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‘The public is too subjective’: public involvement at different levels of health-care decision making

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Abstract

There are a number of impulses towards public participation in health care decision making including instrumentalist, communitarian, educative and expressive impulses and the desire for increased accountability. There has, however, been little research looking systematically at the public's preferences for being involved in particular types of rationing decisions, nor indeed, has there been a critical examination of the degree of involvement desired by the public. The research reported here uses findings from focus groups and in-depth interviews to explore these questions. Eight focus groups were conducted with a total of 57 informants, four amongst randomly selected members of the public and four with informants from health and non-health related organisations. Nineteen interviews were conducted to allow the elaboration of focus group comments, to probe views more deeply and to pursue emerging themes. The findings show variations in the willingness of members of the public to be involved in health care decisions and consistency across the different forms of the public as represented by the focus groups with randomly selected citizens and pre-existing organisations. There was a strong desire in all the groups for the public to be involved both at the system and programme levels, with much less willingness to be involved at the individual level. At the system and programme levels informants generally favoured consultation, without responsibility for decisions, but with the guarantee that their contribution would be heard and that decisions taken following consultation would be explained. At the patient level informants felt that the public should participate only by setting criteria for deciding between potential beneficiaries of treatment. The public has much to contribute, particularly at the system and programme levels, to supplement the inputs of health care professionals. © 2002 Elsevier Science Ltd. All rights reserved.

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Introduction

Health care resources may be allocated in any number of ways within two organisational extremes. At one

extreme, scarce health care resources may be distributed through the market system, with allocation by price according to the interaction of demand and supply. Here participation by the public is an intrinsic part of the mechanism of determining the pattern of health care provision, similar to the role of consumer. At the other extreme, resource allocation takes place through a centrally funded system according to any one or more

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criteria which may be either explicitly stated or implicit. Here there is a less pre-defined role for the public who are usually seen as service users or, increasingly, citizens. Yet rising health care costs and constrained budgets mean that there are difficult decisions to make about which services to provide for which patients in which circumstances (Coast & Donovan, 1996). The notion of participation in health care decision making has gained momentum (Maynard & Bloor, 1998).

It is suggested that public participation in decision making can promote goals, bind individuals or groups together, impart a sense of competence and responsibility and help express political or civic identity (Putnam, 1993; Verba & Nie, 1992; Verba, Schlozman, & Brady, 1995). Parry, Moysera and Day (1992) suggest four reasons for the impulse towards participation: instrumentalist, communitarian, educative and expressive. First, the instrumentalist argument is that participation should promote or defend the goals of participants: it is essentially self-interested and in health care is particularly linked to participation among users. This desire to participate is strongly expressed both by policy makers (NHS Management Executive, 1992; Department of Health, 1999) and by users themselves (Barnes & Shardlow, 1997). Second, the communitarian argument relates to the common interests of a particular community and in health care is linked, for example, to public participation in commissioning by primary care groups, with the assumption that the expertise of the public should lead to more appropriate provision of local health services (Department of Health, 1999). Third, educative arguments are concerned with the development of citizen senses of competence and responsibility, and the concern to enhance democracy by encouraging citizens to reach their full potential (Calnan, 1997), which links with the fourth argument for participation—the expression of political identity and belonging (Parry et al. 1992).

A further theoretical reason for participation is the desire for local accountability, one that has frequently been proposed in health care. This stems largely from the fact that the NHS is a publicly funded service and that managers and health professionals should therefore be accountable to actual and potential consumers—patients and local people (Donovan & Coast, 1996; Calnan, 1997). As patients and members of the public are becoming more knowledgeable about health care and expecting more from it, it has been suggested that decisions should be made more explicit and open to public scrutiny (Doyal, 1997; Klein, 1984; Charles & DeMaio, 1993). It has been argued that the historical lack of accountability is a primary reason for formalising public participation in decision making (Langton, 1978).

A broad definition of participation is that it involves “taking part in the process of formulation, passage, and

implementation of public policies [through] action by citizens which is aimed at influencing decisions which are, in most cases, ultimately taken by public representatives and officials” (Parry et al. 1992, p. 16). This definition does not, however, take into account the degree of public participation that is required for local health care decision-making. Arnstein proposed a model of participation consisting of a ladder with eight rungs representing different degrees of involvement. The first two rungs are seen as non-participatory, with ‘manipulation’ being the persuasion of citizens to support existing plans and ‘therapy’ the diversion of citizens from the real issues. A second set of rungs consists of modest degrees of involvement: informing citizens; consulting simply in terms of conforming with statutory legislation but without obligation to act or take notice of citizens’ views; and placation, where there is a guarantee that citizens’ views will be heard but no guarantee that they will be heeded. The higher rungs on the ladder identify forms of participatory activity in which the public has increasing power and where there is a commitment to ongoing integration of the views of the participants fully within the wider decision-making process. These range from partnership (sharing responsibility for decision-making) through delegated power (citizens have the dominant power) to citizen control (governance by citizens who are given control of a program or project within a budget provided by a central authority (Arnstein, 1969)). Others have reduced the complexity of Arnstein’s model (but have correspondingly lost some of the nuances of meaning (Eyles & Litva, 1998)), with Feingold suggesting five degrees of participation (informing, consultation, partnership, delegated power, and citizen control (Feingold, 1977)) and Charles and DeMaio reducing it to three: consultation, partnership, and lay domination (Charles & DeMaio, 1993).

Participation is thus a complex concept in theoretical terms and its complexity is exposed by the ways in which it has been applied in health care. The degree of participation in practice depends upon both the disposition of those in control and the needs of the particular decision-making situation. Public input into health care decision making, at least in theory, is clearly advocated in the UK (Department of Health, 1989, 1997, 1999; NHS Management Executive, 1992) and elsewhere (Checkoway, 1981; Government Committee on Choices in Health Care, 1992; Swedish Parliamentary Priorities Commission, 1995; Working group on health care prioritisation, 1995; Nova Scotia Department of Health, 1994; National Advisory Committee on Core Health and Disability Support Services, 1992, 1994; National Health Committee, 1998; Waterworth & Luker, 1990), although in practice the degree of influence that citizens have in making decisions is variable and undefined. This variability may arise in

part because the contexts of different levels of health care decision-making are very different. Klein suggests that rationing decisions are made at a number of levels including at the national level (for example between health and education), at the level of commissioners deciding about priorities between services (for example between oncology and mental health services), and at the micro levels of deciding about priorities within services, including allocating resources between different types of treatments and between different patients (Klein, 1993; Hunter, 1993). The degree of citizen participation may vary across these different levels of decision making and, indeed, citizens may have views about the degree of participation that they themselves feel is appropriate at each level. No critical analysis of these questions has yet been undertaken.

Despite this, many health authorities in the UK have been prompted to obtain public views with varying mechanisms and degrees of success (Health Committee, 1995; Bowie, Richardson, & Sykes, 1995). Evidence from survey research has indicated that members of the public think that the public should be consulted about health care decisions (Richardson, Charny, & Hammer-Lloyd, 1992; Bowling, 1993); it has also shown that most of the public thinks that rationing decisions should be taken by doctors (Richardson et al., 1992; Myllykangas, Ryyanen, Kinnunen, & Takala, 1996; Worth, 1999). Evidence included in a recent review concludes that decisions should be left to experts although the public should be consulted: “the public’s view seems unambiguous: doctors—not managers, politicians, or the general public—should be left with the final decision over what to prioritise” (Kneeshaw, 1997). These results contrast to some extent with findings obtained using methods which offer informants an opportunity to discuss their ideas with others before coming to a conclusion. Citizens’ juries conducted in the UK have included only small numbers of individuals, but have found that those wanting increased public involvement are in the majority and those preferring decisions to be left to experts are in the minority (Coote & Lenaghan, 1997; McIver, 1998). Research in Canada using a deliberative polling technique (where people are informed about the decision) found a preference for a combined decision making body (Abelson, Lomas, Eyles, Birch, & Veenstra, 1995).

There are likely to be a number of reasons for these differing results. First, citizen willingness to participate in decision making may depend on the particular level of decision being contemplated. Second, there has been uncritical use of terms such as involvement and participation so that apparently comparable findings may actually relate to different concepts. Third, different research methods have been employed, ranging from simple surveys through interviews, focus groups and deliberative polling to citizens’ juries, each of which

allows for different degrees of information provision, reflection and discussion and thus, ultimately, the potential for different results.

A further question concerns representation of citizens. Four broad types of representation can be identified (Desario, 1987): elected representation, for example local and national government; advocacy by experts, for example health professionals; random samples of citizens, for example representing a locality; special interest groups, for example user and charitable groups. By the nature of their professional lives, elected representatives and health professionals, are already playing roles within the health care decision-making process.

In this paper we attempt to bring these issues together by exploring, among members of the public, whether the public should be involved at different levels of health care decision making. In this study we included two representations of the public: random samples of citizens from particular localities and members of health and non-health interest groups. These ‘publics’ do not normally take part in decision-making but could potentially be involved in the process. The term “involvement” was deliberately chosen because it is broad enough to encompass all rungs of Arnstein’s ladder and would allow informants to discuss its meaning in relation to each particular decision making context. Similarly, the term “public” allowed informants to discuss who should be involved in these different contexts. Further, informants could explain what they thought they could contribute to each of these decisions, including the degree to which they would wish to be involved themselves. Qualitative research methods were used, with focus groups chosen specifically because they allow exploration of ideas among a number of individuals who may also reach consensus views. These were supplemented with in-depth interviews to obtain a more reflective and detailed understanding of the basis for individual views.

Methods

The study grew out of a collaborative interest in public participation and priority setting, particularly in the context of the range of decisions that have to be made in public health planning and the requirement to obtain public views about such decisions (NHS Management Executive, 1992). As indicated above, our intention was to explore the willingness of various constructions of the ‘public’ to participate in particular decisions within one health authority in the UK. There were three types of public:

- (i) Individuals randomly selected from electoral rolls
—Given the importance of socio-economic status

in health (Wilkinson, 1996), two localities were identified through consultation with the health authority as 'middle' and 'working' class. 1991 census data relating to proportions of people owning cars, aged over 65, renting property and having central heating were used to identify an average ward from each locality. Two hundred people in each ward were then randomly selected from the 1997 electoral rolls using a random number generator. Each individual was approached by a single letter inviting them to attend a meeting in a locally convenient place to discuss public involvement and health care decision making. Four focus groups were conducted, two in each location.

- (ii) Pre-existing health-related interest organisations—A community guide (1997) was used to obtain a list of all local health-related organisations (i.e. concerned with the caring, maintenance or management of illness, disease or disability). One existing organisation provided members for one focus group; the other focus group comprised individuals from randomly selected organisations who were each invited to send two representatives.
- (iii) Pre-existing non-health-related organisations—Non-health related organisations (i.e. not concerned with illness, disease or disability) were identified as in (ii) and recruited to form two focus groups.

In consultation with the local health authority in which the research was conducted, three distinct levels of decision-making were identified. These were based in part upon the theoretical levels of priority setting described by Klein (1993) (see above), thus covering decision making at the purchasing level (decisions a and b below) and at the micro or clinical level (decision c below). It was also important that these decisions should reflect the levels of decisions that are taken in practice, could potentially benefit from public involvement and were sufficiently different to investigate whether there were variations in public views across these types of decisions. The three levels of decision making chosen were:

- (a) At the health system level, determining the location of services within the authority, and exemplified by the placement of emergency services in either one specialist centre or more basic care in two local hospitals;
- (b) At the programme level, determining the funding of particular types of specialist services, represented by the choice between funding a new cancer or mental health ward;
- (c) At the individual level, determining the particular patient who should receive a treatment, exemplified by a choice of which of two patients should receive an expensive and effective drug treatment.

These types of decisions were discussed in the focus groups which were held in the early evenings in easily accessible public facilities. Informants were offered travel expenses and expenses incurred through child care or care of other dependants. The focus groups were facilitated by AL or JC with two note-takers to aid transcription and interpretation of the data. All informants provided consent to participate, including permission to audio-tape the focus groups and interviews. Assurance was given that information would be confidential and presented anonymously. A workbook describing the three decisions was used to assist in structuring the meetings, with space for informants to make written comments about each decision (see Fig. 1). In addition, each informant completed a short questionnaire concerning their socio-demographic characteristics (age; sex; employment status, including whether a health service worker; use of health services; educational status) and indicated their consent for a future face-to-face interview. During the focus groups, discussion centred around the decisions, with informants encouraged to express their views. Groups were not asked formally to come to a consensus on the decisions, and each informant was asked to indicate their own view in the space given in the workbook.

Semi-structured interviews were also conducted by AL and JC with a sample of focus group attendees to allow the elaboration of comments made in the focus groups, to probe views more deeply, to explore the origin of individual views and to pursue emerging themes in greater depth. Interviewees were selected purposefully to include the range of views about willingness to participate in decision making, those who did not express their opinions in the focus groups, and those expressing strong beliefs or with particular knowledge.

This combination of focus groups and face-to-face interviews allowed access to informants' attitudes, feelings, beliefs, experiences and reactions to decision-making. Focus groups encourage discussion and reflection on issues of public concern such as rationing (Dolan, Cookson, & Ferguson, 1999), and the emergence of common or shared views (Bowie et al., 1995; Kitzinger & Barbour, 1999; Morgan & Kreugar, 1993). A combination of pre-existing and specifically constructed groups was used to ensure a range of group dynamics (Kitzinger, 1994). Interviews allowed for triangulation and explication of the focus group findings (Denzin, 1970; Silverman, 1993).

All meetings and interviews were tape recorded and fully transcribed using a standard set of rules developed from Poland (1995). Each transcript was checked for accuracy by either AL or JC. Socio-demographic information and text comments made in workbooks were incorporated in a database. In addition to the transcripts and participants' written comments, field

Decision 1 Types of service

The Health Authority can provide either one very well equipped casualty department or have basic emergency care at two hospitals. Would you want the public involved in deciding which service will be funded?

Yes No Unsure

Please use the rest of this page to write down any comments (a full page was provided)

Decision 2 Types of programme

The Health Authority has enough money to fund either a new cancer ward or a new mental health ward. Would you want the public involved in deciding which programme receives the funding?

Yes No Unsure

Please use the rest of this page to write down any comments (a full page was provided)

Decision 3 Deciding between two patients

Two people require an expensive and effective drug treatment but the health authority only has the money to fund one patient. Would you want the public involved in the decision about which patient gets the medication?

Yes No Unsure

Please use the rest of this page to write down any comments (a full page was provided)

Fig. 1. Decisions presented in the workbook.

notes of emerging themes as well as details of the context, mood and atmosphere of the focus groups were used in the analysis. The initial coding of the transcripts was undertaken by AL and triangulated with JC using the qualitative software package NUD*IST (Richards & Richards, 1994) and word-processing files. Secondary and tertiary categories were developed to enhance understanding of the codes, their meanings and relationships (Charmaz, 1990). Descriptive accounts were produced and discussed by members of the research team. These accounts formed the basis of the findings presented in this paper.

Quotations are used below to illustrate the themes presented and to allow the reader to judge the veracity of the interpretation. They were selected across the range of informants and because they were particularly illustrative of the theme. Quotations are from focus groups unless otherwise indicated, with ellipses (...) denoting the omission of text and immediately repeated words omitted for ease of reading. Information about the age and sex of the informant and the type of group attended is provided for each quotation. All names and places have been changed to protect anonymity.

Characteristics of the informants

Eight focus groups were conducted, four amongst randomly selected members of the public in the two areas, and four from health and non-health related organisations. Interviews were subsequently conducted with 19 informants with data available from 18 transcripts (see Table 1).

For the randomly selected focus groups and excluding those not living at the postal address indicated or who were deceased, the effective sample sizes were 194 in the working class area and 192 in the middle class area. In the working class area, 23 (11.9%) positive (that is, expressed a desire to be involved) and 72 (37.1%) negative responses were received. Of the 23 positive responses, 20 (10.3%) agreed to attend the meeting and 15 (7.7%) actually attended. In the middle class area, 47 (24.5%) positive and 71 (37.0%) negative responses were received. Of the 47 positive responses, 25 (13.0%) agreed to attend the meeting and 19 (9.9%) actually attended.

Four organisations agreed to send representatives for the health interest focus groups, with nine people agreeing to attend and eight actually attending. Two

Table 1
Description of sampling strategy by group

Group	Sampling type	Number of groups	Number attending group	Number interviewed
<i>Random public</i>				
Working class	Random	2	15	4
Middle class	Random	2	19	5
<i>Mixed interest groups</i>				
Health	Purposive random	1	8	4
Non-health	Purposive random	1	2	1 ^a
<i>Single interest groups</i>				
Health	Purposive snowball	1	6	1
Non-health	Purposive	1	7	4
	Total	8	57	19

^aData are missing from this informant due to tape failure.

Table 2
Socio-demographic information by focus group

Type of group	Number in group	Number of females (males)	Median age (range)	Number employed full-time	Number having worked in the NHS	Median age at which left full-time education (range)	Number having seen a GP in last twelve months	Number with out-patient appointment in last twelve months	Number having stayed in hospital in last twelve months
<i>Random public</i>									
Working class group 1	6	2 (4)	44 (18–78) ^a	1 ^a	1 ^a	16 (16–21) ^b	5 ^a	1 ^a	0 ^a
Working class group 2	9	3 (6)	42 (31–73)	2	1	16 (14–21) ^c	7	4	1
Middle class group 1	11	7 (4)	50 (25–77)	5	2	16 (15–22)	9	5	3
Middle class group 2	8	5 (3)	62 (29–66)	2	3	17.5 (14–23)	8	3	0
<i>Health interest</i>									
Single organisation	6	5 (1)	46.5 (30–60)	1	0 ^a	15 (15–17)	6	4	0
Mixed organisations	8	6 (2)	50 (39–58)	4	3	18 (16–24)	7	3	1
<i>Non-health interest</i>									
Single organisation	7	3 (4)	63 (51–76) ^b	0	2	15 (14–17)	7	4	1
Mixed organisations	2	1 (1)	^a	0	0	24 (21–27)	1	1	0

^aData missing for one informant.

^bData missing for two informants.

^cData missing for one informant (teacher).

rounds of random sampling were required to find sufficient non-health related organisations willing to send representatives to the focus groups. From the twenty groups approached, three indicated that they would send a representative, and one representative from each of two groups finally attended. Six people participated in the single organisation health related focus group and seven in the single organisation non-health related focus group.

Socio-demographic details for informants in each of the groups are shown in aggregate form in Table 2. The random public groups were basically similar, although the middle class groups were on average older and had more contact with health services. In the health and non-health interest focus groups, there were again few variations, although there were more women in the health interest groups and higher levels of education in the mixed groups. Interestingly, twelve informants

Table 3
Willingness of the public to be involved in decision-making

Type of decision	Agreement to public involvement <i>n</i> (%)			
	Yes	No	Unsure	No answer
System level	39 (68)	4 (7)	9 (16)	5 (9)
Programme level	29 (51)	15 (26)	4 (7)	9 (16)
Patient level	12 (21)	30 (53)	7 (12)	8 (14)

currently, or had previously, worked in the National Health Service.

These findings show that some sections of the public appear more willing and able to attend groups to discuss health care decision making than others. Individuals with special interests unrelated to health care were generally unwilling to attend, with those from health interest groups more willing to attend but still yielding relatively small numbers of people. Citizens randomly selected from the electoral rolls were willing to attend such meetings and although, as expected, response rates were relatively low, this sampling method was the most successful. There were no clear differences between the views of those in the different types of group, and so the findings below are not presented separately for each group.

Findings

Table 3 provides an overview of the written responses to the focus group workbooks. There is statistical evidence (using the Stuart–Maxwell test (Fleiss, 1999) in Stata (1999)) that informants reported different views between the three levels of decision making in these workbooks. For each comparison (that is health system against programme level, programme against individual level and health system against individual level), informants were more likely to answer ‘yes’ to the question of whether the public should be involved for the higher level decision making. Even after applying a Bonferroni correction to the three pair-wise comparisons, all three are statistically significant at the overall 5% level. Qualitative data are described below in relation to the major themes at each of the three decision making levels.

Decision-making at the health system level

The majority of informants in all groups felt that the public should be involved in decision making at this level concerning the provision of emergency health care. In their responses to the workbook question, 39 informants (68%) indicated that the public should be involved in these decisions, 4 (7%) that they should not, with 9

(16%) unsure and 5 (9%) not responding in writing. There were no significant differences in response between males and females or by different age groups (Fisher’s exact tests $p = 0.89$ and $p = 0.76$).

In all focus groups there was a strong degree of unanimity regarding the meaning of “involvement” at this level. There was no desire for the public to be responsible for making decisions. Health professionals were seen both to be paid for and to have the expertise to take responsibility for such decisions:

Public should be able to inform decision made by ‘them’, i.e. health authority, but not make the overall decision or be responsible for that decision. (Written comment, mixed health interest group female, aged 39)

To gain opinion only. I would not be expert enough to make a firm decision. The final decision should be made by the professionals. (Written comment, random public, working class male, aged 31)

There was a strong view in all groups, however, that the public should be consulted to provide creative solutions and apply ‘common sense’ to particular problems:

... there should be a consultation. ‘This is what we intend to do. This is why we intend to do it. This is the amount of money we’ve got. This is how we’re spending it and this is why. Now if you can see anything wrong with that or if you can tell us a better way of doin’ it then this is what the discussion will be about and let’s take it from there.’ But I think that would be a far better way of approaching it—to involve the public. (Random public, middle class male, aged 66)

I think the decision must be made by a professional body. However, a consultation in great detail would be welcomed and for the public opinions to be taken into consideration. (Written comment, random public, working class female, aged 40)

Such consultation should also be ‘real’ with decision makers being open to incorporating ideas from the public that might change their minds about the decision. Otherwise, the public may become cynical about the process:

It is lack of information and lack of honesty about what the intention is ... and if you’re going to have the public having input, then it’s got to be accepted that some notice is taken of it. It’s not a bit of good having “Oh well, we’ll have a meeting and invite the public and then just ignore any of the things they ask for.” And I think this is what we all get cynical about, isn’t it? [someone murmurs agreement] No-one really takes any notice and they’ll do what the hell they

want anyway. (Random public, middle class male, aged 66)

Well there ain't no point in 'aving a say because the people don't listen to you. (Single health interest group, female, aged 30)

The last respondent identified the need for information. The need for accessible information was recognised by many informants in all the groups so that the public would be able to contribute rationally and reasonably, not emotively, to the decision-making process:

As long as they have the sort of information that will help them to make a reasonably informed decisions, that it's not just purely emotive... (Random public, middle class female, aged 62)

Information- key part of process. Impossible for this to be non-biased but as far as possible provide it in a form which makes it accessible to many (videos, drama group, personal reflections, as more formal statistics, graphs, etc.) (Written comment, mixed health interest group, female, aged 48)

A small number of individuals were opposed to involvement at this level, citing the following sorts of reasons:

I think the 'public' would be emotionally involved and not make the right decisions based on facts. (Written comment, random public, middle class female, aged 50)

I think it's putting more responsibility ... consuming time of the medical profession to have to organise meetings (Single non-health interest group, female, aged 68)

However, as indicated previously, over two thirds of informants were in favour of public involvement because they believed lay knowledge could make an important contribution to the decision:

Facilities, service, accessibility, are issues that the local public should know plenty about... (Written comment, random public, middle class male, aged 41)

I think the public can come up with some very good ideas, that the people in authority ... wouldn't even think of, wouldn't even look at. (Random public, working class female, aged 44)

Another part of involving the public is to ensure opportunity to get information from them. Personal experiences. (Mixed health interest, female aged 48)

Involving the public was expected to lead to greater accountability, although previous experiences could lead to cynicism:

If one is involving the public in some manner of decision-making the public surely would expect that that involvement ... is going to carry with it some part of the power which goes with that ... in other words if they say we want this and it doesn't happen they wanna know why ... and that's accountability (Mixed health interest group, male, aged 58)

Well ... if all these top knobs come in and says, "Oh, can we have your say on this question?" And you tell them and they ... go away and say, "Well, don't worry ... we'll just do it." (Female, aged 30)

They might not listen to you but at least you feel better by gettin' it off your chest and lettin' them know 'ow you feel. (Female, aged 52)

All right, you've got it off your chest. But it still ain't gonna get you nowhere (Female, aged 42)
(Discussion in single health interest group)

Decision making at the programme level

When commenting on the decision between mental and cancer health services, approximately one half (29) of the informants indicated that the public should be involved, with 15 (26%) indicating that they should not, 4 (7%) unsure and 9 (16%) not responding. There were no significant differences in response between males and females or by different age groups (Fisher's exact tests, $p = 0.33$ and $p = 0.95$, respectively).

As at the health system decision making level, the favoured form of public involvement was described by the informants as consultation in that they wanted to be involved in the process, but with responsibility for decision making firmly under the control of the professionals:

The public cannot actually make such decisions but should be involved by consultation, and their views should be valued by those who have the final decisions to make. (Written comment, mixed health interest group, female, aged 50)

I think, perhaps, not necessarily everyone needs to become involved but maybe some members, or representatives of the public could be involved... (Random public, middle class female, aged 25)

I would find this very difficult. I really need to be a professional (e.g. doctor, therapist) dedicated to working within the medical field. (Written comment, random public, working class female, aged 40)

Many of the informants asked why such a choice between such services would need to be made:

There shouldn't be a decision {murmur of agreement}. They're both equally important. (Random public, working class female, aged 35)

Views against public involvement were more strongly articulated than with the broader system decision. These revolved around concerns about a lack of knowledge on the part of the public and how emotional and personal factors might predominate:

I think the public is too subjective because you have those that come from a background that have had mental illness and they would vote for that reason. Perhaps not objectively as to what is known to be the greater priority of the area. (Single non-health interest group, male, aged 63)

My gut feeling would be that the needs of the mental health or people with mental problems would be greater than that of those with cancer. But that's only my gut feeling. I don't know the facts you see. So if I had to have an opinion, I would say, 'Well then. I'd go for mental health'. But then I could change my mind if all of the facts came in. {sounds of several others agreeing} (Male, aged 31)

Yes, that's right. Without the facts, it's not a decision. It's just an opinion. (Male, aged 42)

(Discussion in random public working class group)

The need for information if the public were to be involved in decision making was just as great for this decision as previously. There was a concern that the information should be unbiased:

Any member of the public will never know if they've been given all the information or the information has been slanted to a particular way ... (Male, aged 45)

"We only want you to know what we wanna tell you" {laughter} (Male, aged 68)

(Discussion in random public working class group)

Providing again you've got all the information. It could be a personal battle between two department (Random public, middle class male, aged 65)

Yet, again, it was felt that the public could bring their experiences and empathy to decisions at this level:

There is a lot of emotion from the public because it's an emotional topic. But sometimes emotion does have to come into decision making. It can't just be all straight forward, non-emotional and...you can't put money to everything. There must be some emotion somewhere to make people realise how the decision-making does affect people... (Interview comment, random public, working class female, aged 44)

Decision making concerning choices between patients

In their response to the workbook question, only 12 informants (21%) indicated that the public should be involved in making choices between patients, with 30 (53%) indicating that they should not, seven (12%) unsure and eight (14%) not responding. There were no significant differences in response between males and females or by different age groups (Fisher's exact tests $p = 0.78$ and $p = 0.27$, respectively).

Informants overwhelmingly thought that health professionals should be responsible for these decisions because of their appropriate knowledge, skills and qualifications, including their ability to deal with the emotional impact of making the decision. On the other hand, the public do not feel they have the right or ability to decide, and some could not cope with the consequences of such decisions:

I mean those doctors know all there is to know about these patients. They know their life expectancy ... I mean, doctors really, OK, they play God. I don't think the public should. (Mixed non-health interest, female aged 51)

I haven't got the knowledge basically, I wouldn't know anything about it at all. I'm not a medical person so I wouldn't want to make that decision. (Random public, middle class female, aged 25)

And you've gotta sleep at night after making the decision... I couldn't, my conscience wouldn't let me... I'd be condemning somebody to death. (Random public, working class male, aged 68)

Some informants identified logistical difficulties with involving the public:

... if people got involved in it, you'd never get the decision made. An' prob'ly they'd both drop dead by the time somebody's made a decision {murmurs of agreement here} about it... (Single non-health interest group, male, aged 51)

The public's role was thus seen as limited in relation to this type of decision. Some informants suggested that they might set particular criteria for decision-making that would assist those making these difficult decisions:

The public should not be involved in the final decision about the two patients concerned but it would be very helpful for them to set the criteria by which the decision can be made. (Written comment, random public, middle class female, aged 54)

Who out of all of us would want to have to make that decision? I wouldn't want to make that decision and I don't think they [doctors] want to. So, they want to be given criteria set out with some reasonable overall

opinion that they are getting the right criteria ... They want guidelines to follow because they don't want to play God in any shape or form. Do they really? (Mixed health interest, female aged 50)

In summary, the majority of informants were clearly unwilling to have any role in making these types of decisions:

Decisions like this should be left to those who are fully aware of all the facts surrounding the patient. (Written comment, single non-health interest group, female, aged 68)

Discussion

The findings from this research show variations in the willingness of members of the public to be involved in health care decisions and consistency across the different forms of the public as represented by the focus groups with randomly selected citizens and pre-existing organisations. There was a strong desire in all the groups for the public to be involved both at the system and programme levels, with much less willingness to be involved at the patient level. Two issues are found in all groups and at all decision-levels: the need for information and to take account of public experience and emotions.

The research findings can be interpreted in relation to the impulses to participation noted by Parry et al. (1992). Among these publics, and in relation to these decisions, the desire for involvement by the public showed both instrumentalist and communitarian concerns, with the public wanting decisions that more appropriately meet their needs. Their perception was that this could be achieved by taking account of their practical knowledge and personal experience. Emotions were also seen to play an important role. A common perception was that the public's emotional reactions to issues could interfere with their ability to participate in decision making. A smaller number of informants, however, suggested that some decisions, particularly at the patient level, should not be taken without due consideration of the emotions involved.

The public showed little of the educative impulse as presented by Parry et al (1992)—although they did constantly demand more information about how decisions are currently made. This demand for accessible, understandable and unbiased information suggests that attention should be paid both to the content of the information provided to the public and to its presentation. The final, expressive, impulse to participate may have been reflected through the public's desire to be involved in the NHS which, as a publicly funded

institution, is perceived to be owned by the citizenry as a whole.

A major question arises about the meaning of public "involvement". Informants spoke extensively about what their involvement should be at each of the different levels. At the system and programme levels they referred consistently to this as "consultation". Members of the public were able to see that their involvement might not change decisions, and indeed there was little desire among most of the public to share in the *responsibility* for decision making even at the health system level. (It should be noted that health authorities in fact bear statutory responsibility for decision making.) Nevertheless informants regarded public involvement as a way of improving the decision and its acceptability by incorporating lay knowledge and increasing the openness and accountability of the decision. They believed they could contribute by expressing their views and wanted some guarantee that this contribution would be heard. Importantly, they also wanted the decisions that were made following consultation to be explained. For example, people wanted to express their views about access to a unit but if the decision was made on grounds outside the public's expertise this was considered to be acceptable as long as the reasoning behind the decision was explained.

It is notable that this empirical meaning of "consultation" does not relate well to the theoretical models of Arnstein and others (Arnstein, 1969; Feingold, 1977; Charles & DeMaio, 1993). These models have defined consultation as providing "an opportunity for individuals to express their views, but offer[ing] no guarantee that individual views will be taken into account" (Charles & DeMaio, 1993) and have suggested that consultation is merely a token form of involvement (Arnstein, 1969). The next level of participation in these models tends to be defined as "partnership" with responsibility for decision making shared between professionals and the public. There is thus a considerable gap between these degrees of participation and interestingly the informants in this study wanted their involvement to be located in this gap. This study suggests that these models should be amended to include a form of involvement in decision making best characterised as 'accountable consultation'—contribution to decisions by expressing views, a guarantee that this contribution will be heard, no responsibility for the decision but an explanation of the rationale for the decision ultimately made.

At the patient level, appropriate public involvement was seen to be much more limited. The extent to which the public should be involved was in assisting in the setting of criteria for deciding between potential beneficiaries of treatment. The decisions themselves should properly be taken by health professionals who have the relevant knowledge, skills and qualifications.

This finding supports Lomas' conclusion that the public do not feel comfortable in making choices, that they reject the task as requiring expertise that they do not possess, and that elicitation of underlying values and principles is the only area in which they see themselves as appropriately involved (Lomas, 1997). Again, this desired level of involvement does not accord with the various models of citizen participation which are concerned only with involvement in decision making and in which forms of involvement associated with defining the criteria for decision making do not appear.

It should be noted that these conclusions may be limited in that they are only able to explore the views of individuals who are willing to participate in this type of research. Previous research has shown that low response rates are common for participation in health care decision making and also that those participating tend to have a direct interest in the topic under investigation (Oregon Health Services Commission, 1991). However, the response rates in this study for randomly selected members of the working/middle class public (12/24% agreeing to attend with 8/10% actually attending) are high when participation research in other areas is considered. (For example, even with local issues such as the location of unwanted land-uses and developments, participation is low (1–2% at most) and usually limited to the middle-aged, middle-class and those in professional occupations (Burnett, 1984; Cox & McCarthy, 1982; Jones & Eyles, 1988)). Future researchers may wish to employ similar methods of recruitment, especially the inclusion of randomly selected members of the public and pre-existing health interest groups although there is a need to over-sample in working class areas where response rates tend to be lower. Involving groups selected to represent an interested and committed public but without a specific health interest is, from our experience, challenging.

This research, through focus groups and interviews, has provided a detailed exploration of members of the public's views about being involved in making health care decisions at different levels. Its results should be particularly useful for those engaged in involving the public, in helping them to design their participation protocols in a manner which will be acceptable to the public given the particular level of decision making involved. In particular, the desire for 'accountable consultation' suggests that future consultation should be designed as a two stage process, allowing both for initial consultation and explanation of the final decision. The focus group format seems to provide a means of ensuring participation, especially if it occurs in a time and place convenient to the prospective participants and it was also found to allow informants the opportunity to present and clarify their views. It is likely that representation will be based on a commitment to the issue at hand—a personal or professional interest in

health issues (Marmor & Morone, 1980; Zakus & Hastings, 1988). If there is that interest and willingness the public has much to contribute, especially at the system and programme levels, to supplement the inputs of health-care professionals.

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