5 *Community participation in health systems development*

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Introduction

Much of the global dialogue around policies for health today focuses on the need for community participation in health systems to ultimately improve health among populations. Participation is not only promoted in the context of provision and utilization of health services but also as a key factor in the wider context of social determinants of health and health as a human right (World Health Organization, 2008a). Despite the growing interest in the role of participation, the evidence that links participation directly to better health remains weak (Rifkin, 2014), which creates barriers to gaining full support of governments, funding agencies and health professionals to promote this concept (Atkinson et al., 2011).

This chapter suggests important lessons for policy-makers, planners, managers and service providers who wish to enhance and promote community participation in health systems. It examines important underlying assumptions and different theoretical perspectives that provide the foundation to advocate for the benefits of community participation in health systems. Furthermore, it presents empirical evidence from a series of recent reviews and studies and identifies challenges to assessing the contribution of community participation to health systems and people's health.

The evolution of community participation in health systems

Early experiences of community participation in health systems can be traced to the early 20th century, with experiments in China using local lay people to help provide health services in poor rural areas. Local residents were trained to provide basic health care to their communities and this experiment expanded in countries in Asia and Africa under the banner of the International Institute of Rural Reconstruction (Taylor-Ide

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& Taylor, 2002). Other examples include experiences in Africa, with King (1966) describing the involvement of local people assisting doctors in surgery and other interventions as part of their missionary work. The value of these approaches was seen in not merely having 'another pair of hands' but also of bringing skills and awareness to communities of the contribution of modern medicine to open their understanding of the link between science and behaviour for health improvements.

However, it was only the Alma Ata Declaration of 1978 that placed community participation on the global health agenda as part of a commitment to primary health care for World Health Organization member countries. The declaration identified health as a fundamental human right and stated that inequalities in health are "politically, socially and economically unacceptable" and that health care must be made "universally accessible to individuals and families in the community through their full participation" (World Health Organization, 1978, p. 1). The document highlighted equity and participation as key principles of national health policy, noting that "the people have the right and duty to participate individually and collectively in the planning and implementation of their health care". However, while the evidence to support policies addressing equity successively strengthened, gaining momentum with the World Health Organization's publication on the social determinants of health (World Health Organization, 2008a), policies to promote community participation have struggled to find strong evidence and direction.

Alma Ata helped to promote the creation of a core of community health workers inspired by the 'barefoot doctor' scheme in China that scaled up earlier experiments of the 1920s. Like their predecessors, barefoot doctors (subsequently village doctors) were local people who received medical training to provide first-line medical care and public health services to mobilize communities to focus on sanitation and the eradication of infectious disease (Cui, 2008). They were considered 'change agents' and seen to play an important part in modernizing health care in rural China. Elsewhere, similar national experiments in countries such as Columbia, Botswana and Sri Lanka were less successful, however, mainly because of conceptual and implementation problems, which failed to reap the wider benefits to be gained by developing community workers as change agents (Walt, 1990).

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A different form of community participation in the health system was promoted by the Bamako Initiative, a joint WHO/UNICEF initiative that was implemented to varying degrees in countries in sub-Saharan Africa from the late 1980s (Mehrotra & Jarrett, 2002). The Initiative sought to decentralize health decision-making to the district level, and to involve the community by contributing financial resources and giving them a 'voice' in the management of the services. While seen to be successful in terms of community action as such, it was noted that community participation had not been as well-defined as originally thought; also, there was a lack of significant community empowerment. The overall acceptance of the Initiative was found to have been less than hoped for, because of poor local infrastructure, corruption and variable government support (McPake, Hanson & Mills, 1993).

Decentralization of decision-making to promote community participation gained wider traction during the 1990s, with the creation of committees composed of local people to make decisions about financial allocations to health, education and community development (Zakus & Lysack, 1998). Still, this approach to governance failed to gain universal acceptance. Challenges have been contextual, with for example resistance of governments to allow central authority to be reduced (Bossert & Beauvais, 2002). And although there have been examples of positive impacts, such as participatory budgeting as a format for community participation in countries such as Brazil, securing government support has not been always possible, especially in low resource settings (Boulding & Wampler, 2010).

The policy push for promoting community participation was further strengthened in the context of the Millennium Development Goals (UN General Assembly, 2001), along with subsequent calls for people-centred health systems (World Health Organization, 2008b) and the concurrent report on the social determinants of health (World Health Organization, 2008a). These documents promote an active role for individuals, families and communities as the intended beneficiaries of health systems in decision-making about planning and implementing health services and policies. Most recently, the Sustainable Development Goals highlight the importance of responsive, inclusive, participatory and representative decision-making at all levels (UN Sustainable Development Goals, 2015).

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What we know about the contribution of community participation in health systems

The understanding and value of involving communities in health services and systems has greatly increased (World Health Organization, 2008b). In countries at all levels of development, governments, non-governmental organizations and private groups are recognizing the importance of including those who need and demand their services in decisions about how those services are delivered. However, it remains challenging for policy-makers, planners, managers and service providers to define outcomes and the factors that influence these outcomes (Milton et al., 2012; Popay, 2006; Preston et al., 2010; Rifkin, 2014; Wallerstein, 2006). This challenge is not restricted to the health field.

Reviewing the evidence of the value of community participation in development programmes, Mansuri & Rao (2013) found that community participation had made beneficial contributions to improving people's lives, but impacts varied by the nature of programmes. For example, they found that community-based development efforts have had limited impacts on income poverty, while participation in health service and education showed modestly positive results overall. However, at the same time it showed that people who benefit (most) tend to be the most literate, the least geographically isolated, and the most connected to wealthy and powerful people. The authors concluded that the overall evidence base remains thin, highlighting concerns about lack of effective systems of monitoring and evaluation and of attention to context in programme design. As a result, they argued, participatory development projects are likely to continue to be "driven more by ideology and optimism than by systematic analysis, either theoretical or empirical" (p. 3) and struggle to make a difference.

Assumptions underlying the contribution of community participation in health

One major reason for the relative lack of robust evidence around the contribution of community participation to health improvements is that relevant strategies tend to rest on a number of assumptions regarding the nature, role and outcomes of community participation. Rifkin (2012), in a review of community participation in health policy, found that these assumptions are rarely formally articulated or considered in

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the design and evaluation of initiatives to involve local people who are the intended beneficiaries in health services and systems. Yet despite the growing interest in community participation there has been little attempt to validate these assumptions. Rifkin (2009; 2012) has identified four key assumptions, which we discuss in the form of key lessons that have been learned so far.

There is a need to define 'community participation' at the outset of an intervention

Preston et al. (2010) carried out a research synthesis of empirical studies that sought to link rural community participation and outcomes. They found that only a few studies presented robust evidence of the benefit of community participation in terms of health outcomes. They noted that programmes had frequently failed to formulate realistic outcomes of what could be achieved and that without such clarity it would be challenging to measure whether they had met their goals. They further showed that even in those cases where the terms had been clarified at the beginning of an intervention, the outcomes tended to be context specific and not generalizable. There have been many different approaches to involving communities and the term community participation has been defined and theorized in many different ways (Kenny et al., 2013); we will come back to this issue below.

It cannot be assumed that people have the desire to be involved in decisions about their own health care

One driving force behind the Alma Ata Declaration was the assumption that people have the desire to be involved in decisions about the planning and implementation of their health care. Yet available evidence suggests that people, individuals and communities do not prioritize health care unless they have health problems. For example, McCoy, Hall & Ridge (2012), in a systematic review of health facility committees with community representation in low- and middle-income countries, concluded that members of the community did not want to be involved in decision-making about health care as such but rather they wanted access to care when they needed it. Priorities may be on more immediate needs such as food production, education or income generation, especially in low-resource settings, and there are often unrealistic expectations

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about the ability of the poor and marginalized to participate (Rifkin, 1985; Brett, 2003). Encouraging people to get involved in the planning or oversight of the delivery of services that are outside their personal health concerns has been shown to be difficult in both low- and middle-income countries (McCoy, Hall & Ridge, 2012; Rifkin, 2012) as well as in high-income settings (Carter, Tregear & Lachance, 2015; Farmer et al., 2015). For example, a recent cross-sectional study of the general population's desire to be involved in health care decisions in Sweden and England found that among those surveyed, only 44% reported wanting to be involved in local decisions about the organization and provision of services (Fredricksson & Tritter, 2017). Importantly, the study also found that individuals who wanted to make their own treatment decisions were also more likely to want to be involved in organizational decision-making. Available evidence has also highlighted the complexity of involving community people in activities dominated by health professionals. These complexities most often include dealing with local politics and ultimately power relationships.

It cannot be assumed that providing information to people about how to improve their health will result in positive behaviour change

There has been a long-standing assumption that providing health education and information will help people to change behaviour towards improved health. Examples include mass campaigns that historically were often focused on the control of disease and led by health professionals with little or no contribution from the intended beneficiaries (Gonzales, 1965). Mobilization efforts expanded following the 1978 Alma Ata Declaration, promoting 'community participation' in, for example, immunization uptake and acceptance of family planning. This largely profession-led approach was, however, challenged by the 1986 Ottawa Declaration (World Health Organization, 1986), which recognized that to ensure sustainable change, people needed to be empowered to engage in critical thinking and gain confidence through making their own decisions on actions and commitment. Defined as 'providing opportunities for those without power to gain knowledge, skills and confidence to make choices about their own lives' (Rifkin & Pridmore, 2001), the term 'empowerment' has come to replace 'participation', drawing attention to the need for active participation and

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transformation of thinking in order to create sustainable health changes (DeVos et al., 2009)

It cannot be assumed that once empowered, people will act the way professionals think they should

Experience not only in the field of health suggests that although empowerment is recognized as important, once communities are empowered they do not necessarily follow the expectations of those who facilitated this process. Whether the expected results are achieved depends on a number of factors, including leadership, trust, bonding with facilitators, compassion and building of partnerships (Rifkin, 2009), among others. This can be illustrated by the example of village health (or development) committees in low-income countries (McCoy, Hall & Ridge, 2012). There is an assumption that these committees would give the local population a 'voice' in decisions about health care delivery. However, available evidence suggests that these committees have had difficulty in fulfilling this role. For example, analysing community participation through facility boards and committees in the development and implementation of council health plans in Tanzania, Kilewo & Frumence (2015) identified several challenges, including lack of experience of committee members, lack of awareness about the role of the committee in the wider population, poor communication among committee members and officials, and lack of finances to carry out chosen projects. This highlights that it can be difficult to ensure that the desired results of empowerment actually lead to the expected outcomes. Power is about control and it is challenging in all circumstances.

Table 5.1 summarizes the key assumptions underlying the contribution of community participation in health as identified by Rifkin (2012). Taken together, this points to an overarching assumption about the nature of human agency, which conceives of human action to be uniform and predictable and that the provision of information will lead to behaviour change. Commonly referred to as the 'rational choice' model, this understanding of human action has, however, been shown not to be very effective in achieving sustained behaviour change (see, for example, National Institute for Health and Care Excellence, 2007). A large body of social science literature attests to the complexity of human actions and the ways in which not only agency, but also community participation and decision-making are embedded in particular social

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Table 5.1 *Assumptions underlying the contribution of community participation in health: a summary*

Assumption	Experiences
Communities It is not necessary to define 'community' and/or 'participation' before a participation process begins	Without clarification of underlying concepts and expectations, programmes will have difficulty in clearly stating objectives and thus have been unable to make rigorous evaluations. There have been many different approaches to involving communities and the term has been defined and theorized in many different ways.
Motivation People want to be involved in decisions relating to their health care	People's motivations are complex and often context specific.
Behaviour Giving people information will change their actions	Available evidence shows that the provision of information alone has limited impact and that any change achieved is rarely sustained over time.
Empowerment	Once given a role in decision-making about health care, people often do not act the way professionals think they should.

Source: based on Rifkin, 2012

and political contexts. Even apparently small differences in local contexts can influence both the process and the outcomes of participatory interventions (Derges et al., 2014). In the following section we discuss examples that illustrate the complexity and unpredictability of public participation in health systems development.

Constructs and rationales for community participation

"Community engagement [aka participation] is an umbrella term that encompasses a range of different approaches to involving communities of place and/or interest in activities aiming to improve health and/or reduce health inequalities. It therefore refers to an eclectic arena of

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activity with no single defining value base and no specific formal qualifications for practitioners."

(Popay, 2006, p. 2)

There are no standard definitions of 'community' or 'participation'. While in health promotion there is a broad acceptance that communities often constitute groups of people with common interests and/or identities, such as people with disabilities or the LGBT (lesbian, gay, bisexual and transgender) community, elsewhere community is most often defined in terms of people living within a given geographic area (MacQueen et al., 2001). Participation too has many definitions and as Popay (2006) stresses, it is important to recognize that the broad rubric of 'community participation' covers many different ways in which communities can be involved in health systems development, which are underpinned by differing sets of values and theoretical constructs. There is a vast literature on community participation, with contributions from many different academic disciplines including political science, sociology, anthropology development studies, psychology, public administration, communication studies and so forth, each of which conceptualizes participation in a different way.

Rifkin (1985), in an early analysis of community participation models in South-East Asia, and taking the perspective of planners, described different approaches to help understand how community participation has been implemented (Table 5.2). Importantly, her work highlighted early on that community participation is a process and not an intervention (Rifkin, 1996), which is core to identifying the challenges related to establishing a direct link between community participation and improved health outcomes. These challenges have been theorized in a number of ways. For example, Marent, Forster & Nowak (2012), in a review of community participation in the field of health promotion, identified seven social theories that have been used in the literature to articulate the function and process of community participation (critical theory, critical pedagogy, post-structuralism, social theory, political philosophy, critiques of modernity, and actor network theory). They found that the different theories provide different answers to and perspectives on key questions of participation in terms of the function of participation within specific social and political contexts, how lay actors are constituted as agents, and how the process of participation itself is understood.

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Table 5.2 *Conceptual approaches to community participation in health*

Approach	Interpretation	Underlying rationale
Medical approach	Defines health as the absence of disease and participation as 'having people do what professionals ask'; often referred to as community mobilization	Utilitarian
Health service approach	Defines health as "the physical, mental and social well-being of the individual" (World Health Organization, 1948) and participation as community contribution in the form of time, materials and money to a project as defined by professionals	Combination of utilitarian and normative/ empowerment
Community development approach	Defines health as a human condition and participation as the planning and managing of activities by the community with professionals providing resources and facilitation	Normative/ empowerment

Source: Rifkin, 1985

Embedded within these different theoretical constructs of community participation are also differing rationales in terms of what are seen as the reasons for and benefits of community participation. Morgan (2001) identified two dominant rationales, the utilitarian model and the empowerment model. The utilitarian model argues that the reason for involving communities in the design of health services is that there is some demonstrable gain in efficiency and/or cost reduction. Others have referred to this as the substantive rationale, that is, participation will lead to better decision-making and to more effective health services by incorporating public or community views, and the instrumental rationale, namely people are more likely to accept decisions if they have had a role in making them (Fiorino, 1990). Alternatively, the empowerment rationale is based on the normative assumption that people and communities have the right to be involved in those decisions that affect them and their lives irrespective of demonstrable gains, and further that this process will empower them. It broadly equates to the

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democratic rationale that emphasizes the importance of equity and empowerment and their value in society (Wait & Nolte, 2006). There is also a consumerist perspective, which draws upon economic theory and the importance of consumer choice in enhancing not only markets, but service provision (Wait & Nolte, 2006). It is not possible to reconcile these different models of participation because they are based on different sets of values, but it illustrates the complex and contested nature of participation.

Most policy documents advocating community participation contain a mix of these different rationales, but differing approaches to and rationales for participation can give rise to tensions. These tensions in part derive from contrasting ideological and political values and also from concepts of citizenship (Martin, 2008). For instance, is the purpose and value of community participation only to improve the efficiency of service delivery by improving uptake of interventions, or should it be linked with broader concerns, such as equity, the reduction of health inequalities, governance and citizenship (Cornwall & Gaventa, 2001; Rifkin, 2003; Sen, 1999)? Another recurring source of tension is the issue of power, and specifically the extent to which it is or should be devolved to community members (Morgan, 2001; Nelson & Wright, 1995). This issue has been the focus of much critical commentary, particularly the backlash against participatory development as promoted by agencies such as the World Bank, in which, it was argued, participation had been co-opted as a technocratic solution that excluded the wider issues of poverty and inequality (see, for example, Cooke & Kothari, 2001). Others also point to unrealistic expectations regarding the ability of the poor and socially marginalized to participate in such programmes (Brett, 2003).

However, there is not merely the challenge of providing a standard definition of community participation and a standard theoretical approach within the context of health systems. Members of the public (community) may occupy very different roles, possibly simultaneously, as users, patients, consumers or citizens including community leaders and professionals themselves. Each of these roles carries with it different reasons for involvement, with implications for the mechanisms of involvement and their impact on decision-making (Callaghan & Wistow, 2006; Fredricksson & Tritter, 2017). We have highlighted earlier the common assumption that there is a desire among people to get involved in decision-making, but this cannot be taken for granted. Motives for

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wanting to be involved are also complex and can be conceptualized in different ways.

Experiences of community participation in health system design and development

As we have noted in earlier sections of this chapter, there is renewed interest in community participation internationally and within Europe. The World Health Organization has placed community participation as central to the improvement of primary health care (World Health Organization, 2008b) and integrated health services (World Health Organization, 2015), as well as to reducing inequalities in health (World Health Organization, 2008a). Within the context of Europe, the Council of Europe (2000) recommended that all member states should ensure citizen participation in all aspects of the health care systems from local to national levels and create structures to ensure this goal is achieved. To facilitate this, World Health Organization Europe has also produced a number of manuals on how to achieve community participation in health services (see, for example, World Health Organization Europe, 2002; Ferrer, 2015).

In this section, we explore a range of experiences in European settings that illustrate the different conceptualizations and rationales for community participation in health system design and development as described above. It is beyond the scope of this chapter to provide a comprehensive overview of the entire spectrum of experiences of community participation in health service design across European countries. Many experiences, particularly those at local level, are not formally documented and/or available in languages other than English. For these reasons, we mainly draw upon a number of recent systematic reviews of participation and related concepts: Conklin, Morris & Nolte (2015); Crawford et al. (2002); Dalton et al. (2016); Milton et al. (2012); Mockford et al. (2012); Ocloo & Matthews (2016); Tempfer & Nowak (2011). We also consider comparative overviews of approaches from a range of European countries as for example provided by the World Health Organization (World Health Organization Europe, 2006; World Health Organization, 2015) and the European Institute for Public Participation (European Institute for Public Participation, 2009).

It should be noted that within the published literature of studies on European experiences, examples from the United Kingdom dominate,

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perhaps reflecting the policy emphasis on public involvement in service delivery especially under the Labour government of 1997–2010 and its programme of public sector reform, which is perhaps best typified by the 2002 Wanless Report on the NHS that stressed the importance of increasing public engagement (Wanless, 2002). In addition, as indicated, there is a bias towards English-speaking countries generally, including the United States, Canada and Australia.

At the outset it is important to note 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, and we examine these issues in turn.

Who is involved?

The majority of approaches to community participation that are documented in the literature focus on groups with shared health concerns. Groups whose participation has been sought include patients' groups who share a common illness (for instance, those with cancer or those who are HIV positive), users of specific services (for instance, primary care and maternity services), social groups who are seen as vulnerable (for instance, older people and those with mental illnesses), and hard-to-reach or disenfranchised groups (for instance, the LGBT community and the Roma). Participants are variously described as users, clients, consumers, citizens, patients, lay and/or community members, and these terms are often used interchangeably. The reasons for which involvement is sought are similarly varied and range from the narrow (for instance, how to improve the access to particular services) through to involvement in wider decision-making (for instance, regarding service reorganizations, budget allocations and possible hospital closures).

Why are people involved?

A wide range of methods or activities is used to involve people: focus groups, interviews, consultation meetings and workshops, citizens' juries/panels, and membership of boards or committees. Running through these experiences is a mix of the differing rationales that were described above. The utilitarian rationale appears to dominate, with the expectation that community participation will make things 'work better' in some way, but also the normative rationale that people have a right to

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be involved and the instrumental rationale that communities are more likely to accept decisions they have been involved in. In contrast, the empowerment rationale is less often mentioned, although in England patient empowerment has been a key element of the NHS Realising the Value Programme launched in 2014 (Wood et al., 2016).

What approaches are being used to involve communities?

The reviews considered in this chapter also show a mix of the approaches as defined by Rifkin (1985) (Table 5.2), and we illustrate these with three examples. Box 5.1 describes a community mobilization programme for mental health promotion among Cape Verdean immigrants in the Netherlands. This example can be seen to represent a medical approach to community participation (*see* Table 5.2), as it set out to mobilize the Cape Verdean community to engage with services as thought appropriate, but it also incorporated elements of the health service and community development approach as community members became involved in decision-making.

Box 5.2 describes a general approach to citizen participation in the Italian health care system, which illustrates a form of health services approach to community participation in which community members, as representatives of service users, were consulted and to some extent engaged as collaborators in local decision-making processes.

Box 5.1 The medical approach: community mobilization for mental health promotion among Cape Verdean immigrants in the Netherlands

Project Apoio was established in Rotterdam in 2000 to address the high rate of psychosocial problems among the small Cape Verdean community, who, while reporting a high rate of problems, were not utilizing the mental health care services available to them. The aim of the project was to engage this minority group and gain their views and insights in defining problems, designing solutions and also in decision-making. To this end, a user committee was established that included both community members and experts. The committee planned and executed various activities, such as

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Box 5.1 (cont.)

home visits, radio programmes and organizing events to disseminate information. The project commenced as a form of mobilization in seeking the Cape Verdean community to engage with services as thought appropriate, but it also incorporated elements of the health service and community development approach as community members became involved in decision-making.

The project was deemed very successful and one of the outcomes was the creation of a therapeutic group in mental health care services designed specifically for the Cape Verdeans. Community members of the user committee also described the experience as empowering in that they felt more confident to act to improve their own lives and those of other community members. However, the project ended in 2009 due to lack of continued funding.

Source: De Freitas et al., 2014

Box 5.2 The health service approach: citizen participation in the Italian health care system

In 1994 the northern Italian region of Emilia-Romagna established mixed advisory committees in order to monitor and improve the quality of health care delivery by incorporating user perspectives. The principal membership of the committees included representatives of patients and service user associations, who were also responsible for coordinating the committees. The committees also included a minority membership of service delivery representatives (managers and health professionals). The purpose of the committees was to monitor and assess the quality of existing services from a user perspective. This approach can be considered as a health service approach in which community members, in this case representatives of service users, were consulted and to some extent engaged as collaborators.

An evaluation of the advisory committees used interviews and observations to examine the experiences of committee members and the impact of the committees in influencing the decisions of

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Box 5.2 (cont.)

the health professionals. It found that in terms of providing a decision-space that brought together different actors, the committees were seen as successful in achieving participation and bringing together different perspectives and cultures and some successes in service delivery were achieved (e.g. reduction in waiting lists, better organization). Overall, however, most of the user and patient representatives felt that their influence on decision-making was limited. A number of constraints were identified including the unwillingness of health services managers to cede control and the commitments required of the user representatives, whose participation decreased over time.

Source: Serapioni & Duxbury, 2014

Box 5.3 illustrates what Rifkin (1985) (Table 5.2) described as the community development approach, using the example of community participation in the design of rural primary care services in Scotland, in which the responsibility for decisions regarding new service plans was delegated to the community members themselves.

Box 5.3 The community development approach: community participation in the design of rural primary care services in Scotland

This study examined a community participation process in four rural Scottish communities, the Remote Services Futures, conducted in 2008–2010 to identify local health needs and to plan new services to meet these needs. A participatory action research approach was explicitly used with the aim of not only consulting but also empowering community members. In each community, four workshops were held that moved from examining what the community considered their current and future health needs to the identification of priorities and services to meet these needs within a designated budget. Health professionals also attended some of the workshops to share information with community members,

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Box 5.3 (cont.)

but the responsibility for decisions regarding new service plans was delegated to the community members themselves as in the community development or empowerment model of participation.

While the health delivery priorities in the early stages of the consultation process were very similar across all four communities, the communities engaged very differently and this led to different outcomes. Thus, one community decided to replicate their existing service as it met their needs, while two other communities developed new service plans to meet their local needs. The fourth community, however, withdrew from the final part of the process in which the new service models were designed and failed to develop a plan. The precise reasons for the withdrawal were unclear, with various external factors such as the weather and venue given as explanations, but it was also suggested that community members felt that participation represented a form of compliance or collusion with the health authority and the imposition of top-down changes. This example illustrates the need to understand local contexts and the complex reasons community members have to engage or to choose to not engage. It also shows that the process of community participation can be 'messy' and the outcomes unpredictable.

Source: Farmer & Nimegeer, 2014

How do different European countries approach 'community participation'?

The European Institute for Public Participation presented, in 2009, a review of European experiences in public participation with a focus on Germany, Italy and the UK. It found that while there were mechanisms for public participation in all countries and across a number of different sectors, including health system governance, the experiences and expectations varied greatly, reflecting different cultural contexts and political structures. This, and similar reviews, such as that by the Ninth Futures Forum (World Health Organization Europe, 2006), show that public participation, as it is practised, can be very variable in terms of the rationales and the approaches taken. For instance, in the UK many public policies relating to health care now set out a formal and legal requirement for

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people (described variously as patients, citizens, users, consumers and communities) to be involved and consulted in various aspects of health care delivery from all levels from national to local (Martin, Carter & Dent, 2018; NHS England, 2015). In comparison, public participation in the health system in France can be seen to be more limited, although patients and their representatives may participate in regional health conferences in defining public health priorities at the regional level, including development of the regional strategic health plan. The 2016 Health Reform Law has put in place mechanisms to further strengthen public involvement in health systems development (Chevreul et al., 2015).

As noted earlier in this chapter, the perceived value of community participation in health systems development is based on a series of assumptions, including an assumed desire of community members to be involved and how they will respond once engaged (Wait & Nolte, 2006). The process by which individuals participate, their motives and any benefits that may accrue to them remain largely unexamined[1], although a small number of empirical studies points to the complexity of people's reasons and subjective benefits gained. Fienig et al. (2012), in a study of citizen participation in the Netherlands, found that participants had multiple motives to take part in a health promotion programme, some of which related to personal benefits (achieving a sense of purposeful action, self-development and enhanced sense of status) and others that were more altruistic (making a contribution to others). In another European study, Van Eijk & Steen (2016) explored citizen participation in a number of different public service projects, including health service delivery, which comprised client councils in health care for older people in the Netherlands, and user councils for the health care of people with disabilities in Belgium. The authors found that people's reasons for participating combined a mix of self-interest and altruism. They argued for the need to understand the interplay between personal characteristics, including feelings of self-efficacy, and characteristics of the wider community, such as social capital, with high levels of social connectedness providing both opportunities and constraints to

1 There is a large body of literature on volunteerism, however, which shows the complexity of people's reasons for volunteering, the benefits that accrue to people from volunteering and factors that might influence this. See for example, Haddad (2004), Jenkinson et al. (2013) and Weng & Lee (2016).

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participation. While positive benefits may be gained for individuals, a rapid review by Attree et al. (2011) of the experiences of community participation for individuals found that there were also some unintended negative consequences, such as stress and tiredness caused by demands placed upon people. These findings echo the argument of Brett (2003) that some community participation programmes fail because of unrealistic and sometimes excessive demands on the ability of the poor and marginalized in particular to participate.

The multiple definitions of and differing approaches to community participation make it challenging to draw any robust conclusions on the outcomes of community participation. A major reason is that most examples do not clearly specify the type of participation achieved and who participated (e.g. representatives of health care users or ordinary citizens), which makes it difficult to link participation with the intended outcomes (Conklin, Morris & Nolte, 2015). Also, few experiences are formally evaluated and documented. That said, one broad finding which is consistent across all of the reviews cited here is that community participation can make a difference, but not always. Findings are not sufficiently consistent to suggest that any particular approach is more or less successful. Indeed, Milton et al. (2012) concluded that while some studies show positive impacts on some elements of service delivery, such as planning, the evidence is not conclusive, in part due to the multiple influences on service delivery. Tempfer & Nowak (2011) also advised caution, but they identified a number of factors that can be associated with positive outcomes, including appropriate financing of the initiative, logistics, and systems of communication, and partnerships with relevant organizations. Importantly, while there is lack of clear empirical evidence on the outcomes of participation, as Conklin, Morris & Nolte (2015) pointed out, we must not lose sight of the other reasons for public participation, namely the democratic, empowerment and normative rationales that people have a right to be involved and that the process of participation can have its own benefits and intrinsic value.

Lessons from experiences of community participation in health systems development

Experiences of community participation in health systems development as described in the preceding sections mirror the observations discussed in earlier parts of this chapter, which are relevant to policy-makers,

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planners, managers and service providers who wish to strengthen community participation in health systems.

First, community participation in health systems development has been interpreted differently in different system contexts. Much of the early work around community participation originates from low- and middle-income countries as we have highlighted in earlier sections of this chapter, whereas in high-income settings the discussion has focused more on the involvement of people in the decision-making processes at levels ranging from the local to the national depending on the national context. There are a number of rationales behind pursuing participation as noted, but it is not always recognized that differing rationales have consequences for how a participation process might be designed and implemented and how the outcomes (if any) are used (or not). Similarly, the terms patient, user, consumer, citizen, community and public are often used interchangeably without recognizing that each of these framings implies different roles and reasons for their engagement (*see also* Chapter 3). Especially in the context of low-resource settings, much emphasis for participation is seen in specific health service programmes, such as universal health care, although there is also concern on the broader issue of health as a human right (DeVos et al., 2009).

Second, viewing community participation as a process rather than an intervention demands a better understanding of this process. Understanding community participation as a means to move from information sharing to empowerment needs to be documented in specific situations and on a national scale. At present, much of the literature focuses on the success of programmes and does not document failures. As a result, important lessons about the process and its challenges are missing.

Third, the utilitarian rationale to community participation is promoted by the neo-liberal environment that has dominated many countries over recent decades. It is based on the assumption that enhancing participation will lead to more (cost-)effective services and systems. Yet as we have seen, the evidence that community participation will lead to, say, more effective service delivery remains, at best, patchy. There is thus a need to be explicit, from the outset, as to what a given strategy is seeking to achieve and, importantly, the approach that will be most suited to achieve the objectives. We have found that the medical approach and health service approach tend to dominate practice while the community development approach often dominates the rhetoric. As

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a result, not only is the process top-down rather than bottom-up but it is also controlled by professionals rather than communities challenging empowerment goals.

Fourth, a continued lack of conceptual clarity regarding both the nature and the purpose of community participation makes it hard to draw any firm conclusions regarding its role in achieving improved health outcomes or in improving health service design and development. Much of the writing on the contribution of community participation in low- and middle-income countries has sought to use the randomized controlled trial design as the evaluation framework (Rifkin, 2014). This approach has been criticized because it is difficult to meet the criteria of reliability and replicability of outcomes as standard definitions of 'community' and 'participation' do not exist. It remains difficult to reconcile the demands of scientific rigour with evidence from case studies and systematic reviews. There is the tension between documenting a process that is context specific and one which is seeking to identify generalizations that can be used to scale up programmes. This dilemma is one which is found in complex interventions in health.

A way forward

As this chapter shows, identifying, understanding and replicating the outcomes of community participation in health systems development are not simple. Mansuri & Rao (2013) noted, in the context of low- and middle-income countries, that the evidence for benefits of participation in public service programmes are mainly based on optimism and ideology, and they highlighted the need for more robust evidence on the outcomes and impacts of participation. The reviewed experiences provide pointers to ways to evaluate and implement the loosely documented but clearly perceived benefits of community participation for improved outcomes in people's health. The following suggests a way forward.

First, there is a need to understand the context, history and culture of those who are meant to benefit from participation. Available evidence does not allow for generalizations about the contribution of community participation to health improvements particularly in service development, design, implementation and evaluation. There is a need for policy-makers, programme managers and community people to agree on a definition of community and participation and on theoretical concepts and approaches to inform the design and implementation of community

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participation in health programmes. Because of the difficulty in providing a standard definition of these terms and a common theoretical context, this agreement might be best done in the context of a specific programme. While there is no blueprint to ensure that community participation will produce predictable and positive successes, it is possible to learn from the various experiences that we have illustrated here to create a programme-specific definition of terms to identify programme objectives, processes and outcomes.

Second, there is a need to promote empowerment by involving people and to recognize the role of power and control. An often not stated but implicit goal of participation is to ensure changes are sustainable. This requires ownership of the intervention by the community (targeted or inclusive) rather than imposition by policy-makers or professionals. For this reason, it is imperative to examine questions about power and control to ensure that participatory interventions do not unintentionally reinforce potentially harmful social structures and actions that are inherent in community participation (George et al., 2015). Marston et al. (2016) explicitly identified power-sharing as key to enable a transformation of community action to foster new relationships and systems capable of identifying, acting upon and sustaining health improvements envisioned by those promoting community participation. There is thus a need for better documentation of successes and failures of community participation in health systems development to help inform the design and implementation of community participation approaches.

Third, there is a need to view participation as a process and not as an intervention. The medical approach to community participation as discussed in this chapter is largely rooted in the biomedical model and tends to view community participation as an intervention. This is problematic because if community participation is aimed at truly empowering the community through community development, there is a need to consider the wider context beyond the medical model to understand community dynamics. Otherwise there is a risk that approaches to participation continue to reproduce unsuccessful experiences that view communities as a single entity that acts in accordance and consents to health inventions proposed by professionals.

Fourth, there is a need to use evaluation procedures that examine the process and identify both intended and unintended outcomes. Existing evaluations rarely identify the importance of context, history, and intended and unintended outcomes of community participation

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in programmes. This has changed more recently, with approaches increasingly using realist-approaches in order to assess the outcomes of health interventions in community-based services (Greenhalgh et al., 2015; Prashanth et al., 2012; Vareilles et al., 2015). However, such approaches have rarely been applied to assessing the role of community participation in health systems development.

Conclusion

This chapter has examined some of the key underlying assumptions of and different theoretical perspectives for the benefits of community participation in health systems, reviewed empirical evidence and identified challenges to assessing the contribution of community participation to health systems and people's health. It found that there is some evidence to suggest that community participation in health systems development in different settings can make beneficial contributions to health improvements (Mansuri & Rao, 2013; World Health Organization, 2015). However, there is no linear association between community participation and sustained improved health of local people and we have described a number of reasons for this.

We have shown that there is a need now to more systematically address the underlying definitional, conceptual and methodological challenges and to use frameworks that are more suited to explore participation as a complex and dynamic process and that considers the 'community' as a complex and dynamic process in itself while also taking full account of the intended beneficiaries' (i.e. the community's) ideas and preferences, including a potential choice of not wanting to be involved. The Alma Ata Declaration highlighted that the purpose of involving communities in health care and health systems development is to improve the lives of people, particularly those who have been marginalized by existing social developments. Health policy-makers, planners, managers and service providers who seek generalizable approaches can easily overlook this aim and fail to respond to the basic goals of equity and participation.

References

Atkinson JA et al. (2011). The architecture and effect of participation: a systematic review of community participation for communicable disease

https://doi.org/10.1017/9781108855464.008 Published online by Cambridge University Press

control and elimination. Implications for malaria. *Malaria Journal*, 10:225. Available at: http://malariajournal.com/content/10/1/225 (accessed 27 June 2017).

Attree P et al. (2011). The experience of community engagement for individuals: rapid review of evidence. *Health and Social Care in the Community*, 19(3):250–60.

Bossert TJ, Beauvais JC (2002). Decentralization of health services in Ghana, Zambia, Uganda and the Philippines: a comparative analysis of decision space. *Health Policy and Planning*, 17(1):14–31.

Boulding C, Wampler B (2010), Voice, Votes, and Resources: Evaluating the Effect of Participatory Democracy on Well-being. *World Development*, 38(1):125–35.

Brett EA (2003). Participation and accountability in development management. *Journal of Development Studies*, 40:1–29.

Callaghan GD, Wistow G (2006). Public, patients, citizens, consumers? Power and decision making in primary health care. *Public Administration*, 84(3):583–601.

Carter MW, Tregear ML, Lachance CR (2015). Community engagement in family planning in the U.S.: a systematic review. *American Journal of Preventive Medicine*, 49(2 Suppl 1):S116–23.

Chevreul K et al. (2015). France: Health system review. *Health Systems in Transition*, 17(3):1–218.

Conklin A, Morris Z, Nolte E (2015). What is the evidence base for public involvement in health-care policy: results of a systematic review. *Health Expectations*, 18(2):153–65.

Cooke B, Kothari U (2001). *The tyranny of participation*. London: Zed Books.

Cornwall A, Gaventa J (2001). From users and choosers, to makers and shapers: repositioning participation in social policy. *IDS Working Paper* 127, Brighton: IDS.

Council of Europe (2000). *Recommendation no. 5 of the committee of ministers on the development of structures for citizen and patient participation*. Strasbourg: Council of Europe Committee of Ministers.

Crawford MJ et al. (2002). Systematic review of involving patients in the planning and development of health care. *BMJ*, 325(7375):126.

Cui WY (2008). China's village doctors take great strides. *Bulletin of the World Health Organization*, 86(2):909–88.

Dalton J et al. (2016). Service user engagement in health service reconfiguration: a rapid evidence synthesis. *Journal of Health Service Research and Policy*, 21(3):195–205.

https://doi.org/10.1017/9781108855464.008 Published online by Cambridge University Press

De Freitas C et al. (2014). Transforming health policies through migrant use involvement: lessons learnt from three European countries. *Psychosocial Intervention*, 23:105–13.

Derges J et al. (2014). 'Well London' and the benefits of participation: results of a qualitative study nested in a cluster randomised trial. *BMJ Open*, 4:e003596.

DeVos P et al. (2009). Health through people's empowerment: a rights-based approach to participation. *Health and Human Rights*, 11(1):23–35.

European Institute for Public Participation (2009). *Public participation in Europe: an international perspective*. Bremen: EIPP.

Farmer J, Nimegeer A (2014). Community participation to design rural primary healthcare services. *BMC Health Services Research*, 14:130–40.

Farmer J et al. (2015). An exploration of the longer-term impacts of community participation in rural health services design. *Social Science & Medicine*, 141:64–71.

Ferrer L (2015). *Engaging patients, carers and communities for the provision of coordinated/integrated health services: strategies and tools*. Copenhagen: WHO Europe.

Fienieg B et al. (2012). Why play an active role? A qualitative examination of lay citizens' main motives for participation in health promotion. *Health Promotion International*, 27:416–26.

Fiorino DJ (1990). Citizen participation and environmental risk: a survey of institutional mechanisms. *Science, Technology, & Human Values*, 15(2):226–43.

Fredricksson M, Tritter J (2017). Disentangling patient and public involvement in health care decisions: why the difference matters. *Sociology of Health & Illness*, 39(1):95–111.

George A et al. (2015). Community participation in health systems research: a systematic review assessing the state of research: the nature of interventions involved and the features of engagement with communities. *PLoS ONE*, 10(10):e0141091.

Gonzales CL (1965). *Mass campaigns and general health services*. Geneva: World Health Organization.

Greenhalgh T et al. (2015). Protocol – the RAMESES II study: developing guidance and reporting standards for realist evaluation. *BMJ Open*, 5:e0088567.

Haddad MA (2004). Community determinates of volunteer participation and the promotion of civic health: the case of Japan. *Nonprofit and Voluntary Sector Quarterly*, 33(3):8S–31S.

https://doi.org/10.1017/9781108855464.008 Published online by Cambridge University Press

Jenkinson CE et al. (2013). Is volunteering a public health intervention? A systematic review and meta-analysis of the health and survival of volunteers. *BMC Public Health*, 13.

Kenny A et al. (2013). Community participation in rural health: a scoping review. *BMC Health Services Research*, 13:64.

Kilewo EG, Frumence G (2015). Factors that hinder community participation in developing and implementing comprehensive council health plans in Manyoni District, Tanzania. *Global Health Action*, 8:10.3402/gha.v8.26461.

King M (1966). *Medical care in developing countries*. Nairobi: Oxford University Press.

McCoy D, Hall JA, Ridge M (2012). A systematic review of the literature for evidence on health facility committees in low and middle-income countries. *Health Policy and Planning*, 27:449–66.

McPake B, Hanson K, Mills A (1993). Community financing in Africa: an evaluation of the Bamako Initiative. *Social Science and Medicine*, 36(11):1383–95.

MacQueen KM et al. (2001). What is Community? An evidence-based definition for participatory public health. *American Journal of Public Health*, 91(12):1929–38.

Mansuri G, Rao V (2013). *Localizing development: does participation work?* Washington, DC: World Bank.

Marent B, Forster R, Nowak P (2012). Theorizing participation in health promotion: a literature review. *Social Theory & Health*, 10:188–207.

Marston C et al. (2016). Community participation for transformative action on women's, children's and adolescents' health. *Bulletin of the World Health Organization*, 94:376–82.

Martin GP (2008). 'Ordinary people only': knowledge, representativeness, and the publics of public participation in healthcare. *Sociology of Health and Illness*, 30:35–54.

Martin GP, Carter P, Dent M (2018). Major health service transformation and the public voice: conflict, challenge or complicity? *Journal of Health Services Research & Policy*, 23(1):28–35.

Mehrotra S, Jarrett S (2002). Improving basic health service delivery in low-income countries: 'voice' to the poor'. *Social Science and Medicine*, 54:1685–90.

Milton B et al. (2012). The impact of community engagement on health and social outcomes: a systematic review. *Community Development Journal*, 47:316–34.

https://doi.org/10.1017/9781108855464.008 Published online by Cambridge University Press

Mockford C et al. (2012). The impact of patient and public involvement on UK NHS health care: a systematic review. *International Journal for Quality in Health Care*, 24(1):28–38.

Morgan L (2001). Community participation in health: perpetual allure, persistent challenge. *Health Policy and Planning*, 16:221–30.

National Institute for Health and Care Excellence (2007). *Behaviour change at population, community and individual levels*. London: NICE.

Nelson N, Wright S (eds.) (1995). *Power and participatory development: theory and practice*. London: Intermediate Technology Publication.

NHS England (2015). *Planning, assuring and delivering Service Change for Patients*. London: NHS England/Operations and Delivery.

Ocloo J, Matthews R (2016). From tokenism to empowerment: progressing patient and public involvement in healthcare improvement. *BMJ Quality Safety*, 25(8):626–32.

Popay J (2006). *Community engagement and community development and health improvement: a background paper for NICE*. London: NICE.

Prashanth N et al. (2012). How does capacity building of health managers work? A realist evaluation study protocol. *BMJ Open*, 2:e000882.

Preston R et al. (2010). Community participation in rural primary health care: intervention or approach? *Australian Journal of Primary Health*, 16(1):4–16.

Rifkin SB (1985). *Health planning and community participation: case studies in South-East Asia*. Dover, NH: Croom Helm.

Rifkin SB (1996). Paradigms Lost: Toward a new understanding of community participation in health programs. *Acta Tropica*, 61:79–92.

Rifkin SB (2003). A framework linking community empowerment and health equity: it is a matter of CHOICE. *Journal of Health, Population and Nutrition*, 21:168–80.

Rifkin SB (2009). Lessons from community participation in health programs: a review of the post Alma Ata experience. *International Health*, 1:31–6.

Rifkin SB (2012). Translating Rhetoric to Reality: a review of community participation in health policy over the last 60 years. Available at: http://www.wzb.eu/sites/default/files/u35/rifkin_2012_rhetoric_to_reality_a_review_of_cp_and_health_policy.pdf (accessed 1 August 2016).

Rifkin SB (2014). Examining the links between community participation and health outcomes: a review of the literature. *Health Policy & Planning*, 29:ii98–ii106.

https://doi.org/10.1017/9781108855464.008 Published online by Cambridge University Press

Rifkin SB, Pridmore P (2001). *Partners in Planning. Information, Participation and Empowerment*. London: Macmillan Education Ltd.

Sen A (1999). *Development as Freedom*. Oxford: Oxford University Press.

Serapioni M, Duxbury N (2014). Citizens' participation in the Italian health-care system: the experience of the Mixed Advisory Committees. *Health Expectations*, 17(4):488–99.

Taylor-Ide D, Taylor CE (2002). *Just and lasting change: when communities own their futures*. Baltimore: Johns Hopkins University Press.

Tempfer CB, Nowak P (2011). Consumer participation and organizational development in health care: a systematic review. *Wiener klinische Wochenschrift*, 123(13–14):408–14.

UN General Assembly (2001). Road map towards the implementation of the United Nations Millennium Declaration. Report of the Secretary-General. Available at: http://www.un.org/millenniumgoals/sgreport2001.pdf?OpenElement (accessed 7 November 2017).

UN Sustainable Development Goals (2015). Website. Available at: http://www.un.org/sustainabledevelopment/sustainable-development-goals/ (accessed 27 June 2017).

Van Eijk C, Steen T (2016). Why engage in co-production of public service? Mixing theory and empirical evidence. *International Review of Administrative Science*, 82(1):28–46.

Vareilles G et al. (2015). Understanding the motivation and performance of community health volunteers involved in the delivery of health programs: a realist evaluation protocol. *BMJ Open*, 5.

Wait S, Nolte E (2006). Public involvement policies in health: exploring their conceptual basis. *Health Economics, Policy and Law*, 1:149–62.

Wallerstein N (2006). *What is the evidence on effectiveness of empowerment to improve health?* Copenhagen: WHO Regional Office for Europe. Available at: http://www.euro.who.int/__data/assets/pdf_file/0010/74656/E88086.pdf (accessed 7 November 2017).

Walt G (ed.) (1990). *Community Health Workers in nation programmes: Just another pair of hands?* Milton Keynes: Open University Press.

Wanless D (2002). *Securing our future health: taking a long-term view. Final Report*. London: HM Treasury. Available at: https://www.yearofcare.co.uk/sites/default/files/images/Wanless.pdf (accessed 22 August 2016).

Weng SS, Lee JS (2016). Why Do Immigrants and Refugees Give Back to Their Communities and What Can We Learn from Their Civic Engagement? *Voluntas*, 27:509–24.

https://doi.org/10.1017/9781108855464.008 Published online by Cambridge University Press

Wood S et al. (2016). *At the heart of health: realising the value of people and communities*. London: Nesta.

World Health Organization (1948). *Constitution Basic Documents*. Amended forty-fifth edition, Supplement, October 2006. Available at: http://www.who.int/governance/eb/who_constitution_en.pdf (accessed 22 August 2016).

World Health Organization (1978). *Primary Health Care*. Geneva: World Health Organization.

World Health Organization (1986). *Ottawa Charter on Health Promotion*. Geneva: World Health Organization.

World Health Organization (2008a). *Commission on the Social Determinants of Health. Closing the gap in a generation*. Geneva: World Health Organization.

World Health Organization (2008b). *World Health Report 2008 – Primary Health Care. Now More Than Ever*. Geneva: World Health Organization.

World Health Organization (2015). *People-centred and integrated health services: an overview of the evidence*. Geneva: World Health Organization.

World Health Organization Europe (2002). *Community participation in local health and sustainable development: approaches and techniques*. Copenhagen: World Health Organization Europe.

World Health Organization Europe (2006). *Futures forum on health systems governance and public participation*. Copenhagen: World Health Organization Europe.

World Health Organization Europe (2015). *Engaging patients, carers and communities for the provision of coordinated/integrated health services: strategies and tools*. Copenhagen: World Health Organization Europe.

Zakus D, Lysack L (1998). Revisiting community participation. *Health Policy and Planning*, 13(1):1–12.

https://doi.org/10.1017/9781108855464.008 Published online by Cambridge University Press

https://doi.org/10.1017/9781108855464.008 Published online by Cambridge University Press