Health care

Whose health is it anyway?: enabling participation

E Russell, C Smith

Public and patient participation in the healthcare decision making process.

Current policy rhetoric promises the public and patients wider participation in decisions about health care, and in the research that informs it, with an implication that participation is likely to generate substantial health benefits. However, it is not yet clear what can be done to make it happen effectively.

The British National Health Service (NHS) was built on an ethos of community spirit, solidarity, and sharing. Current media coverage suggests that this ethos has now been replaced by individualism and the blame culture for which Britain is now rightly infamous. As a result, the focus of participation seems to have become complaint rather than constructive debate. Compensation for adverse events that occurred when the risks were unknown has been described as a "moral right" (M Smith (Scottish Health Committee Chair), BBC Radio Scotland, Thursday 9 Jan 2002). Yet there is no logical or ethical leap from individual freedom to be healthy to a societal obligation to provide the services that might improve that health. A screening test that, by definition, does not provide certainty leads to accusations of negligence by the screeners when false negatives become known. The drive to report "medical error" and the National Patient Safety Association are two of the manifestations in 2001 that reflect the government's moves to deal with the loss of trust and respect that has been so loudly expressed.

It should not be denied that mistakes and adverse events occur, but the current response to them fails to acknowledge that risk is a part of all aspects of life including science and medical care, and especially at the cutting edge of new techniques before they have been observed in practice. This sets a false basis for any discussion. If the aim of greater involvement of patients in care and of the public in decision making is cooperation and shared decision making then an adversarial position is an inappropriate first step. There is a real possibility that such participation will simply be regarded as a right through which individual special interests can prevail, rather than as a path to mutual and common understanding of health issues and priorities.

Key points

- The policy emphasis on public and patient participation is widely welcomed.
- However, if it is to be real then its effects on planning and priority setting must be accommodated.
- Mutual respect is the key to effective involvement at both individual and health system levels.

A symposium in Aberdeen last year brought together some relevant perspectives to address the question, "Whose health is it anyway?" The main conclusion was that, until relationships between doctors and patients, between health systems and the public, between researchers and researched, become more honest and, crucially, respectful, there is not going to be much progress towards the 21st century paradigm of participation that is internationally espoused in recent legislation. So how can mutual respect be established? The starting point of the symposium was to try to understand what was undoubtedly a marked change in the relationship between medicine and its users during the 20th century. Kenneth Boyd, in a superb analysis of the doctor-patient relationship since the time of Hippocrates, noted that participation in health is hardly a new idea. Hippocrates said "It is not enough for the physician to do what is necessary, but the patients and the attendants must do their part as well and circumstances must be favourable".[1] This was said in the context of the need to establish a "therapeutic friendship between strangers", a need that was the stimulus to develop medical ethics as we still know it. Boyd argues that this "therapeutic friendship" was severely challenged in the 18th and 19th centuries by the creation of a tacit contract between patients and hospital doctors to exchange taking part in experimental medical technology for the possibility of new benefits to their personal health. Anecdote suggests that this tacit contract, based on the hope of a win-win outcome, continued until the second half of the 20th century, when access to health care became an expectation and the success of medical science, in the media and the public mind, became a certainty not a hope. We forgot the end of the Hippocratic definition of medicine, which says: "knowing that everything is not possible to medicine".[2] In the view of the majority, who are healthy, medical care has become something that in the UK we have on tap, that we have a right to use when we need it, and that will make us better. Although sometimes when one became a patient (or close to a patient) the perception of absolute access and absolute certainty began to waver, it is only very recently that this perception is more widely expressed.

Trust in the NHS has had two very important effects for public health. Firstly, on prevention, if you believe that rescue is available and effective there is little need to invest in prevention, or to vote to ensure that there is enough rescue to go round. Secondly, the fact that in society as a whole solidarity is being eroded by individualism has led to a failure to recognise that giving everybody the same as each of us wants individually from the NHS adds up to a lot of resource. And again the professions have been no different from the public, as Alan Maynard was not slow to highlight at the Aberdeen symposium. Those who can use evidence based medicine have the strongest card in the pack for their particular funding need to be met without comparison with the needs of others. On all counts, there was unanimity that unless a more honest relationship between government, the NHS, public health, and the public is opened up soon then there is very little hope of achieving effective participation in health related decisions, whether individual or communal.

Easily said, but everyone recognised that this will be a long slow and sometime difficult process. Nick Partridge, who chairs the Consumers in NHS Research group, showed with examples how participation can help both service and research to become more relevant and effective. The first task of that group was to recommend how consumer involvement could be enhanced at each stage of the research and development (R&D) process. The consumers said that they found it hard to get involved because they did not understand the structures. Slowly, however, by clarifying the different parts that consumers might play at successive stages of R&D, and by training them for the task, their involvement is "reaching audiences that other researchers just can't reach". But it takes time, information, and respect to empower consumers to play a part. And it may be most difficult for medical doctors, as Sarah Stuart-Brown pointed out. Years of being trained that one's role is to take responsibility for other people's wellness is extremely difficult to reverse when it comes to trying to empower, to enable, to share, and to compromise with what your consumers want.

So the issue really is, how do we enable people to have realistic expectations of their health care and how do we then deliver a health service that meets these expectations? Workshop participants at the symposium recognised that there are many different publics. Rather than seeking a single "public" value for something, planners and researchers should accept and adapt to the fact that people value interventions differently when they are well to when they are ill, and that professionals sometimes reflect their own values as patients as well as practitioners. Honesty and explicitness—currently sadly lacking in government and service pronouncements about the NHS—require open discussion of rationing, and negotiation on the basis of values and expectations of (sometimes uncertain) outcomes. However, planners and researchers, especially in public health, must be aware that gesture politics to involve potential end users could be counter-productive if the latter's views were blatantly ignored. We could learn from non-health state bodies about how honestly and productively to move forward, and it should be expected that as a result of involvement both public health and research goalposts would move. The practical challenge is how to give people the information they need to enable them to discuss their expectations and then, crucially, to see that the system meets the expectations that emerge. Both individuals and the health system must respect people's views and work to earn their respect in return. It will be slow, but it needs to begin; if ever there was an issue that epitomises the tension for public health between advocacy and meeting needs, it is participation in health.

Policy implications

- Invitations to communities and public to participate in decision making about health care will be counterproductive unless they carry a commitment of time and effort to allow people to feel that they are active partners, and unless policies and plans are open to change as a result of their contribution.

The context of the symposium was the NHS of the United Kingdom. The principles are likely to be relevant to other publicly funded health systems. In the private sector the community and the consumer become the customer. North American total quality management and continuous quality improvement programmes derived from commercial and industrial settings depend on customer satisfaction and feedback to drive improvements in quality of care. Community and patient participation in the developing world is encouraged by bilateral and multilateral funding agencies who require such participation as a condition for the development of funding application. However, it is as yet unclear in developing countries to what extent such participation improves health and health care, but then that is also true in the developed world.[3] This lack of evidence is not the same as absence of effect. Healthcare providers need to enable participation by patients and by communities as a matter of accountability to those for whom the service is provided, who in many countries also fund the service.

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Osteoarthritis

Shoes and lower limb osteoarthritis

E Pascual

Is there an association?

Key point

- Different mechanical factors weigh heavily in the development and progression of bearing weight joints in osteoarthritis, and also in the occurrence of symptoms in this condition, for which treatment is essentially symptomatic. Chances are that specific shoes, by modifying these factors, are likely to result in symptom reduction and decrease in the need for medication. Research in this field to produce evidence seems to be worthwhile.

Osteoarthritis (OA) is among the most common types of joint disease and a frequent cause of pain and physical disability. It is the fourth most frequent predictor of health problems worldwide in women, and the eighth in men[1]; in countries such as the United States, United Kingdom, or Canada its total economic costs have been estimated as 2% of the gross national income, second only to cardiovascular diseases.[2] OA is now considered as a dynamic process in which what appears to be the consequences of the older idea of mechanical wear and tear of the joint coincides with remodelling