

BRISTOL ROYAL INFIRMARY INQUIRY

PHASE TWO

Service: Empowering the public in the health care process

Summary Report

This is a summary report of the key points emerging from the seminar discussion on *Service*, which took place in Bristol on 28 March 2000.

The following were points put to the Panel in discussion; they do not necessarily reflect the views of the Panel.

Summary of the discussion

The purpose of the seminar was to look at the issue of empowerment of the public and patients at a general level and for individual patients. Seminar participants included representatives from a range of public sector, voluntary and academic organisations. The seminar began by considering why it is important to involve the public in decisions about health care and discussing different models of involvement and methods to promote it. A number of factors were identified as constraining the development of more effective public involvement in health service policy decisions and some strategies to address these were then discussed. Consideration was given to the role of information in empowerment and to the particular opportunities and hazards associated with the current rapid increase in information available through new electronic technologies. Attention then shifted to patient empowerment at an individual level and a number of problems were discussed. The final session focused on the issue of informed consent, and a number of shortcomings in current practice were identified. The key points emerging on each of these topics are summarised below. Many of the issues are elaborated further in the position papers that were submitted in advance of the seminar and are published on the Phase Two section of the Inquiry's website.

1. Involving the public in policy making

1.2 Reasons to involve the public

(i) Seminar participants were invited to discuss the proposal that greater public involvement in health service policy is a good thing. Three main benefits of public involvement were identified:

- Improvement in the relevance and sensitivity of the service by ensuring that decisions are informed by lay as well as professional priorities;
- Influence over how patients are regarded and treated by health professionals, encouraging the latter to view them as people with complex lives, rather than just collections of symptoms;
- a necessary expression of democratic solidarity and collective interest in a public service.

It was pointed out that, when talking about public involvement, it may be useful to distinguish between advisory and executive power. It was suggested that the power to be heard and listened to should be regarded as a right, whereas the power to make decisions must be earned, either by election or experience or other qualifications and be subject to a system of accountability.

1.2 Models of public involvement

(i) The model of public involvement which has predominated in recent years is that of people as customers or consumers, whose role is defined in terms of their economic relationship to the service i.e. they are receivers rather than producers of care. The language of consumerism has pervaded the health service since the late 1980s and has been seen as an advance in replacing more patronising assumptions about the passivity and dependence of patients. However, the consumer model sees empowerment primarily in terms of choice and individual rights. It does not address the need for empowerment of the public in respect of the political issues associated with the health service and those to do with its value base. An alternative perspective is one which starts with the assumption that the public are owners of the health service and co-producers of their own health. This perspective emphasises the scope and need for shared decision-making with the professionals who are there to support people in managing their own needs for health care.

(ii) These two models are not mutually exclusive, and people value both at different times. For example, when people decide where to go for treatment, their priority is to get good information about the quality of care in different hospitals so that they can choose a service much as they might in other aspects of their lives. But once the choice is made, they may wish to be treated as a co-producer by the professionals involved in making decisions about their care. It was suggested that one of the key difficulties in engaging health professionals with the model of shared decision-making is a lack of agreement about the scope of patient ownership. Does a patient, for example, own their own body, the parts inside it, access to those parts, the disease affecting it, the information generated by their illness, the cure and recovery process or the story of what happened to them? All these issues require more exploration and negotiation than they usually receive.

1.3 *Mechanisms for involving the public*

A number of different ways to involve the public were identified and discussed. These included:

(i) *deliberative methods (including citizens' polls and citizens' juries, shadow health authorities and focus groups)*

These were described as valuable if properly conducted and resourced. However, concern was expressed that methods which identify dominant or consensus views may ignore the interests of minorities with particular needs. There is a particular hazard of missing the perspective of hidden communities whose interests are not clearly visible nor defined by geographical locality.

(ii) *lay representation*

There are lay representatives on a wide range of NHS decision making bodies. Their value lies in the fact that they are not health professionals and therefore represent a different voice. However, the value of lay representation is constrained by the difficulty of acting as a token representative of an entire community whose interests are inevitably diverse. It was suggested that lay representatives who are selected by election may have greater legitimacy than those nominated or invited to participate on the basis of commitment or experience. However, as regards representatives who are currently elected, not all have the time, knowledge or commitment to make a valuable contribution.

(iii) *self-help groups and advocacy*

There was discussion of the role of self-help groups in helping to distill experiences and identify shared concerns. Such groups may also provide advocacy for their members' interests, developing expertise, campaigning on their behalf and providing information and support.

(iv) *community health councils (CHCs)*

Attention was drawn to the CHCs as government-funded patient organisations, which is something few other countries have. Strengths of CHCs are that they are not dominated by health professionals and have no direct involvement in providing the service which might complicate their role as patient advocates. However, CHCs are constrained by lack of resources and limited powers.

1.4 *Obstacles to greater public involvement*

A number of factors were identified as constraining the development of more extensive or effective public involvement in health service policy. These included:

(i) *lack of support from above*

Although there is government support in principle for public involvement, this is not reflected in health service priorities. For example, developing services responsive to the concerns of the public is not defined as a senior management target and efforts to do so would not be taken account of in performance review.

(ii) *limited scope for influence at local level*

Much of the resource for health care is already committed in reflection of earlier decisions and patterns of care. There is flexibility only around the margins, and relatively little scope for negotiation. There is also a tension between empowering public choice at local level and maintaining equity between communities.

(iii) *limited public interest*

It was noted that, for many people, the health service is associated with anxiety and discomfort, and is something they prefer not to think about when they do not need to use it. Motivation to influence the service may be greater for those who make most use of it, but their health problems may limit their ability to get involved.

(iv) *emphasis on technical aspects of decision making*

A further reason for the lack of public interest in getting involved is that these decisions are presented as being purely technical, with emphasis on effectiveness and

costs, for example in decisions about resource allocation. The value base used for resource allocation decisions is not explicitly discussed and the potential influential role of the public is thereby underplayed.

(v) *problems of engagement*

It was noted that members of the public unused to speaking out in a professional environment may feel intimidated. Particularly in communities with transient or deprived populations, there may be difficulties in developing sustained engagement of the public and finding people with the time, resources, energy and confidence to get involved.

(vi) *problems of hearing what the public has to say*

From the professional point of view, the lack of tradition of listening to patients' views is not easily overcome. It was suggested that "even if the spirit and intellect are willing, professional habits take a long time to dissipate".

(vii) *problems of 'transparency'*

One hazard of enforced greater openness about decision making and sharing information with the public is that those who are uncomfortable with this may take steps to evade genuine engagement. Activities such as deliberately holding meetings when lay people are unable to attend were described by one participant as constituting 'user abuse'. Participants noted the lack of and need for clinicians and healthcare space and time to be vulnerable and receive support.

1.5 *Strategies for more effective involvement of the public*

(i) Key principles identified as necessary to ensure more effective involvement of the public included:

- *transparent decision making* - all decision making should be transparent unless there is some compelling reason why this is not possible;
- *universal public involvement* - patients should be present in all arenas where decisions are made, including professional organisations such as the Royal Colleges;
- *honesty about the scope of involvement* - some decisions can and should be made by the public, others cannot and probably should not. Some decisions can be made at local level, others (for example those relating to very rare conditions) must be considered on a national scale. The boundaries of public involvement should be

clarified. The time of the public should not be wasted on considering trivial issues or those where their views will have no influence;

- *honesty about the extent of involvement* - on each occasion when members of the public are involved, their role (to rubber stamp or make changes, to lobby or to lead decision making) should be discussed and agreed by everyone involved;
- *equity* - steps should be taken to ensure that opportunities for public involvement do not disempower those who do not take part or give disproportionate benefit to those who do, and
- *effectiveness* - mechanisms for public involvement should be evaluated and evidence-based, not adopted because of whim or fashion.

2. The role of information

A key issue for empowerment of the public is 'information'. There was extensive discussion of the implications of the present growth in electronically accessible information and of the opportunities and potential problems associated with greater access.

2.1 Implications of the new technologies for information

(i) It was agreed that widespread access to health and health care information via the internet is already having a considerable impact on:

- *the balance of power* between professionals and users as the knowledge gap between the two decreases;
- *the balance of types of information* available, with greater access not only to scientific information but also to alternative analyses and users' own accounts of their experiences;
- *the direction of information transfer* which has traditionally been seen as a one-way process, with patients and the wider public as passive participants. There are increasing opportunities for sharing and exchanging information and assistance and support for making informed decisions about healthcare between patients and professionals.

(ii) However some concerns were voiced about the limitations of this information source. These included:

- *the potential for increased inequity* between those who have access to the internet and those who do not. It was noted that sophisticated databases available, for example in Trust libraries, may not be accessible to lay members of Trust boards or to the general public;
- *the variable and unregulated quality* of much of the information available and the dominance of North American cultural references, which are not always appropriate to the UK;
- *the impossibility of assimilating* or making appropriate selection from the excess of information available;
- *continuing imbalances* in what data gets collected and what types of information are valued. It was noted that topics for systematic data collection and research continue to reflect professional agendas and priorities and unsystematic information has lower status.

2.2 *Problems of increased information*

(i) There was general agreement that more and better information for users and the public is, in principle, welcome. However it was noted that in some circumstances the consequences can be problematic. For example, more and better information:

- about hazards and possible side effects may cause unnecessary concern for individuals about investigations (such as breast screening or immunisation), despite the benefits at the population level;
- about the performance of particular organisations or clinicians may affect staff morale, undermine patient confidence and create anxiety especially where there is no alternative choice of treatment;
- about tests and procedures (such as genetic testing during pregnancy) may have considerable resource implications in terms of the time and costs associated with providing counselling and follow-up and
- about complex issues may increase accuracy but make the issue harder to understand.

3. **Empowerment of individual patients**

The focus shifted from the public and patients in general to consideration of empowerment of patients as individuals.

3.1 *Obstacles to patient empowerment*

(i) Various structural and relational features of health care were identified as obstacles to empowerment. These included:

- *the imbalance of power* between health professionals and patients, not only in terms of clinical knowledge but also knowledge about the health care system, its organisation and institutions. This imbalance may be exacerbated by differences of status between professional and patient in terms of class, gender, ethnicity and by the patient's need to believe in the competence of their doctor and other carers;
- *structural factors* inhibiting patient confidence including brief consultations and awareness of the lack of time available, the physical circumstances of the consultation (where the patient is often sitting or lying at a lower level) and the ward round, where patients get little opportunity to participate actively.

(ii) It was suggested that the extent and nature of disempowerment varies according to the type of illness, with patients with chronic problems having greater expertise about their own condition and consequently a more equal relationships with their clinicians and carers. Other seminar discussants questioned whether this is necessarily the case, as the morale of someone with a chronic illness can be undermined by the multiple losses (control, mobility, social contacts) they experience and the need to deal with a multiplicity of services.

(iii) It was noted that problems of disempowerment may be exacerbated by poor inter-personal skills on the part of clinicians. Doctors are selected on the basis of academic ability rather than inter-personal skills and are not necessarily good at communicating, although it was noted that some specialties tend to be better than others. In the past there was no training in communication skills. For the current generation of medical students this has been rectified, but once young doctors go out into practice they do not necessarily find good role models among their seniors.

(iv) It was noted that the care of individual patients involves care not just from doctors or nurses but includes a wide range of other health professionals, porters, domestics, ministers and lay carers. Patient empowerment can be undermined by poor communication within and between these extended teams.

3.2 *Patients' needs for information*

(i) The following principles were identified regarding patients' needs for information:

- information should be given in different ways and reinforced over time;
- information should be tailored to individual needs but patients should always be given opportunities to question what they are told, ask for clarification, and ask for more (or less) information;
- patients should be told and shown what is going to happen to them beforehand and have opportunities to review what has happened afterwards;
- patients should be supported in dealing with the additional anxiety sometimes generated by greater knowledge.

Participants recognised that clinicians needed training and support to help them to meet the information needs of their patients.

3.3 *Methods of empowering individual patients*

A variety of strategies to empower patients through better information were discussed. These included:

(i) *advocacy*

There were various suggestions for some form of advocate or third party to mediate in the doctor-patient relationship (especially where there are particular communication difficulties associated with language or literacy). However, some participants felt that such initiatives might divert attention from the need to improve the primary relationship within the consultation. It was noted that greater training in managing the consultation potentially gives the doctors even greater power over what takes place. What is needed is not just better skills but greater commitment to genuine partnership with the patient.

(ii) *Decision support*

Currently much of the information available to patients, for example in leaflets about treatment, is of very poor quality. Problems include excessive optimism and a tendency to downplay or omit mention of side effects, risks, uncertainties and controversies. It is important that it is not left up to the professionals to decide what information patients should receive, as they often under-estimate what patients can

cope with or will understand. Nobody but the person involved can weigh up the options available to them, as the balance of advantage depends on their individual situation. An advantage of new technology (such as interactive videos) is that it offers opportunities for patients to tailor questions to fit their own particular circumstances.

(iii) *Patient-held records*

It was proposed that ownership of information resides with the patient and they should therefore have a right to hold all their own notes unless they choose not to.

4. Informed consent

(i) There was discussion of the concept of 'informed consent'. It was agreed that consent should be seen as an ongoing process of informed decision-making permeating the whole process of care rather than a one-off event associated with obtaining formal agreement to specific procedures. It was pointed out that many patients go through entire episodes of care, including those involving surgery (such as episiotomy) without encountering the formal process of consent.

(ii) Shortcomings of current practice in obtaining formal consent include the tendency to:

- assume that the patient's presence and cooperation implies consent;
- view the task of 'consenting' as one of persuading the patient to sign the paper agreeing to the procedure in question, rather than ensuring that their informed agreement is genuinely obtained and
- delegate the task of 'consenting' to junior medical staff who may be neither involved in giving the proposed treatment nor capable of performing it.

(iii) It was agreed that the consent procedure is considerably better handled in relation to research than in routine clinical settings. Two areas of practice particularly singled out as poor were the use of patients for teaching purposes and the process of screening, where possible adverse consequences of being screened (such as false positives and negatives) are frequently not mentioned to patients at all.