhaeghe notes, there is a lack of evidence about ‘best practices’ regarding the nature and scope of information that should be provided, or the training or support needs of service users. Likewise, while there is some evidence that personal budgets can improve choice, control, well-being and quality of life, evidence of their impact on health outcomes, costs and value for money remains scarce. There is thus a need for better understanding of what strategies work best for whom and under what circumstances, and of what people want. Available evidence suggests that while people wish to be informed about available options they do not necessarily want to make decisions themselves without adequate (professional) support (Davidson et al., 2013). Verhaeghe asserts that the provision of financial support through the use of personal budgets is only one way towards more personalization in health and social care and that any such scheme must be embedded in wider policies towards people with health and social care needs.

Partnering in the care process

Chapters 11 and 12 explore the role of individuals as participants in their own care. Légaré et al. focus on the role of shared decision-making (SDM) in the clinical encounter, which they define as an “interpersonal, interdependent process in which health professionals, patients and their caregivers relate to and influence each other as they collaborate in making decisions about a patient’s health care” (p. 284). They trace the origins of SDM to the early 1970s in the USA as a potential solution to address observed practice variation as well as over-, under- and misuse of services through enabling people to choose alternative treatments in line with their preferences. The concept has subsequently been taken up widely in national and international policy, and it is generally seen to form a core component of person-centred care (Coulter, 2017), along with self-management (*see below*) and personalized care planning (Coulter et al., 2015). Yet, as Légaré et al. caution, while we know much about the impacts of SDM tools (such as decision aids), our understanding of the full complexity of SDM and its implementation in clinical practice remains inadequate, and this might explain why its adoption by physicians has been slow.

Reviewing the experience in Europe and elsewhere, the authors find widespread acceptance of the ‘ethical imperative’ for health care professionals to share important decisions (Salzburg Global Seminar, 2011). Many countries have formally recognized SDM in policy and regulatory frameworks as part of a move towards more person-centred care, typically in the context of legislation on patients’ rights to informed consent and information (Chapter 13). Moreover, countries are also stepping up their efforts to develop broader strategic policy frameworks for SDM, such as through formally incorporating SDM in medical education and training, the promotion of coordinated, nationwide implementation bringing together professional associations and patient organizations, or national initiatives to make available patient decision aids (Härter et al., 2017). Yet despite this progress, the routine implementation of SDM into daily practice or at the system level has yet to be achieved (*see also* Box 3.3). They cite evidence of barriers at the level of the individual patient and health care provider as well as the organizational and system levels. These barriers, they argue, result from a combination of individual attitudes, beliefs and trust, but more importantly perhaps, the inconsistent evidence base about the risks and benefits of SDM and a continued lack of agreement on ‘best practices’ that would enable systemic support for the routine implementation of SDM at the different tiers of the system.

A particular challenge identified by Légaré et al. relates to the issue of power, which we have seen to be of concern also for the implementation of patient and public involvement in service development and research discussed earlier (Chapters 5 and 6). Thus, the authors argue, SDM requires an explicit sharing of power and knowledge in a relationship that has traditionally been dominated by the clinician, and this might be difficult to achieve in more deferential cultural contexts. This highlights the need for the development of approaches that take account of context and that involve stakeholders from diverse backgrounds, in particular those groups that may find it challenging to understand risk–benefit information. The authors further note that much of the work on SDM has focused on the doctor–patient relationship and there is lack of understanding about perceptions at organizational and system-level decision-making.

It is against this background that Légaré et al. support the need to move to a more complex model of engagement that considers people’s values and preferences at the level of the individual patient–professional

Box 3.3 Assessment of the 2015 Patient Act, Sweden

The Swedish Patient Act came into force in 2015. Its overarching aim was to strengthen and clarify the position of the patient and further promote their autonomy, self-determination and participation (Vardanalys, 2017). Seeking to protect patients' rights and interests, it stipulates that individuals are to be informed about their health problem and the treatment options that are available. Patients have the right to participate in all decisions about their care and they must also be informed about where they can obtain the care they need (1177 Vardguiden, 2016).

An assessment of the implementation of the Patient Act over the period 2014–2017 found, however, that the patient's position had not perceptively strengthened since its introduction (Vardanalys, 2017). Drawing on a survey of patients, legal guardians of children and the population more widely pre- and post-implementation of the law, the analysis found that respondents' perceptions of some aspects had actually worsened between 2014 and 2016. Examples include the perceived accessibility of health services, the provision of adequate information, or their participation in their own care. In seeking to explain this observed lack of impact, the authors suggested that the Act had failed to strengthen the legal position of patients overall. This was in part attributed to a lack of clarity in terms of legal provisions, but more importantly perhaps, to a lack of enforcement, that is the implementation of some form of supervision, control or other type of monitoring of adherence to the legislation, both at the national level and at the level of the health service itself. Furthermore, the stipulations as set out by the Patient Act did not take the form of granting individuals legal rights that they could then use for enforcement themselves. The authors also noted that there had been little concerted effort at the different administrative tiers of the system to raise awareness and institute support tools to facilitate access to information and active participation. Based on these insights, the assessment called for a collective strategy to consolidate and strengthen the patient's position further, through both strengthening their legal position and accelerating health services' efforts to help implement and enforce these rights.

relationship (micro level), as well as the organizational (meso) and the governance and finance, along with wider societal (macro) levels in order to systematically implement SDM. Such an approach, they argue, would require the development of social and cultural norms that systematically consider public views and participation at the various tiers of the system. While SDM is mostly applicable to the individual clinical encounter, its effective implementation into routine practice will require concurrent efforts at meso and macro levels, including investment in supporting the public, as patients, clinicians or decision-makers, in acquiring the skills and competencies to critically engage, ask questions, express values and preferences, and understand risks.

The need to consider the individual, organizational and societal levels in the design and implementation of effective person-centred strategies is also emphasized in Chapter 12 by Nolte and Anell, who review the evidence base for self-management and support. As indicated above, self-management is widely regarded to be a core component of person-centred care, along with SDM. Support for self-management is important in enabling service users to move from passive recipients to active partners in care, and essential to providing high-quality care for those with chronic disease (Wagner, 1998).

Somewhat similar to the evolution of public and patient involvement in research (Chapter 6) and of personal budgets (Chapter 10), the emergence of self-management in the health field can be linked to the self-care and self-help movements of the 1970s in particular. The focus was on achieving equality between the provider and service user in terms of making decisions and the capacity to determine the direction of their own care. However, more recently, as self-management and support have entered national, regional or local strategies, there is an expectation that supporting service users increases their confidence, strengthens preventive activities and ensures appropriate use of services, and will thus reduce costs and make service delivery more sustainable. There is also an expectation that it will improve service users' experiences of health care, give people more control over their lives, empower them as partners, and improve health outcomes and well-being.

Whether and how these varied ambitions can be achieved remains uncertain, however, as the authors argue. Similar to what we have seen for SDM, one main reason is an inconsistent evidence base, with only some forms of support for self-management found to impact positively on some of these anticipated outcomes and only for some service user

groups. Importantly, robust evidence that self-management efforts will reduce service utilization has so far been established for selected (hospital) services and specific conditions only (Taylor et al., 2014). There are several reasons for this. For example, existing outcome measures are frequently developed without appropriate service user input; also, interventions may not be suited to achieve desired outcomes such as reduced service use. A strong focus has so far been on psychological mechanisms, which tend to neglect the social context within which people live (Ong et al., 2014). As a result, relevant approaches might benefit only those who are capable of taking up these roles and this is likely to further disadvantage more vulnerable groups, who are already at a higher risk of multiple health problems (Barnett et al., 2012) and such approaches might thus inadvertently increase health inequities.

Nolte and Anell highlight that among the key challenges remains a disjoint of interpretations of self-management among lay people, health care professionals, managers and decision-makers, although the views of the latter two groups are inadequately understood. For example, while individual patients tend to emphasize the quality of the relationship between themselves and the professional, seeing self-management as a collaborative partnership, health professionals frequently view it as a tool to promote compliance with expert advice and treatment. Contemporary approaches to self-management and support tend to focus on managing people's condition/s in terms of biomedical outcomes or disease-control ('narrow approach'), rather than emphasizing supporting people to manage well (or live well) with their condition/s ('broad approach') (Morgan et al., 2016). This divergence may cause tensions, in particular, where it involves differing understandings of the responsibility for self-management, along with what is understood to be 'good' self-management. For example, the patient's wishes and preferences might not align with what the professional considers as the 'right' course of action, or user choices might lead to increased costs to the system (Harvey et al., 2015).

Nolte and Anell caution that there may be a risk that contemporary strategies and approaches to self-management and support continue to emphasize the 'narrow' focus, which stresses individual responsibility for management and behavioural change 'in order to function optimally'. This conclusion could also be drawn from a review of support efforts in Europe as described in Box 3.4. It finds that contemporary approaches to self-management support tend to emphasize medical and behavioural

management with less or little attention on the wider social context within which people live.

Box 3.4 Self-management support strategies in European countries

Decision-makers across Europe have recognized the need for implementing policies and strategies to support self-management mainly in the context of chronic diseases (Nolte & Knai, 2015). But approaches vary widely between and within countries in terms of content, format, provider and availability. A review of diabetes self-management arrangements in Bulgaria, Greece, the Netherlands, Norway, Spain and the UK found that the majority of approaches comprises educational or training programmes, typically, although not always, emphasizing behavioural change as an important goal (Kousoulis et al., 2014). Similar variation in levels of support provided was demonstrated by Nolte, Knai & Saltman (2014) in a review of some 50 approaches across 13 countries in Europe. Here, the focus tended to be on education for self-management, which was frequently delivered in a group-based context or on a one-to-one basis and most often in the context of disease management programmes. The education offered tended to focus on disease control through the provision of information about the disease, healthy behaviours and practical instructions concerning, for instance, blood glucose monitoring, foot examination, or insulin injection. Most approaches used support materials in the form of information brochures to complement patient education programmes, with a smaller number using interactive websites or telephone-based support services to provide patients with personalized information on how to manage their disease. In the majority of cases, self-management support was provided by health professionals including physicians, or, more frequently, by trained nurses within primary care settings, highlighting that, with a few exceptions, approaches in place tended to be professional- or service-driven. Most aimed at disease control rather than offering more general support strategies that target the wider social context within which people live and that draw on a wider potential support network including other patients, peers or volunteers, among others.

Overall, there is a need for self-management support strategies to be based on social models that specifically address differences in expectations and abilities to take responsibility in terms of learning self-management skills, and to tailor professional support accordingly. Better understanding of managers' and policy-makers' views and priorities will be important, given their role in developing and funding services that support self-management. Strategies have to go beyond the immediate health care context in order to take full account of the broader influences that impact self-management activities.

Exercising rights as taxpayers and citizens

Finally, in Chapter 13 Palm et al. examine the role of legal frameworks in seeking to ensure that people can exercise their rights as taxpayers and citizens. Drawing on a mapping of provisions for patients' rights in 30 countries in 2015, the authors explore the role of patients' rights for person-centred care, and what is needed to realize their potential to contribute to achieving person-centred health systems. Locating their origins within the human rights movement, the authors explain the specifics of patients' rights within this broader context, distinguishing the right to health and the right to health care, along with individual rights (protecting the individual from harm) and social rights (safeguarding people's entitlement to, and ability to access, care). Most commonly, patients' rights are defined within the context of health care and the relationship with the individual health care provider while also noting wider responsibilities at the organizational and system levels.

Based on an analysis of four influential European frameworks, the authors identify six categories of patients' rights, which are reproduced in Table 3.1. These, they argue, require specific action or measures for implementation, as opposed to other aspects also seen to be core to person-centred care, such as treating people with respect, which, the authors argue, cannot be reinforced by legal means. Similarly, the authors do not consider the right to collective participation here as, they argue, it should be considered a 'basic citizen right' that goes beyond the individual as a patient.

The review finds that countries in Europe vary considerably in the implementation of legal frameworks to ensure patients' rights, with most having instituted specific legislation dedicated to this purpose. Using the rights' categories described in Table 3.1, Palm et al. report that patients'

Table 3.1 *Principal categories of patients' rights based on a review of four European frameworks**

Principal category	Individual patients' rights
Self-determination	The right to (informed) consent The right to participate in (clinical) decision-making/ to choose treatment options
Confidentiality	The right to data confidentiality The right to access one's medical record
Access to health care	The right to benefit from medical treatment according to needs The right to safe and high-quality treatment received in a timely manner
Choice	The right to choose health care provider The right to a second opinion
Information	The right to information about one's health The right to information about health care providers The right to information about rights and entitlements
Redress	The right to complain The right to compensation

Source: Chapter 13

Note: * The four European frameworks are the Amsterdam Declaration on the promotion of the rights of the patient in Europe (1994); the Convention on Human Rights and Biomedicine (1997); the European Charter on Patients' Rights (2002); and the EU Directive on the application of patients' rights in cross-border health care.

rights frameworks in European countries generally seek to ensure the right to self-determination, including shared decision-making (Chapter 11) and confidentiality. However, the right to access care and provider choice is intrinsically related to the provisions of the statutory health system more broadly (Chapter 8) and as such is typically addressed outside specific patients' rights legislation. Differences remain regarding the status of rights afforded, for example, whether the rights are directly legally enforceable, are enforceable via wider public sector regulation (quasi-legal), or take the form of a charter or code of conduct (moral rights). This may impact the way patients' rights are implemented in

practice. For example, we have seen from the assessment of the 2015 Swedish Patient Act as described in Box 3.3 that the observed lack of impact of this law has, at least in part, been attributed to the failure to define patients' rights as a legal right (Vardanallys, 2017). However, as Palm et al. note, enforcement can also be ensured through other means, such as through formal dispute settlement mechanisms.

A key aspect is the right to information to enable individuals to make informed decisions about their health and care, an issue we have seen to be core to any strategy that seeks to ensure person-centred services. Palm et al. distinguish the right to information about the individual's health status as a prerequisite to inform the right to consent and shared decision-making; the right to information about health care providers as a requirement to help inform provider choice; and the right to information about rights and entitlements as a condition to enable people to exercise their rights in the first place. It remains unclear to what degree national frameworks make the provision of this information a legal requirement, although the 2011 EU Directive on the application of patients' rights in cross-border health care requires EU Member States to make available relevant information as far as cross-border health care is concerned.

Crucially, while most countries have implemented patients' rights frameworks, evidence of their impact remains largely absent, with a few notable exceptions (*see* Box 3.3). At the same time, recognition of the importance of this issue as evidenced by the widespread introduction of dedicated patients' rights frameworks could be seen as a significant step towards establishing the prerequisites for health systems that are more person-centred and that see the individual as an active partner rather than a passive recipient of care. However, as Palm et al. caution, the main challenge remains in reinforcing provisions for patients' rights, which may render this strategy possibly less effectual than it could be and it would be important to monitor progress and identify examples of good practice.

Summary and conclusions

In this chapter we have synthesized the evidence of different strategies seen to promote more person-centred care at the different tiers of the health system through examining the different roles people take as service users, active members of the community and citizens, evaluators,

decision-makers and care managers. Building on the principal framework of voice, choice and co-production, we find that each perspective can contribute to the advancement of more person-centred health systems while highlighting challenges and possible unintended consequences for related policies and strategies. It is important to reiterate that the notions of voice, choice and co-production are not mutually exclusive, but they co-exist and are frequently performed simultaneously.

In synthesizing this evidence, we identify a series of common themes, and these relate to:

- the drivers behind relevant strategies and policies, and how they have evolved over time;
- the evidence of their impact and the role of context in interpreting this evidence; and
- the implications of lessons learned for the further advancement of person-centred health systems.

We discuss these themes briefly in turn and examine some of the pertinent issues in further detail in Chapter 4.

There are several drivers behind person-centred strategies which are conflicting and potentially undermine the goal of achieving a person-centred health system

At the risk of simplifying what is inherently complex, we can observe that person-centred strategies as conceptualized in this book have evolved, largely, from broader social movements that emerged in the western world in the 1960s and 1970s. Most notably, although not exclusively, the independent living and disability rights movement and self-care and self-help movements more widely have been important. These have argued for greater self-determination and emphasized equality between the provider and service user in terms of making decisions about the services that affect their lives. The Alma Ata Declaration of 1978 explicitly linked this debate to inequalities and called for health care to be made “universally accessible to individuals and families in the community through their full participation” (World Health Organization, 1978).

At the same time, there has also been recognition of a ‘democratic deficit’ more generally in public services and this has initiated the notion of deliberative democracy and interest representation in the political process. For example, the Council of Europe interpreted

the rights of patients and citizens to participate fully and to determine the goals and targets in health care as an integral part of any democratic society and proposed that governments should promote policies that foster citizen participation (Council of Europe, 2000). The democratic perspective tends to assume that involvement is a good thing either in itself (an intrinsic value), or else impacts positively on public decisions or protects citizens from others making decisions against their interest (Conklin, Morris & Nolte, 2010). It relates to people or 'the public' in their capacity as citizens and taxpayers with rights to use public services and duties to contribute to and participate in society (Lupton, Peckham & Taylor, 1997).

The arguments based on the 'intrinsic' value of participation, alongside the rights-based approach, are in contrast to an emphasis on what has variously been described as the utilitarian or performance-based approach. In the neo-liberal agenda from the early 1990s, this became the consumerist approach, which introduced a greater focus on marketization of health care and consumer choice, along with increased 'responsibilization' in many systems (Bevan, Helderman & Wilsford, 2010; Jacobs, 1998). The underlying assumption was that involving people will correct for the inherent failures in health care markets, including information asymmetry, and ultimately lead to reduced cost, greater efficiency and performance of public services (Wait & Nolte, 2006). Consumer preferences are viewed as the lever to enhance competitiveness between providers and, in doing so, reaffirm the rights of users to information, access, choice and redress in relation to a specific service or product (Lupton, Peckham & Taylor, 1997). It presumes that the removal of obstacles to participation, such as lack of information or lack of motivation, will lead to an informed service user who behaves in ways that will ultimately improve the quality of their care and their health (Mittler et al., 2013).

Considering the overall evidence as presented in this book, it is the utilitarian or performance-based perspective that appears to have dominated the different person-centred strategies. While some strategies may have initially had a focus on the intrinsic value of person-centredness, this has often been replaced by the performance-based perspective in the implementation phase. This transformation is particularly visible in the area of choice reforms and can be linked to how different stakeholders view person-centredness and what they have to gain or lose. This process involving competing views across stakeholders may

also explain some of the continued challenges that systems face in systematically translating promising strategies into routine practice. The dominance of stakeholders representing professional, organizational and policy-maker views is also linked to the available evidence base, which we examine next.

The evidence of impact of person-centred strategies remains inconclusive

A key insight emerging from the reviews of person-centred strategies in this book is that the evidence of impact remains largely inconsistent. In most instances we only find that *some strategies* impact positively on *some anticipated outcomes* for *some populations* in *some settings*. More broadly, the evidence tends to be stronger for individual-level approaches such as shared decision-making and self-management support and in the context of a 'narrow' perspective on person-centredness. This is in sharp contrast to the call for 'broader' approaches developed in Chapter 2.

Clearly, evidence of impact needs to be interpreted in the context within which individual studies have been carried out, as well as the design of both the relevant strategy and its evaluation. A core challenge is that many strategies lack a clear formulation of the theoretical basis that would explain how activities will lead to anticipated outcomes. There is a need for rigorous evaluation that takes account of context, and systematically considers equality and diversity. This need is echoed in the wider literature that has examined public and patient involvement in health services and systems and in public services more widely (Madden & Speed, 2017; Martin, 2009). Examples include patient safety (Ocloo et al., 2017), commissioning of health services (Peckham et al., 2014), health service reconfiguration (Dalton et al., 2016; Martin, Carter & Dent, 2017), and health care decision-making more broadly (Conklin, Morris & Nolte, 2015), including health technology assessment (Weeks et al., 2017).

The lack of consistency in the evidence base can be seen to undermine the wider roll-out or 'routinization' of potentially promising initiatives, as has been argued for shared decision-making in particular (Chapter 11). However, various authors have also highlighted that available policy instruments and strategies may not be suitable to achieve the (often implicit) aims of cost reduction and greater efficiency, at least in

the short term. They thus could inadvertently undermine meeting the broader goals of enhancing person-centredness in the system overall. For example, there is so far no evidence to support that choice policies have increased efficiency or welfare at a population level (Chapters 8 and 9). Likewise, evaluations of personal budgets have thus far failed to produce robust evidence of their impact on costs and value for money (Chapter 10). However, there is some evidence that personal budgets can improve control, well-being and quality of life, and such improvements do offer value, even if they do not reduce costs.

Overall, we find that there is a need to better understand what strategies work best for whom, under what circumstances and in what settings. Crucially, there remains an urgent need to systematically consider the voice of individuals as service users, carers and members of the community in research and that seeks to inform health services and systems design more broadly. We observe that much of the evidence presented in this book remains dominated by professional, organizational and policy-makers' perspectives. Alongside this, there is a need to better understand what people want, whether and how they wish to be involved, the nature and scope of information they desire in order to support them in making decisions, including the option of choosing not to choose, and their support needs more broadly.

What are the implications for the further advancement of person-centred health systems?

Based on the evidence reviewed in this book we observe that existing models and strategies continue to fall short of systematically including the 'public voice' in health services and systems. There is a need to move to a more complex model of engagement that considers people's values and preferences at the level of the individual patient–professional relationship as well as at the organizational and the governance and finance, along with wider societal levels in order to systematically implement person-centred strategies.

Achieving truly person-centred services and systems will require a shift of the power balance away from a sole focus on professional knowledge and authority towards "negotiated participatory spaces" between lay and professional actors (Dean, 2017, p. 4). Here, careful attention needs to be given to the degree to which the range of strategies

to enhance person-centredness leaves the dominant culture and practices of provider-centric and expert-based health services and systems essentially unchanged and structurally unchallenged (Dunston et al., 2009). This is most likely to be the case for choice policies and public involvement approaches that perhaps seek public input, for example through consultation, such as through patient surveys, but where the process of service production remains profession-led. A shift of power will require moving to a system where the individual as a service user or a citizen becomes *part* of this process.

There is a wealth of experience already as shown in several contributions to this volume, but initiatives that are being undertaken tend to be disjointed and lack an overarching strategic approach. Madden & Speed (2017) pointed to the rich experience of social movements, charities and non-governmental organizations in different types of participatory mechanisms that have helped to bring together citizens and experts in new forms of cooperative inquiry. These used a range of participatory techniques that seek to strengthen civil society while also critically reflecting on how participation works. There is potential to learn from these activities in order to strengthen engagement initiatives within the health system.

Services and systems will need to systematically invest in supporting the public, as patients, clinicians or decision-makers, in acquiring the skills and competencies to critically engage, ask questions, express values and preferences, and understand risks. Such investment also requires careful attention to the interlinkages between the different tiers of the health system and how these can be optimized in order to ensure systematic and systemic implementation of effective person-centred strategies and minimize unintended consequences.

Decision-makers need to consider the wider implications of individual policy options and how they may require potential compromises between different options. These are perhaps most obvious for choice policies where it has been argued that they involve trade-offs between the degree of choice and the principle of equity of access and service. Further, choice of provider and/or payer might increase system fragmentation and undervalue wider public health interventions, so undermining person-centred systems. At the same time, while provider or payer choice might not increase efficiency or reduce costs, it might still be seen as a value in itself. In either case, any such option needs to be firmly embedded within the wider policy context.

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