

Chapter 2

Patient Involvement: Who, What for, and in What Way?

IV The people have the right and duty to participate individually and collectively in the planning and implementation of their health care. 'Declaration of Alma-Ata' (WHO 1978)

Before heading on to the theoretical and methodological part of the study, it is necessary to take a somewhat closer look at patient involvement and its definition. There is a wide variety of reasons why patient involvement is to be desired. Hirschman's famous '*Exit, Voice and Loyalty*' (1970) has contributed theoretically to the topic. It entailed much scholarly discussion, inspired many contributions to the theme, and is used by actors from diverse backgrounds (for a small selection cf. Barry 1974; Bundeszentrale für gesundheitliche Aufklärung (BZgA) 2000; Dowding, John, Mergoupis & van Vugt 2000; Forster & Gabe 2008; Greß, Delnoij & Groenewegen 2003; Greß, Höppner, Marstedt, Rothgang & Thamm 2008; Greß & Rothgang 2008; Grit & Bal 2009; LeGrand 2006, 2007; Rodwin 1997; Young 1974). Somewhat exaggerated it might be said that while free-market liberals tend to rather support the idea of *exit*—or, in its later alternative framing, *choice*—and *voice* should get no 'louder' than in customer/patient surveys, it is the latter that is highlighted by many involved in the self-governance of social insurances or in patient organisations.

However, developments over the past decade have increasingly shown that voice and exit are neither exclusive nor conflicting instruments, and which should be prioritised over the other is difficult to decide upon (Saltman & von Otter 1989; cf. also Chinitz 2000, pp. 64–65). Already in 1978, the World Health Organisation in its famous 'Declaration of Alma-Ata' (WHO 1978) formulated the desideratum that patients should be 'individually and collectively' involved in health care, a demand that was reiterated with the 'Declaration on the Promotion of Patients' Rights in Europe' some 15 years later (WHO 1994). This, amongst other reasons, has also led politicians, policy advisers, and researchers to become involved in a slow-moving discourse about involvement and governance (cf., e.g., Berwick 2002; Department of Health 2012; Eurohealth 2013).

Rega (2007, chap. 2) discerns several aims of patient involvement: There are normative and utilitarian arguments for involvement such as self-determination and the dignity of the individual, democratisation of health care, or transparency (cf. also Potvin 2007; Tritter, Koivusalo, Ollila & Dorfman 2010). There are functional reasons including patient safety, the optimisation of health care services, capacity planning, and, more generally, the goal attainment of (social) policy aims that grant a patient the status of an expert (cf. Badura 2000; Barnes, Newman & Sullivan 2007, pp. 34–37; Coulter 2000; Tritter & McCallum 2006; WHO 1978, 1996; WHO Regional Office for Europe 2006). And lastly there are psychological reasons—that might in some cases be translated into functional ones—which include higher patient satisfaction, ‘greater confidence, reduction in anxiety’, ‘better relationships with professionals’, as well as the feeling to be involved—to which numerous additional reasons might be added (Farrell 2004, pp. 2–3; cf. also Potvin 2007; Thompson 2007).

In the following sections, we will take a look at different kinds of involvement the question in what way to involve whom.

2.1 Forms of Involvement and Legitimacy

[I]nvolvement means: You do not stay sitting behind your geraniums, but you make yourself heard, you make yourself seen, while co-determination, in my experience, [is] a somewhat more formal spot. (interview 6; author’s translation)

The underlying issues are essentially the same—‘nobodies’ in several arenas are trying to become ‘somebodies’ with enough power to make the target institutions responsive to their views, aspirations, and needs. (Arnstein 1969, p. 216)

In practical terms, involvement takes different shapes depending on the respective tradition of the health care system in a country. Nevertheless, it can be argued that most, if not all of them are linked to what may be called a *chain of legitimacy*, which—even though other reasons play in—is essential in the context of this book.¹

While for MARKET-LIKE SOLUTIONS in health care legitimacy basically is created through a contract between patient—or, in more contractual terminology: purchaser of services—and physician—provider of services—this is more complicated in countries with solidary funding. In COUNTRIES WITH SELF-GOVERNANCE in social insurances the predominant form of involvement is traditionally targeted at the insured, who in a modernised form might be called users or clients, which,

¹This is not the place to go into details about the wide field of studies on legitimacy and accountability (for an overview of different types of legitimacy cf., e.g., Nedlund 2012, chap. 2). In this context it shall suffice that democratic states need to legitimise their expenditures—in particular those funded by taxes or solidary contributions. This can be done in several ways and affects different facets of legitimacy. Of most importance for this study are input legitimacy—in short: what have citizens to say about policies—and output legitimacy—i.e. basically the question ‘who gets what, when, how’ (Nedlund 2012, pp. 34–44).

in turn, creates a mixed form of legitimacy. In COUNTRIES WITH SOME TYPE OF NATIONAL HEALTH SYSTEM (NHS) legitimacy has traditionally been created via general elections of MPs in charge of health care policies, be it on the national or regional level, who then on behalf of the citizens direct or order health care services. They are, in turn, accountable to the population.

These different forms might be the expression of differences in focus, purpose, (ideological) preference, and quality of involvement. One of the first attempts to systematise several types of involvement and get definitions straight was Arnstein's 'ladder of citizen participation' (Arnstein 1969). Its basic idea is that there are different degrees of being involved, with only the three uppermost categories comprising real citizen power. According to this view, citizen control and, thereby, full insight and self-determination of citizens is the main goal in an ideal world. Arnstein discerns eight different, hierarchical steps:

- (a) Citizen Control
- (b) Delegated Power
- (c) Partnership
- (d) Placation
- (e) Consultation
- (f) Informing
- (g) Therapy
- (h) Manipulation

The fact that several scholars followed up on her research (to name just a few: Rocha 1997; Thompson 2007, for an overview cf. Tritter & McCallum 2006) shows the relevance of and the interest in such a classification.

However, as much as being a starting point, Arnstein's typology was also subject to considerable criticism. Main reasons mentioned are that it is too hierarchical and oversimplified an approach, that it lacked specifications of the (potential) methods and means of involvement, and that it failed to reflect about different capabilities of those to be involved. It has also been said that it underestimates the complexity of decision making and that it might end up in misallocating resources by a too lop-sided consideration of interests (for an overview cf. Tritter & McCallum 2006). In my opinion much more important in this context, however, is the fact that there is not the one and only ideal form of involvement, but that there can and should be several forms/levels of involvement that can be adapted to the specific geographical, organisational, or individual need (cf. also Tritter & McCallum 2006, chap. 7). However, most often there is a focus solely on one or two forms of involvement, while other forms are not as explicated in the literature.

Collective involvement can be organised differently. It might, for instance, occur under the aegis of general consumer organisations, be represented via patient organisations, be included in a larger corporatist system, formed as a committee, constitute a council, or be incorporated into decision-making bodies that exist anyway—with all their respective advantages and disadvantages (cf. also Simmons, Birchall, Doheny & Powell 2007). Tightly interwoven is the question about the constitution of the respective form of involvement for which, amongst other ways,

elections, appointment, access via membership, or the acceptance of volunteers can be thought of. Both the different variants of forms of involvement as well as their constitution are accompanied by different degrees of legitimacy. Usually, elections are seen as the most democratic means of constituting boards and committees, while appointment is often rather seen as a second class solution (cf., e.g., House of Commons 2010; Simmons et al. 2007, pp. 462 et seq., 470–471). Literature on patient involvement shows at the same time that pensioners and individuals with a higher educational background are the two groups whose share in most forms of voluntary involvement is higher than their share in the general population (cf., e.g., de Savornin Lohman 2000), which might play its part in decreasing legitimacy. It is also known that a short residence time, varying mental capabilities, and frailty affects the possibilities of involvement in nursing homes, so that the decision about its form and constitution is often a delicate balancing act. This shows that what holds true for individual involvement in treatment decisions holds even more so true for collective involvement: It is not only due to preferences, but also other critical factors, for instance, time, educational resources, and various constraints that not everyone easily can compensate for (cf. van de Bovenkamp 2010, pp. 155 et seq.). If, now, only is striven for what Arnstein calls ‘citizen power’, this would automatically exclude larger societal groups from being involved. Moreover, there are voices claiming that real influence requires participation in decision-making. Others maintain that participating and co-deciding in health care would rather give rise to interest conflicts among patients and the risk to be worn down between professional, more powerful actors, for instance, the pharmaceutical industry, health insurances, and multi-national hospital corporations. To conclude, it is safe to say that it is difficult terrain for which no ready-made recipe is available.

Next to this difference in focus there is nowadays talk of citizen, patient, beneficiary/insured, member, user, consumer, or client involvement depending on the respective country and perspective. The different terminology partly reflects different traditions, partly different target groups, but does not necessarily describe different forms of involvement, let alone different rights or qualities of involvement. While, for instance, the terminology used in the Netherlands is one of the user and client involvements, the term ‘public and patient involvement’ (PPI) is the common one in England describing by and large the same. While the terminology of the respective country will be applied with regard to this country, the term PPI will be used in a more general context as a wider, more encompassing term that also reflects the interest of net tax/contribution payers as well as potential patients.

On the other hand, while the target group is not necessarily a good indicator to characterise involvement, there are in particular vast differences in what is actually meant by the specific label: Sometimes there is talk of involvement, sometimes participation, co-decision making, or empowerment to just mention a few. As they denote completely different concepts, the following questions need to be posed: How much involvement is necessary and how much involvement is possible? Is it really necessary and desirable that patients decide about every little thing in the everyday practice of a health care organisation? There are good reasons to ask for a seriously intended involvement in a sincere discussion about key issues that

affect the group in question, as early on as possible, that take considerations from each side as seriously as the other and without preconceived opinion; taking control of the everyday business, however, would question the advantages of professional specialisation in general. An assessment of these questions, however, might differ from case to case, so that no global answer can be given.

Yet, one underlying question of Arnstein's ladder still waits to be answered: What aim is pursued with patient involvement, what function should it have? Even though not identical in organisation and aims, a look at patient organisations might be useful, the more so since they in some cases considerably influenced the early ideas of patient involvement. On a very abstract level, the aim of patient organisations can be summarised as helping to stop the passive reception of medical treatment (Oudenampsen 1999, p. 58). On a more concrete level Trappenburg (2008, pp. 40, 42, 46, 68–70) identifies six different functions of patient organisations (cf. also Coulter 2000, p. 141):

- (a) Raising awareness for the problems experienced
- (b) Representing and lobbying towards greater society and the state
- (c) Representing, lobbying against, and co-operating with the medical profession
- (d) Taking things in own hands
- (e) Making contact between fellow sufferers
- (f) Helping each other.

In particular the points (a) and (c), depending on the type of involvement (b), too, are of equal importance to patient involvement, even though the medical profession as the addressee is exchanged for the management of a nursing home or hospital or for politicians. Transverse to these functions runs the potential tension of the two aims of solely representing co-patients and co-residents, on the one hand, and to rather steer health care providers and/or politicians on the other (Simmons et al. 2007, pp. 459–461).

Against that backdrop, the definitional, somewhat crude differentiation between three different ways of involvement—which can exist parallel to each other—is made in order to elucidate what kind of involvement this book is primarily dealing with. It is a rather pragmatic approach to delimit terms that are of importance in this study, which includes the awareness and necessity of other definitions, of which, again, given different context factors all and none are right or wrong (cf. also Simmons et al. 2007).

PATIENT PARTICIPATION will be used in the sense of co-decision making, in a formally or de facto equal position of management and patient side. In a somewhat lengthy definition Potvin describes participation very aptly as

“[...] a generic term to encompass: those practices that involve collaborative relationships in the form of exchanges of opinion, knowledge or other resources between various groups of actors concerned by, and willing to, devote time and resources to issues of relevance to health in order to participate in decision making regarding priorities, planning, implementation or evaluation of public health programs.” (Potvin 2007, p. 111)

Distinct from patient participation is PATIENT INVOLVEMENT, which gives patients the opportunity to have their say in suggesting topics to be discussed with the management, complaining about deficiencies, and consulting the management on intended developments, strategies, investments, etc. The abovementioned definition can be altered for patient involvement, if ‘participate in decision making’ is interchanged with ‘consult in the process of decision making’.

As collective involvement most often necessarily involves only a smaller fraction of patients, large scale ONE-WAY FORMS OF COMMUNICATION, for instance, patient satisfaction surveys can complement collective patient involvement. Though the possibility to engage in discussions is naturally limited, it can create a larger image of what is going on.

Having said that and following the two acts in question here, what is in the focus of this book is patient/resident *involvement*. The definitional distinction points out that collective patient *involvement* is not about (co-)decision making, but about being given a serious possibility to have a say, to have a voice, and discuss things with decision makers. In front of this backdrop, although patient involvement may be interwoven into the organisational structure of a health care provider and a state or subordinate authority, it is still (formally) not part of the decision-making process in its narrower sense, since the final say is left to the professional decision-makers. In that sense, it has less competency than governance but at the same time reaches well beyond it. Moreover, as mentioned above, this study focuses on the hospital as the institution to be involved in. As the following chapter will show, this does not preclude that other forms of involvement will be dealt with.

2.2 Equivalents to Patient Involvement

As could be shown in the previous chapters, the question concerning the categorisation of patient/citizen participation/involvement incorporates a multitude of facets, which is one of the reasons why Arnstein’s hierarchical, one-dimensional model is rather unsuitable for many purposes. Many of the underlying dimensions of patient/citizen participation/involvement have already been dealt with above, which can be reformulated into questions to help to describe what actually is meant when terms like participation, involvement, or empowerment are employed: What is the overall purpose of participation/involvement? Is it about individual or collective involvement? Which group is targeted? Is it a one-off event or a standing institution? What *competencies* do lay actors hold (summarised in Fig. 2.1 on the facing page).

In the context of this study it is therefore essential to regard potential equivalents to patient involvement. Many other attempts to involve people in health care and receive input from them bear the traits of patient involvement. They might constitute reasons in other countries not to perceive the necessity to implement collective



Fig. 2.1 Dimensions of involvement. Source: Own depiction

patient involvement in hospitals. Table 2.1 on the next page is a first attempt to compile options that potentially serve an equivalent function of involvement. It not only consists of legitimacy structures such as democratic accountability or the patient/customer physician/provider relationship, but also includes other attempts to somehow involve people at some point or another. As it is difficult to gain a good overview and deeper insight into involvement in other countries, the list by no means intends to be exhaustive and needs to be complemented by other options that can be found in the respective country.

Table 2.1 Approaches and equivalents to community involvement

	Values and assumptions	Aims	Downsides
Democratic accountability	People who make decisions on behalf of others should be accountable, requiring open decision making	To call to account	Depending on arrangements varying degrees of direct and close democratic accountability at local level
Research	Research methods are more objective and can identify needs and obtain feedback from local people	To find the facts to inform management	Local people as source of information might lack the broader picture
Consultation exercises	Managers need to manage but also take account of local people's views	To validate and/or legitimate decision making	Local people as advisers, without sharing decisions
Community health councils, LINKS, Patients Forums ^a , <i>HealthWatch</i> ^a	Local people need a channel to keep them informed and help them express their views to the NHS	To enable the views of different sections of the community to be heard	Too much variation in effectiveness and lack of accountability
User groups and voluntary organisations	Voluntary organisations have knowledge and experience of services and can contribute to planning and management	To put forward the views of particular users or communities	Focuses on specific services and interests
Empowering communities	Local people, particularly from disadvantaged communities, need assistance to articulate their needs and act to achieve them	To 'empower' disadvantaged communities to influence local services and their environment	Requires long-term investment
Corporatist self-governance ^a	Representatives of unions and employers are working for the common interest of patients and net-payers	Disburden the state and give members of sickness-funds a say in their own affairs	Low legitimacy owed to decreasing organisation rates and less uniform employment biographies

Ombudsman system ^b	Practical implementation of rights and help patients with their complaint procedures	Representing patients towards providers and politics	Most often only retroactive once damage/ malpractice is done
Patient as complainant ^{a,c}	Patient complains about experienced low quality in health care	To improve health care services for others & prevent them from making the same bad experience	Depending on arrangements unsystematic approach dependent on the willingness of individuals with a varying welcoming attitude towards criticism
Patient as customer ^a	Patient is the informed customer who actively chooses for providers and services	Achieving lower prices, higher quality, and customer-oriented services	Diverse capabilities of citizens to put their interests through

Source: top section of table is adopted from Hogg (1999, p. 109)

^aAdded by author

^bBased on Fallberg (2003)

^cFollowing the results of Bouwman, Bomhoff and Friele (2014)

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