ELSEVIER

Social Science & Medicine 64 (2007) 1297–1310

SOCIAL SCIENCE & MEDICINE

www.elsevier.com/locate/socscimed

The meaning of patient involvement and participation in health care consultations: A taxonomy

Andrew G.H. Thompson

School of Social and Political Studies, University of Edinburgh, Adam Ferguson Bldg, George Square, EH8 9LL Edinburgh, UK

Available online 13 December 2006

Abstract

A number of trends, pressures and policy shifts can be identified that are promoting greater patient involvement in health care delivery through consultations, treatments and continuing care. However, while the literature is growing fast on different methods of involvement, little attention has been given so far to the role which patients themselves wish to play, nor even of the conceptual meanings behind involvement or participation. This article reviews the current models of involvement in health care delivery as derived from studies of professional views of current and potential practice, prior to examining the empirical evidence from a large-scale qualitative study of the views and preferences of citizens, as patients, members of voluntary groups, or neither. Individual domiciliary interviews were carried out with 44 people recruited from GP practices in northern England. These respondents were then included in a second phase of 34 focus groups in 6 different localities in northern and southern England, of which 22 were with individuals unaffiliated to any voluntary/community groups, 6 related to local voluntary/community groups with specific interests in health or health care, and 6 related to groups without such specific interests. A final set of 12 workshops with the same samples helped to confirm emergent themes.

The qualitative data enabled a taxonomy of patient-desired involvement to be derived, which is contrasted with professional-determined levels of involvement identified from the literature. Participation is seen as being co-determined by patients and professionals, and occurring only through the reciprocal relationships of dialogue and shared decision-making. Not everyone wanted to be involved and the extent to which involvement was desired depended on the contexts of type and seriousness of illness, various personal characteristics and patients' relationships with professionals. These levels are seen to provide basic building blocks for a more sophisticated understanding of involvement within and between these contexts for use by professionals, managers, policy-makers and researchers.
© 2006 Elsevier Ltd. All rights reserved.

Keywords: England; Patient involvement; Patient participation; Health care delivery; Consultation

Introduction

The inclusion of patients in health care decision-making, whilst not new, is a current policy imperative in many countries and health systems around the world. The belief in patient participation as a desirable goal of health policy has longstanding antecedents at a broad level (WHO, 1978). Strongly worded directives or normative statements favouring participation are to be found in a plethora of supranational (WHO, 2005), national and sub-national government policy documents. In the UK, neo-liberal administrations since 1979 have made citizen dependency on the State and the

E-mail address: Andrew.Thompson@ed.ac.uk.

0277-9536/$ - see front matter © 2006 Elsevier Ltd. All rights reserved.
doi:10.1016/j.socscimed.2006.11.002

paternalism of health care practitioners a target for reforms to encourage a more active consumerist ethos within welfare services (Winkler, 1987). Patient choice in service delivery was central to the White Paper '*Working for Patients*' (Department of Health, 1989) and further reinforced in '*The Patient's Charter*' (Department of Health, 1992), which included patients' right to make informed choices. In 1996, the Government launched the *Patient Partnership Strategy* (NHS Executive, 1996), which explicitly recognised the need for patient involvement in decisions about their own care.

Since 1997, the New Labour Government could be viewed as in the vanguard of promoting citizen involvement through its modernisation agenda of inclusiveness, stakeholder engagement and partnership working (Department of Health, 1997, 1998). The expected benefits of involvement were laid out in *Patient and public involvement in the new NHS* (Department of Health, 1999), including improvements in service quality, care outcomes and population health. In England, the strategic *NHS Plan* (Department of Health, 2000) emphasised the need for a health service responsive to the needs of patients, lay carers and the public, expecting those on the receiving end of care to take an active part. Better opportunities for patient and lay carer involvement in health care delivery and access to relevant information were key recommendations of the critical Bristol Royal Infirmary Inquiry Report (UK Parliament, 2001a). Subsequently, the *Health and Social Care Act* (UK Parliament, 2001b) made it a legal requirement to involve patients and the public. Recently, patient choice of hospital and treatment has been made central to the marketisation of health services in England (Department of Health, 2003).

Two distinct approaches to the involvement of patients can be discerned that reflect contrasting political values, one espousing individual freedom to make choices and the other a more collective freedom to achieve inclusiveness and equity. The former, consumerist model places health service users in the role of mimicking customers in market-style relationships (Mullen & Spurgeon, 2000), exemplified in the current emphasis on patient choice of hospital in England. Williams and Grant (1998) believe that this contradicts the meaning of person-centredness, while Thompson (1995) argues that it negates their role as co-producers of their own health and health care, not to mention their democratic role as co-owners in the British NHS. The latter approach emphasises the democratic dimension of quality (Pfeffer & Coote, 1991), requiring a developmental process of engagement over time, such as involving the voluntary sector in hospital boards. However, individual actions are not necessarily consumerist, nor collective actions necessarily democratic (Lupton, Peckham, & Taylor, 1998). Both approaches lay stress on patient empowerment, in the former case resting on the power of 'exit' when dissatisfied, or the making of complaints with compensatory redress when there is no alternative, and in the latter case relying on 'voice' to exert change more directly (Hirschman, 1970). Emanuel and Emanuel (1997) see these models as exemplifying the conflict between an economic and a political model of health care, although in essence they are both politically driven.

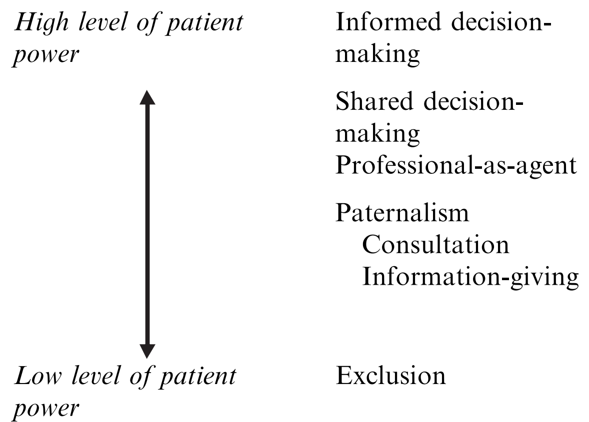
We can identify other influences on the patient–professional relationship within health care encounters. One is a notable increase in lay knowledge about health care and forms of self-help. Olszewski and Jones (1998) identify the steady growth of information outside formal health services, through voluntary group books/leaflets, help-lines, and, more recently, use of the Internet (Eysenbach, 2000). In tandem with recent scandals and negative media reporting, this may be fuelling an increased awareness of health professionals' fallibility and uncertainties in diagnoses, linked to increasing scepticism towards medicine and science (Beck, 1992). In part this also reflects increasing acknowledgement of wider influences on health (Acheson, 1998), as well as increasing evidence of disparities in clinical practise for similar conditions (Wennberg, 2002). A further important contributory factor has been the shift within post-industrialised countries from a focus on acute conditions to chronic health problems requiring continuous and complex management (Holman & Lorig, 2000; McEwan, Martini, & Wilkins, 1983). This has led to policy recognition in the *Expert Patients Programme* (Department of Health, 2001) of the important contribution made by people with chronic conditions to the management of their own health care. It is this perceived '*partnership of equals between patients and professionals*' that encourages Hunter (2004, p. 52) to see potential change in the power imbalance between 'repressed' citizens and the 'dominant' professionals or 'challenging' managers (Alford, 1975). There is also pressure to increase accountability (Barnes, 1997) and to democratise

publicly run health systems (Hogg, 1999), although some cynically view participation as a device to co-opt patients into unpalatable rationing decisions (White, 2000). Finally, there is a discernible shift towards incorporating patients' perceptions, values and preferences into a more subjective medicine, moving health care goals towards quality of life and patients' perceptions of health (Sullivan, 2003).

Models of involvement and participation in consultations

The terminology describing patients taking an active part in their consultations with professionals includes 'involvement' and 'participation'. These concepts are often used synonymously, without a clear understanding of their difference, despite being problematised individually (Elwyn, Edwards, Kinnersley, & Grol, 2000; Jones et al., 2004). In a notable exception, Cahill (1996) distinguished patient participation from the precursor concepts of involvement (basic, often delegated tasks) and collaboration (intellectual co-operation) and the ultimate concept of partnership (joint venture). Patient participation requires a narrowing of the information/competence gap between professional and patient, with some surrendering of power by the professional which conveys benefit to the patient, even if there is no consensus.

Early conceptualisation of the patient–doctor relationship outlined a hierarchy of patient control from passivity to participation (Szasz & Hollender, 1956), since when ideas of shared decision-making and patient autonomy have come to the fore (Coulter, 2002). Arnstein (1969) derived an eight-rung ladder of citizen participation, which spawned many similar frameworks in contrasting applications, including government health programmes (Feingold, 1977), community participatory health research (Cornwall, 1996; Rifkin & Pridmore, 2001) and NHS R&D agenda setting (Oliver et al., 2004). Charles and DeMaio (1993) developed it to include treatment decisions, in which patient involvement is identified as occurring at one of three levels of increasing patient power: consultation, partnership, or lay control. These levels are reflected in four of the currently most discussed models of treatment decision-making: *paternalism*, where the professional knows best and patient involvement is limited to being given information or giving consent; *shared decision-making*, where both the process and outcome of decisions about treatment options are shared between patient and professional; *professional-as-agent*, where professionals possess the technical expertise, but patient preferences are incorporated into their decision-making; and, *informed decision-making*, where the technical expertise is transferred to the patient, who makes the final decision (Coulter, 1997; Charles, Gafni, & Whelan, 1997). Combining these 4 levels with the exclusionary levels of manipulation/therapy identified by Arnstein (1969), we can conceive of professional-determined patient involvement along the following power continuum:



While there is some agreement about different models of patient involvement and the different conditions that would appear to favour each, much research has been limited to certain types of patient in consultation with doctors, often focussed on treatment decisions, rather than broader considerations of citizens (as past, current and potential patients), health care professions, or purposes of consultations. Moreover, the impression gained is of a normative perspective driven by professionals. However, (and see Rogers (1989)), it is important to reflect current meanings as embodied in patients' own understandings of these concepts within specific contexts. As Guadagnoli and Ward (1998, p. 337) conclude, "*participation should be defined by whatever level the patient is most comfortable with*".

In recognition of these trends, pressures and policy shifts, this article aims to explore the extent and contexts in which patients themselves are desirous of greater opportunities for voice, rather than exit, within health care consultations,[1] centred

[1]The term 'consultation' will be used hereafter to refer to any actual health care delivery, whether it is a consultation, provision of treatment, or continuing care.

on an empirical study of patient and citizen views of their preferences. From a synthesis of this material with existing literature on professional views of patient involvement, a taxonomy of involvement and participation within consultations will be constructed to offer conceptual clarity and as a means of enabling health care practitioners and managers to understand the dynamics and realities of patient-centred policy.

Methods

This is an exploratory, qualitative study based on a deliberative design, with the same individuals asked to discuss their views more than once, during 2000–2001. The sampling design was as follows:

(i) *Phase I*: Forty-eight individual, domiciliary, semi-structured interviews, recruited from 3 GP surgeries in northern England (inner city, suburbs and rural north east), reflecting age (18–25, 35–55, 70+), gender and presence/absence of chronic disease. Forty-four of the 48 interviews (92%) subsequently took place.

(ii) *Phase II*: Thirty-six focus groups with three different types of citizens in 3 areas in northern England (as above) and 3 areas in southern England (inner London, London suburbs and rural south east). Of the 36 focus groups proposed, 34 (94%) were achieved:

(a) Twenty-four homogeneous groupings of individuals, unaffiliated to any voluntary/community groups, reflecting combinations of age (as above) and gender, with presence/absence of chronic disease distributed across each. Of the 22 focus groups that took place, those interviewed in Phase I were included here in 6 of their own groups, with a further 16 groups recruiting interviewees from the same areas and other parts of the country;

(b) Six groups of citizens affiliated to local voluntary organisations/community groups with a specific interest in health or health care (hereafter referred to as health voluntary groups);

(c) Six groups of citizens affiliated to local voluntary organisations/community groups without a specific interest in health or health care (hereafter referred to as non-health voluntary groups).

(iii) *Phase III*: Twelve workshops with the same groups as in Phase II: all unaffiliated citizens together (age and gender) and, separately, all voluntary/community group members together in each of the 6 areas.

Table 1 shows the actual response rates, generating 208 individuals in total. While nearly all the groups met, the recruitment of individuals was difficult and declined over the phases.

The geographical areas and GP surgeries were chosen to reflect social class differences within different types of physical environment (as a proxy for access): two rural areas that contrasted relative wealth (south east) and poverty (north east); two suburban areas with mixed levels of wealth and deprivation; and two inner cities characterised by high levels of deprivation. Access was negotiated with each GP surgery (5 multi-practitioner and 1 single-handed) and ethical approval was given by relevant ethics committees.

Table 1
Study design and sample[a]

		Phase I		Phase II		Phase III	
		Interviewed individuals		Individuals	Focus groups	Individuals	Workshop groups
Unaffiliated individuals	Northern areas only	44	⟶	29	6 }	63	6
	All areas			82	16		
Voluntary/community groups	Health			43	6 }	58	6
	Non-health			36	6		
Total		44		190	34	121	12
Response rate	Individuals	92%		58%		37%	
	Groups				94%		100%

[a]Table showing the response rates to each phase of the research ($n = 208$).

Sampling was theoretically driven to derive a broad range of opinions, with age, gender, ethnicity, social class, health needs and experience chosen as the most discriminating variables. For pragmatic reasons participation in this research was limited to adults who could communicate in English, irrespective of ethnicity, with signing made available for deaf people in the focus groups (albeit unused). Having a chronic condition was believed to offer the best proxy for the presence of health needs and NHS experience. The only adults excluded would be those whom GPs deemed to be too ill or unable to participate for clinical reasons. Individuals opted in by confirming agreement to an invitation letter from their GP. Some individuals who turned out to be current/recent members of voluntary/community groups were asked to speak only on behalf of themselves or their dependants.

One member from 8 local voluntary/community groups in each area was invited to attend. Groups representing minority ethnic populations were given priority in selection, where possible. Those who were members of several voluntary groups were asked to speak on behalf of the group from which they had been invited. Paid workers employed in any voluntary group were specifically excluded.

All focus group discussions and workshops were held either in the local GP surgery or a location neutral to the participants, with times arranged to suit the majority and participants receiving remuneration for each meeting they attended to cover travel expenses and care for dependants. All interviews and focus group discussions were tape-recorded and verbatim transcriptions were made for entering into qualitative software (Nud*ist 4) prior to analysis.

Within a broader set of issues for discussion, all respondents were asked to consider their desired type of involvement and that of the public in general at the service delivery level of decision-making. Additional personal and group information was recorded (via self-completion questionnaires for the focus groups).

The combination of individual interviews and focus groups allowed a more deliberative understanding to develop among the respondents, as well as offering the benefits of group dynamics and more personal reflections to form a blend of public and private accounts to inform the analysis (Morgan, 1997; Silverman, 1993). Individuals were chosen from voluntary/community groups, some with greater experience of the NHS, to learn of their collective organisational perspectives on involvement. Unaffiliated individuals were put together to encourage the less experienced to feel safe to explore ideas and opinions through working in groups of similar personal characteristics, thus avoiding, for example, conflicts between genders or age-groups.

The transcripts were thematically coded and analysed by incorporating a combination of categories derived initially from the topic guides for the interviews and focus groups (see Fig. 1) and supplemented or refined with those that emerged spontaneously within these meetings. Due to the voluminous quantity of data, a small sub-sample of text was coded and checked by two researchers. Cross-cutting comparative analyses were conducted by several members of the research team, which

Interviews

- Extent want to be involved in consultation/treatment decisions
- Whether would like to change or improve health services
  - or defend them (if deemed to be good)
- Any motivation to exert influence - have greater say, more responsibility etc

Focus Groups

- Whether you think patients should be involved in health care consultation and treatment decision making
  - if so, to what extent
- Extent to which you want to be involved in consultation and treatment decision making yourself, about your own treatment or of dependants (e.g. children, elderly)
  - why or why not want to be involved
  - what generally happens in practice with decisions about your care & treatment
  - what helps/hinders the process, why

Fig. 1. Prompts about involvement used within the interviews and focus groups.

helped to triangulate the findings. The evidence presented below is drawn from individuals' views, as past, current or potential patients, of involvement in consultations only, from Phases I and II, with respondent face validity confirmed through gauging responses to feedback of initial results in Phase III. Evolving understanding of the concepts and their contextual conditions were discussed and refined within the research team and after various seminar presentations.[2] Quotations have been selected according to three criteria: illustrative of a particular theme; offering a range of views where there was heterogeneity; and, being focussed and succinct.

Overall views of involvement

Unaffiliated individuals' views emanated from direct experiences of self/dependants; second-hand experiences of family, friends, or community contacts; and the media. Involvement for them included one or more of: information, explanations, openness, communication, shared knowledge, emotional care, exploration of choices, dialogue and decision-making. In addition to the above sources, voluntary sector representatives drew from members of their group or cause. Health voluntary groups especially had clear views of the meaning of involvement, including, in addition to the above list, building partnerships and access for all.

Participation in consultations was broadly understood as involving patients in discussions about their condition, providing them with relevant information, asking for their opinion on possible treatments, and involving them in the decision-making process, should they so wish. Many noted that not everyone aspires to being involved at all times and in all situations. This emphasis on rights rather than obligations parallels participation literature in other contexts (UNICEF, 2001).

The findings are presented to illustrate the range of degrees of involvement which participants desired, depending on their own context.

Expressions of desire for involvement

Various reasons were advanced as to why some people could not be involved, including emergency conditions, psychological distress and level of cognitive ability, for which relative youth, dementia and head injuries were examples. Many respondents specifically mentioned lay carers, who were deemed to offer substitute or complementary involvement on occasions. The wide sample range of types of citizen presents a rich diversity of views on involvement, which for reasons of space cannot be fully explored here. However, there appeared to be a high degree of unanimity about the existence of different levels of involvement and participation, whatever the personal proclivities. These levels are now presented in relation to patients' relative power to influence decisions.

Non-involvement

Some, often with limited experience of health care, expressed trust in professionals to do the best for them, showing faith in their knowledge and abilities derived from years of education and training:

> …in the past I've always, even with the kids, tended to leave it up to the doctor because at the end of the day he's the one who makes the decision and you've got to trust his decision, but I've never had a case where a doctor's suggested something and I've had to turn round and say 'Not a cat in hell's chance.'
>
> (Middle aged man, little experience, northern suburbs, interview)

However, as the following extract reveals, greater experience of a negative kind leads to a contrary position:

> RESPONDENT 1: I think it depends a lot on how much trust you've got in the medical establishment and like from my personal [and] family's experience … there's been a lot of mistakes and things made by doctors that have resulted in like my dad, for one, dying. … So … it forces you to have an opinion of the medical profession, I suppose.
>
> RESPONDENT 2: Do you think that's made you want to get more involved with any treatment, that experience?
>
> RESPONDENT 1: Yeah, definitely. And well not just that but not to trust doctors so much as if … they're always right … but to just be a bit more wary about anything.
>
> (Younger men, northern inner city, focus group)

[2] Including the Economic and Social Research Council's 'Patient participation in health care' seminar series, of which the author was a core member.

For others it was more a case of wanting to trust, as a way of coping with fear and reducing anxiety:

> I would just like to trust me doctor … I don't want to know what's wrong with us you know. No I don't, I really don't, cos I'm terrified … so I would sooner just think to meself 'Well, me doctor's … trustworthy … to put us right.'
> (Middle aged woman, rural north east, focus group)

Part of the explanation for trusting professionals appears to reflect a lack of medical knowledge in patients, suggesting low self-confidence or relatively low valuation of their own knowledge:

> … people don't know …; they're not educated in the things that can go wrong with you … we put our faith in the doctors and we accept everything that they tell us and I think … we can only be involved to an extent, because if the doctor tells us something and it's … very high-faluted, or something that's very technical that we don't understand, then … there's not really a lot of point in telling us as far as decision-making.
> (Younger woman, rural south east, focus group)

There were many indications that the responsibility of involvement could be burdensome, which probably explains why choice of being involved has been strongly emphasised:

> He was diagnosed ten days before he died, right. Well he didn't know he had it and, to me, for someone who thinks they know best to go and tell him that he had it, did he want, was he responsible? Was he in a fit state for it to be thrust on him? … To take responsibility for this it's enormous.
> (Health voluntary groups, northern inner city, focus group)

Some clearly saw this responsibility as either life-shortening or requiring unwarranted effort:

> I know that when my husband was very ill we never talked about the illness, never and he lived about four years longer than he should have done quite happily.
> (Older woman, rural south east, focus group)

> RESPONDENT: …like I say, if it works and stuff, cool; if it doesn't, go back to the doctor and say that's not working.
> MODERATOR: But you don't really want to know any more than that?
> RESPONDENT: Not really.
> MODERATOR: Why not do you think?
> RESPONDENT: … laziness.
> (Younger man, northern inner city, focus group)

Others were referred to, often including younger people, who felt alienated from the NHS (and other official bodies) and had difficulties relating to the concept of involvement:

> … alcoholics or people like that … the fact that they may have some say in their own treatment is completely alien to them … cos they've been pushed around and downtrodden by every single official body that they come across … The fact that they could have a say, will have some kind of input to their own health issues, hasn't really dawned on a lot of them; they haven't even thought of it as a concept.
> (Non-health voluntary groups, inner London, focus group)

Information-seeking/information receptive

The following person expressed the view that being given information is a normative expectation and that receptivity to such information is an elementary stage of involvement:

> … you're involved by actually being told what they think the diagnosis is, what the options, the side effects is. In the end there may be no option as it were but at least the fact you've been told … as opposed to … twenty years ago you were lucky if you came out clutching a prescription not knowing what the hell it was going to do …
> (Middle aged man, northern suburbs, focus group)

However, for many this did not contain the vital ingredient of involvement:

> They could always just give you a leaflet and say 'You know that's what's wrong with you, that's what we're giving you, blah-de-blah, and you can go', but you know there's no contact there. I wouldn't say they're involving a patient. They're just informing them. It's not really what you want here …
> (Younger man, northern inner city, focus group)

Understanding the presenting illness or condition was a core requirement:

I'd want to know all the information, but I don't know about me necessarily playing much of an active role in it cos I'm a bit sort of trusting really. So, if a doctor gives me medicine, I'll take it.
(Middle aged woman, northern inner city, focus group)

Furthermore, many felt that information provided a means to maintain some control over their lives:

… I think that the key to anything, in terms of being ill or needing treatment, is your own ability to control that situation and so, therefore, I think you have to have a part to play in that … I think that's crucial to the doctor-patient relationship that you play a role and I know I personally would be unhappy with just being told what to do. That's not to say that I don't defer to the professionalism and the skills, but generally I'm happier if somebody explains things to me or I feel the environment is conducive to actually asking things I don't understand and asking the possible consequences of something that's wrong with me.
(Middle aged woman, northern inner city, focus group)

It was also clear that information was a basic building block for decision-making:

It's very difficult because one has to be, to a certain degree, knowledgeable about the variety of treatments that are available and well versed in the complications of the condition that you may be suffering from. Then you can make a judgement. … I think that there should be more information … freely available … in health centres which deal with the understanding of illness rather than treatment of illness.
(Middle aged woman, inner London, de facto interview[3])

Information-giving/dialogue

Greater confidence in self-knowledge and the need to be listened to and heard exemplify this level:

I think that they should treat you as if you do know what you're talking about. You're the one that's feeling ill and they should actually … 'Well, how are you feeling and do you think that it could be something, or something else?'

(Middle aged woman, London suburbs, focus group)

The chance to explore choices was recognised as requiring discussion, even if it did not lead on to making decisions:

To have, I suppose, informed choice. To be able to have that choice whether to make the decision and to discuss it with somebody who knows all the information and knows the consequences and the risks and to say 'Well, if it comes down to it, I trust you'. And I suppose they'd have overall say, because they know more about it than I do, but I would like to be involved with that and be given as much information myself to at least say 'No, I don't want that', rather than just saying 'Yeah, I'll do whatever'…

(Younger woman, little experience, northern suburbs, interview)

Linked to this discussion was a need for greater openness and honesty from professionals:

… more open and much more honest. But in the end I don't want them to hide behind their professional competence, that I am just as competent at what I do as they are with what they do, so in furtherance of this discussion more honesty, more information and, if it is of a highly technical nature, surely they are intelligent enough to explain it to me. And if it's beyond my understanding, please write it down and I will get it translated.

(Non-health voluntary groups, northern inner city, focus group)

Where professionals were prepared to be open to two-way communication, there was recognised to be a greater chance of rapport and reciprocity in the relationship:

You've got to feel like you're going in and having a discussion rather than them telling you and asking questions and you're just sat there answering. Yeah, you've got to get some form of rapport, haven't you?

(Younger woman, northern suburbs, focus group)

[3]Focus group with 1 attendee.

Shared decision-making

Here respondents wished to exercise an informed choice, being guided and allowed to express opinions in partnership with professionals:

> … I think we're talking about informed choice, so if people are going to be involved in their own health care then it does mean that somebody else has got to take the time to explain to them what is actually wrong with them and what … choices there are for putting it right and then some people get involved in it and feel a part of a team deciding their own future. So I think it's a team, which might be just you and the GP, or it might be you and a wider group of people … but the key to me is the person feeling that they themselves and their opinions are valued in decision making.
>
> (Health voluntary groups, inner London, focus group)

This sharing of decisions was believed to lead to better decisions being made:

> … the last two serious occasions I've gone into the doctor's I've actually told him what I think is wrong. One occasion he's disagreed with me and then been proved that I was right, which is bad news, and on the second occasion he was fabulous, you know, and it was great, 'We've got to do this X, Y and Z' and it's because you're sharing the same information.
>
> (Middle aged man, rural south east, focus group)

Whilst it can be viewed very positively, reasons for desiring involvement at this level can also be an expression of mistrust:

> MODERATOR: Do you think that patients should be involved in decisions about their own care and treatment?
>
> RESPONDENT: Yes … because, very often, I believe that the medical profession and hospitals in particular are very structured societies and they're more interested with the kind of world that they've built up and the control that they can exert than the care of their patients.
>
> (Middle aged woman, inner London, de facto interview)

Autonomous decision-making

While there appeared to be relatively little support for independent decision-making, probably related to concerns about the high degree of concomitant responsibility, there were some who believed they had equal or even superior knowledge about their condition, typically those living with chronic illness:

> With my diabetes they tell me one thing and I'll do something else. Because if you're living with diabetes you know yourself when your sugar's gone and you know when your sugar's too high … I don't tell her [diabetic nurse] nothing … She doesn't listen … I told her the other day I had two hypos in one day and she told me to higher up me insulin. You know you just don't do that. So I stayed to what I was taking anyway … cos I know when I feel good …
> (Middle aged woman, northern inner city, focus group)

Some preferred to be able to manage their condition themselves:

> You know I made a decision to have surgery and radiation but not chemotherapy … I'd read around it a lot and found various advice agencies and I was quite informed … There's a lot of people who's having a really hard time with chemo and stuff like that … because they see the doctors as the experts … rather than managing their own disease.
> (Middle aged man, northern inner city, focus group)
>
> … I think I want … an advised choice … I just generally go and have a chat and we sort of say 'Well, do you think we should do this?' and … I don't leave it to the doctor. I have an input definitely and in the end I make the final decision. I have been known to sort of play around with my doses with my asthma things as well without consulting a doctor, just because I think I know and it seemed to work.
> (Younger woman, much experience, northern suburbs, interview)

Some respondents had an even broader view of health care that extended beyond the traditional reaches of professionals:

> Health care isn't … purely about managing health problems because it has a knock on effect

into social aspects of people's lives. …[P]eople should have a large amount of say in how they conduct their lives in view of the disabilities, or despite the disabilities in a lot of cases.
(Non-health voluntary groups, rural north east, focus group)

Developing a taxonomy

Through linking positive and negative opinions about how citizens would like to be involved, it has been possible to develop a taxonomy with five discrete levels of *patient-desired involvement* in consultations, as shown in Fig. 2. Those levels that can be achieved through self-determination are hereafter labelled as *patient-determined involvement*. While this suggests an active role, the amount of involvement that patients wish to have might be more subtle and reflect an internalised set of normative expectations about their right to receive information, whether demanded or not. Patient involvement in this scenario might depend on how much effort they perceive it to require and how much they are prepared to exert to satisfy those expectations. In other words, apparently passive positions adopted by patients can belie a potential for more assertive articulation of involvement should it be deemed appropriate and worthwhile. The taxonomy also recognises that some may not wish to be involved due to vulnerability, lack of interest, or apathy, although even for these patients it may represent a deliberate act of detachment, or even defiance, in the face of perceived social or personal exclusion.

By comparing this taxonomy with existing theories of patient involvement, five parallel, although meaningfully different, levels of *professional-determined involvement* can be aligned with it, representing how professionals attempt to position patients within consultations. These begin from two paternalistic positions of excluding patients (level 0) or simply giving them information considered necessary by professionals (level 1). Consultation (level 2) is used in the Arnstein (1969) sense of lacking any requirement to reflect the patient's agenda or to act on the findings. The professional-as-agent model (level 3) denotes the incorporation of patients' views and preferences with their own expertise to make the final decisions, which necessitates some prior consultation or dialogue, while informed decision-making (level 4) involves professionals giving their expertise to patients to decide themselves.

Where patients desire to be involved in dialogue or the sharing of decisions, this can only be effected through a matching willingness by professionals, labelled here as *co-determined involvement,* or, reflecting the overall views outlined earlier, *participation*. Dialogue, although occurring at the same level as patients wanting to give information, or professionals asking patients what they think, requires the added component of two-way communication within conditions of openness and mutual respect. Dialogue is seen to underpin the possibility of shared decision-making, although it may be that patients would rather the professional (as agent) took the final decision, based on knowledge of their views and preferences. Participation does not, therefore, necessarily include the sharing of decisions or, by implication, a consensus.

Each level represents a relative position of patient power between the extremes of non-involvement or exclusion (notwithstanding the possible powerful intent of self-exclusion) and full autonomy. This is not to say that more power is necessarily more desirable, since there is a concomitant increase in responsibility for the outcomes, which some would find insupportable. It is assumed that moving up each level beyond non-involvement is typically dependant upon each preceding level having been sufficiently achieved for a particular situation, although this could easily alter when faced with different professionals, settings or illnesses. It is conceivable that patients might make the jump from level 1 to 4, should they wish for any reason to make decisions without recourse to professionals.

Patient-Desired Level	**Patient-Determined**	**Co-Determined** ***[PARTICIPATION]***	**Professional-Determined**
4	Autonomous decision-making		Informed decision-making
3		Shared decision-making	Professional-as-agent
2	Information-giving	Dialogue	Consultation
1	Information-seeking/receptive		Information-giving
0	Non-involved		Exclusion

Fig. 2. Levels of involvement.

However, since use of NHS services requires professional sanction, this could effectively exclude them from formal health care and would be unlikely without much experience at other levels. Nonetheless, full autonomy, it is believed, can mean that patients act with or without any information derived from professionals. The resultant position in which patients are located will depend on their relative power and the willingness of professionals to adapt to them.

Moving between the levels

Despite respondents having clear views about their desired level of involvement, it was usually qualified by a number of determining characteristics, reflecting three distinct contextual dimensions. Firstly, there are two attributes which reflect the nature of the health care need itself: the type of illness, whether it is acute or chronic, with the latter offering greater possibilities for involvement due to prolonged experience:

> … a chronic disease like say, diabetes, as you grow up your knowledge increases so … you know your diabetes probably as well as any doctor … that way they don't have to trust somebody else so much … because they can take control of it. But … acute illness information can be given, but the patient doesn't have a chance to develop … the knowledge that the doctor has, so then you know involvement is going to be more limited …
> (Younger man, London suburbs, focus group)

and the seriousness of the condition, which is related to degree of expert knowledge:

> Well … things that aren't life-threatening in my view would be something that you have a say in. If something's life-threatening you have to hope that you'd be told what to do and it would be the right thing to do … It's really, in my view, about if you've got a choice that can be made on a sort of personal, social level, as opposed to on a medical level, then you should be involved in it … Involvement reduces [for serious illness] but I would say information needs to increase.
> (Younger man, London suburbs, focus group)

Secondly, there are the personal characteristics of patients, which in part are likely to reflect socio-demographic variables, linked to knowledge and experience, and personality:

> …it has to be…a balance between what the individual's personality and character wants and what the overall service should be doing in recognising individual choice, but being open to that…changing, so the person who showed no interest might then say, 'Hang on, now I actually want to engage much more seriously'.
> (Health voluntary groups, inner London, focus group)

Thirdly, there is the patient–professional relationship, characterised by trust, which gives confidence to allow others to act on our behalf:

> Throughout my life I've always had competent GPs and they've always been really helpful … we get on well and that sort of thing. So it's easier to trust someone and trust their decision … But if I was in a new situation where I didn't know my GP, or a new area, that sort of thing, then I would want to know a lot more about what was going on and what was being said …
> (Younger man, London suburbs, focus group)

Trust features where there is little patient experience or knowledge, or where seriousness increases the possibility of decision-making regret. Situations which question or shake this trust can be the spur for greater involvement, until trust can be established or restored, at which point it is conceivable that continued demand for involvement would be less strong. However, trust which emerges through greater involvement may create the conditions for a sustained desire for involvement, as self-confidence and competence grow and mature.

The demand for involvement appears to reflect a combination of these dimensions, as outlined in Fig. 3.

Discussion

Amid the extensive range of views in this study, we can identify five distinct levels of patient involvement in consultations. These levels provide a set of building blocks between basic demands for more information and the ability to share or control decisions about health care, whilst acknowledging that some patients in some contexts would prefer not to be involved at all. The main distinguishing feature between patient involvement and patient participation concerns the degree to which patients take part in the decision-making process, connoting a degree of transfer of power from the professional

	Reduced demand	Increased demand
Need for health care		
Type of illness	acute	chronic
Seriousness	high	low
Personal characteristics		
Knowledge/experience	(variable)	(variable)
Personality	passive	active
Professional relationship		
Trust	high	low

Fig. 3. Dynamic dimensions of involvement.

to the patient in the form of increased knowledge, control and responsibility. The same patient may wish to be involved at different levels in relation to different circumstances and it may change over time for the same person in the same context. Patient involvement is, therefore, a complex, multi-faceted and dynamic concept, for which this taxonomy offers a necessary simplification to assist professionals, managers, or policy makers to respond appropriately.

While there are clear parallels with the work of Arnstein (1969) and others, those levels reflect a concern and perspective that emanates from professionals, rather than patients themselves. This study combined individual interviews with focus groups to generate a rich, narrative understanding of how citizens view involvement and participation in health care delivery. Evidence of construct validity is indicated by the study issues reflecting much of what is already known, while the breadth of the sampling has allowed greater insight into the similarities and differences between and within the 'activists' and 'non-activists' in a way that broadens and deepens our understanding of the complexity of the concept. Those who participated may not have been typical of the general public and they may have been more in favour of involvement. Nonetheless, we have been able to discern a wide variety of viewpoints that enable us to establish the likely range of opinions, including those opposed to involvement. A more quantitative approach would be required to determine the distribution of views across the various publics.

For some purposes a more sophisticated delineation of levels of involvement may be required, such as disaggregating the stages involved in the information process, or incorporating the time dimension within and between various episodes of care (Gafaranga & Britten, 2003). There is also a need to see how such a taxonomy would work with different kinds of therapeutic relationship, contrasting those of the conventional allopathic variety, largely explored here, with other forms that emphasise patient-constituted relationships, such as psychoanalysis (Peräkylä & Vehviläinen, 2003). Despite the broad scope of this study, a consequential limitation has been a lack of attention to in-depth analysis of specific conditions or contexts. The literature partly addresses these, but there is a dearth of evidence from many health care encounters. It is also clear that, despite identifying some socio-demographic differences, significant gaps exist in our understanding of how different ethnic groups perceive involvement. The impact of personality, particularly the emotional disposition to illness, also needs further research.

Hoggett (2001), in warning of the dangers of typologies that characterise individuals, suggests the use of continuums of agency and reflexivity, which explore relative powerlessness and the complexities of choice, to see how roles change over time. We also need to study the social and political contexts that give power, morality and meaning to patient involvement (Glenister, 1994). Reflecting these, this taxonomy offers a way of identifying the contexts that enable patients to determine their own desired level of involvement, as an expression of voice within consultations.

In conclusion, many patients support greater involvement in service delivery, but they want professionals to recognise that this needs to be optional and varies according to the context and probably over time too. Maintenance of trust appears to be crucial, with its erosion likely to lead to increased demand for involvement, although it might also lead to self-exclusion. Participation, when it is the ideal form of relationship, requires professionals to engage in two-way communication and effectively share the power they undoubtedly

have with their patients on the basis of mutual respect and openness.

The proposed taxonomy identifies the different perspectives on involvement and offers a means to link the two. In this way, this study enables an understanding of how involved patients wish to be within different aspects of a consultation and why, alongside professional preferences, offering the possibility of a mutually acceptable arrangement, facilitating more effective communication from professionals and satisfying patients as a result.

Acknowledgements

Special thanks to colleagues in the Health in Partnership project on which this article is based, including Kai Rudat, Sophie Staniszewska, Marcia Kelson, David Gilbert, Sara Bruce, Emily Gray, Malcolm McCrae, Susan Levy and Marilyn Kendall, as well as the Department of Health in England for funding the research. Grateful thanks also to Rosa Suñol, Carol Bugge and Sarah Collins for helpful comments, and to members of the ESRC 'Patient Participation in Health Care Consultations' seminar group for their challenging questions.

References

Acheson, D. (1998). *Independent inquiry into inequalities and health report*. London: The Stationery Office.

Alford, R. R. (1975). *Health care politics*. Chicago: University of Chicago Press.

Arnstein, S. R. (1969). A ladder of citizen participation. *Journal of the American Institute of Planners*, *35*(4), 216–224.

Barnes, M. (1997). *Care, communities and citizens*. Harlow: Addison Wesley Longman.

Beck, U. (1992). *Risk society: Towards a new modernity*. London: Sage.

Cahill, J. (1996). Patient participation: A concept analysis. *Journal of Advanced Nursing*, *24*(3), 561–571.

Charles, C., & DeMaio, S. (1993). Lay participation in health care decision making: A conceptual framework. *Journal of Health Politics, Policy and Law*, *18*(4), 881–904.

Charles, C., Gafni, A., & Whelan, T. (1997). Shared decision-making in the medical encounter: What does it mean? (Or it takes at least two to tango). *Social Science & Medicine*, *44*(5), 681–692.

Cornwall, A. (1996). Towards participatory practice: Participatory rural appraisal (PRA) and the participatory process. In K. de Koning, & M. Martin (Eds.), *Participatory research in health* (pp. 94–107). London: Zed Books.

Coulter, A. (1997). Partnerships with patients: The pros and cons of shared clinical decision making. *Journal of Health Services Research and Policy*, *2*(2), 112–121.

Coulter, A. (2002). *The autonomous patient: Ending paternalism in medical care*. London: The Stationery Office/Nuffield Trust.

Department of Health. (1989). *Working for patients*. London: HMSO.

Department of Health. (1992). *The patient's charter*. London: HMSO.

Department of Health. (1997). *The new NHS: Modern, dependable*. London: The Stationery Office.

Department of Health. (1998). *A first class service*. London: The Stationery Office.

Department of Health. (1999). *Patient and public involvement in the new NHS*. London: The Stationery Office.

Department of Health. (2000). *The NHS Plan: A plan for investment, a plan for reform*. London: The Stationery Office.

Department of Health. (2001). *The Expert Patient: A new approach to chronic disease management for the 21st century*. London: The Stationery Office.

Department of Health. (2003). *Building on the best. Choice, responsiveness and equity in the NHS*. London: The Stationery Office.

Elwyn, G., Edwards, A., Kinnersley, P., & Grol, R. (2000). Shared decision-making and the concept of equipoise: The competencies of involving patients in healthcare choices. *British Journal of General Practice*, *50*(460), 892–897.

Emanuel, E. J., & Emanuel, L. L. (1997). Preserving community in health care. *Journal of Health Politics, Policy and Law*, *22*(1), 147–184.

Eysenbach, G. (2000). Towards ethical guidelines for dealing with unsolicited patient emails and giving teleadvice in the absence of a pre-existing patient-physician relationship—Systematic review and expert survey. *Journal of Medical Internet Research*, *2*(1), e1 〈http://www.jmir.org/2000/1/e1/index.htm〉 (Accessed 30/8/04).

Feingold, E. (1977). Citizen participation: A review of the issues. In H. M. Rosen, J. M. Metsch, & S. Levey (Eds.), *The consumer and the health care system: Social and managerial perspectives*. New York: Spectrum.

Gafaranga, J., & Britten, N. (2003). 'Fire away': The opening sequence in general practice consultations. *Family Practice*, *20*(3), 242–247.

Glenister, D. (1994). Patient participation in psychiatric services: A literature review and proposal for a research strategy. *Journal of Advanced Nursing*, *19*(4), 802–811.

Guadagnoli, E., & Ward, P. (1998). Patient participation in decision-making. *Social Science & Medicine*, *47*(3), 329–339.

Hirschman, A. (1970). *Exit, voice and loyalty*. Cambridge, MA: Harvard University Press.

Hogg, C. (1999). *Patients, power and politics: From patients to citizens*. London: Sage.

Hoggett, P. (2001). Agency, rationality and social policy. *Journal of Social Policy*, *30*(1), 37–56.

Holman, H., & Lorig, K. (2000). Patients as partners in managing chronic disease. *British Medical Journal*, *320*(7234), 526–527.

Hunter, D. (2004). A structural perspective on health care reform. *Journal of Health Services Research and Policy*, *9*(1), 51–53.

Jones, I. R., Berney, L., Kelly, M., Doyal, L., Griffiths, C., Feder, G., et al. (2004). Is patient involvement possible when decisions involve scarce resources? A qualitative study of decision-making in primary care. *Social Science & Medicine*, *59*(1), 93–102.

Lupton, C., Peckham, S., & Taylor, P. (1998). *Managing public involvement in healthcare purchasing*. Buckingham: Open University Press.

McEwan, J., Martini, C. J. M., & Wilkins, N. (1983). *Participation in Health*. London: Croom Helm.

Morgan, D. L. (1997). *Focus groups as qualitative research* (2nd ed.). London: Sage.

Mullen, P., & Spurgeon, P. (2000). *Priority setting and the public*. Abingdon: Radcliff Medical Press.

NHS Executive. (1996). *Patient partnership: Building a collaborative strategy*. Leeds: NHS Executive.

Oliver, S., Clarke-Jones, L., Rees, R., Milne, R., Buchanan, P., Gabbay, J., et al. (2004). Involving consumers in research and development agenda setting for the NHS: Developing an evidence-based approach. *Health Technology Assessment*, *8*(15).

Olszewski, D., & Jones, L. (1998). *Putting people in the picture: Information for patients and the public about illness and treatment. A review of the literature*. Edinburgh: Scottish Association of Health Councils/Scottish Health Feedback.

Peräkylä, A., & Vehviläinen, S. (2003). Conversation analysis and the professional stocks of interactional knowledge. *Discourse and Society*, *14*(6), 727–750.

Pfeffer, N., & Coote, A. (1991). *Is quality good for you?* Social policy paper no. 5. London: Institute for Public Policy Research.

Rifkin, S. B., & Pridmore, P. (2001). *Partners in planning: Information, participation and empowerment*. London: Macmillan.

Rogers, B. L. (1989). Concepts, analysis and the development of nursing knowledge: The evolutionary cycle. *Journal of Advanced Nursing*, *14*(4), 330–335.

Silverman, D. (1993). *Interpreting qualitative data: Methods for analysing talk, text and interaction*. London: Sage.

Sullivan, M. (2003). The new subjective medicine: Taking the patient's point of view on health care and health. *Social Science & Medicine*, *56*(7), 1595–1604.

Szasz, T. S., & Hollender, M. H. (1956). A contribution to the philosophy of medicine; the basic models of the doctor–patient relationship. *Archives of Internal Medicine*, *97*(5), 585–592.

Thompson, A. (1995). Customizing the public for health care: What's in a label? In I. Kirkpatrick, & M. Martinez Lucio (Eds.), *The politics of quality in the public sector* (pp. 65–83). London: Routledge.

UK Parliament. (2001a). *Learning from Bristol: The report of the public inquiry into children's heart surgery at the Bristol Royal Infirmary 1984–1995* [Cm. 5207]. London: The Stationery Office.

UK Parliament. (2001b). *Health and Social Care Act*. London: The Stationery Office.

UNICEF (United Nations Children's Fund). (2001). *The participation rights of adolescents: A strategic approach* Working paper PD/05-01. New York: UNICEF.

Wennberg, J. E. (2002). Unwarranted variations in healthcare delivery: Implications for academic medical centres. *British Medical Journal*, *325*(7370), 961–964.

White, D. (2000). Consumer and community participation: A reassessment of process, impact and value. In G. Albrecht, R. Fitzpatrick, & S. C. Scrimshaw (Eds.), *Handbook of social studies in health and medicine* (pp. 465–480). London: Sage.

WHO. (1978). *Primary health care, Alma Ata*. Geneva: World Health Organisation.

WHO. (2005). *Health promotion in hospitals: Evidence and quality management*. Copenhagen: World Health Organisation.

Williams, B., & Grant, G. (1998). Defining 'people-centredness': Making the implicit explicit. *Health and Social Care in the Community*, *6*(2), 84–94.

Winkler, F. (1987). Consumerism in health care—Beyond the supermarket model. *Policy and Politics*, *15*(1), 1–8.