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The NHS revolution: health care in the market place

What do patients and the public want from primary care?

Angela Coulter

The government hopes that getting patients' views on their priorities for primary care will ensure support for its plans. It is likely to find patients care more about quality of care than structural or financial reform

The UK government has stated it wants the public to help shape the future of the health service. In the run-up to the planned publication of a white paper on care outside hospitals, Patricia Hewitt, secretary of state for health in England, is leading a big public engagement exercise to "genuinely involve patients, public and staff in designing family health and social care to meet the challenges of the 21st century."[1] The secretary of state's commitment to engaging directly with the public is commendable if it is a genuine attempt to listen and learn, but she should also take account of the extensive body of research evidence on what patients and the public want. Patients have diverse needs and expectations leading to different, and sometimes conflicting, views on priorities,[2] but it is possible to discern themes. What does the evidence show?

National Citizens summit organised to get patients' views on health care

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This article is part of a series examining the government's planned market reforms to healthcare provision

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Structure of primary care

A distinction can be made between what patients want as individual healthcare users and what they hope for as citizens or taxpayers (box 1). In general, patients care more about the quality of their everyday interactions with health professionals than about how the service is organised. Furthermore, although there is scope for improvement in primary care, changes that seem to undermine the founding principles of the NHS are likely to be strongly resisted.

Interpersonal care

Patients want primary care professionals who are good communicators and have sound, up to date clinical knowledge and skills. They also want professionals who are interested and sympathetic, involve them in decisions, give them sufficient time and attention, and provide advice on health promotion and self care.[3] A systematic review of the literature on patients' priorities for general practice care, which examined 19 studies published between 1966 and 1995, found that the most important factor was "humaneness," which ranked highest in 86% of studies that included this aspect. This was followed by "competence/accuracy" (64%), "patients' involvement in decisions" (63%), and "time for care" (60%).[4]

Most patients who consult their general practitioner have specific expectations—for example, they want an explanation of their symptoms, treatment, or investigation. Many have their own ideas about what is wrong and what may have caused it, but they do not

Box 1: Healthcare aspirations of patients and citizens

Patients
Fast access to reliable health advice
Effective treatment delivered by trusted professionals
Participation in decisions and respect for preferences
Clear, comprehensible information and support for self care
Attention to physical and environmental needs
Emotional support, empathy, and respect
Involvement of, and support for, family and carers
Continuity of care and smooth transitions

Citizens
Affordable treatment and care, free at the point of use
Safety and quality
Health protection and disease prevention
Accessible local services and national centres of excellence
Universal coverage; geographical and social equity
Responsiveness, flexibility, and choice
Participation in service developments
Transparency, accountability, and opportunity to influence policy decisions

always articulate these.[5] Failure to engage with the patient's agenda can lead to misunderstandings, dissatisfaction, and poor outcomes.[6 7] The good news is that most British patients report positive experiences in primary care. Box 2 gives highlights from the latest national patient survey carried out in all primary care trusts in England, which obtained responses from 116 939 patients (a response rate of 47%).[8]

The results of this survey show the strengths of our primary care system—good clinician-patient relationships, free access, and continuity of care—but they also suggest it is failing to meet patients' expectations in relation to providing information, involvement in treatment decisions, access to records, preventive advice, and support for self care. Clinical targets for care of chronic diseases are mostly met, according to the quality and outcomes framework review,[9] but we urgently need to improve support for self care and self management, for which the current general medical services contract does not provide incentives.[9 10]

The relatively paternalistic nature of the UK system is also reflected in studies comparing patients' experiences in different countries. The UK scores high on doctor-patient communication, continuity, and affordability but low on information and choice.[11 12]

Box 2: Key findings from the 2005 primary care patient survey[8]

Positive experiences
92% said they were treated with dignity and respect by the doctor
82% said the doctor listened carefully to them
74% said they definitely had enough time with the doctor to discuss their problem
76% said they had complete confidence and trust in their doctor
85% had complete confidence and trust in other primary care staff

Negative experiences
41% would have liked more say in decisions about medicines
39% of those prescribed new drugs wanted more information about side effects
70% of patients referred to a specialist were not given copies of referral letters
57% of patients who had phoned the practice had had difficulty contacting the practice
19% of smokers who wanted help to quit smoking had not been offered it

Access

Patients want easier and more flexible access to certain primary care services, including free choice of practitioners, more physiotherapy and complementary therapies, and longer clinic opening hours.[13 14] Most patients are willing to be seen and treated by nurses and other primary care practitioners as well as doctors, suggesting scope to vary skill mix and encourage team working as a means of improving access.[15]

Alternative ways of accessing health advice are becoming more popular. Internet use is growing; a recent UK survey of people aged 45 and over found that 30% of respondents had searched for health information on the web.[10] Not surprisingly, use of the internet was more prevalent among middle aged people and those in higher socioeconomic groups, but use of telephone helplines, such as NHS Direct, was popular among people from lower socioeconomic groups. Email access to general practitioners and other primary care staff is still relatively rare, however. In a recent international survey, only 13% of those in the UK said they could communicate with their doctor by email, compared with 22% in New Zealand, and 20% in the United States.[11]

Choice and continuity

The government wants to promote greater choice in the primary care system. Choice of provider is popular among those waiting for elective treatment,[16] and most patients value the opportunity to choose their general practitioner.[12] There is almost certainly scope to extend the choices available, but the heaviest users of primary care (older people and those with chronic conditions) place particular value on continuity of care from professionals they know.[17] Better community support for carers and for people with long term mental health problems are also perennial themes in patient surveys.[18] These groups require well coordinated local services rather than a diversity of competing providers.

Younger patients, commuters, and those with urgent needs are more willing to trade continuity for faster access to alternative primary care services.[19] Nevertheless, there is little evidence of a desire to dismantle the registered list system, despite the apparent popularity of walk-in centres. Some patients may want freer access to hospital based specialists, but tampering with the referral system risks undermining the important coordination role provided by general practitioners and other primary care staff. Greater provider choice will not be worth having if it undermines the foundations of a system that works reasonably well at present.

Shared decision making

Patients want the opportunity to make choices in relation to their health care, but choosing a provider is only one of the choices they can make. Knowing about the various treatment options available and having a say in these is more important to most patients than having a

choice of where to be treated. Failures in communication of information about illness and treatment are the most frequent source of patient dissatisfaction.[20]

The traditional model of decision making assumed that doctors and patients shared the same goals, that only the doctor was sufficiently informed and experienced to decide what should be done, and that patient involvement should be confined to giving or withholding consent to treatment. However, this paternalistic approach now seems seriously outdated. Many, if not most, patients now expect to be given information about their condition and the treatment options, and they want clinicians to take account of their preferences.[19] Some expect to go further: to be actively engaged in the decision making process or even to take the decision themselves. Evidence is growing that engaging patients in treatment decisions and in managing their healthcare can lead to more appropriate and cost effective use of health services and better health outcomes.[21]

Equity and participation

Patients and citizens do seem to want more personalised and flexible services, but this does not mean they want to have to shop around for all their primary care needs. Geographical equity and needs based allocation are fundamental NHS values which politicians ignore at their peril. The British public remains strongly wedded to the idea that services everywhere should be high quality and equally available to all.[22] Nevertheless, the notion that healthcare providers should be required to account for their performance also attracts strong support, as does the need for independent regulation at arm's length from government, coupled with open reporting on performance.[22]

Including patients in planning developments to the service has had some positive results, but direct involvement is likely to remain a minority activity.[23] Most people are not members of organised patients' groups, and only a minority want to sit on policy committees. Many of the current NHS initiatives that go under the banner of patient and public involvement are little more than window dressing. Including a few token patients on committees is relatively easy, but it does little to tackle the heart of the problem. The really important changes need to occur at the level of individual interactions between patients and health professionals. Improving the quality of these and achieving a shift from paternalism to a partnership approach has the potential to increase the effectiveness of health care.

Conclusion

What most patients and citizens want is the security of knowing that health services will be there when they need them, that their views and preferences will be taken account of by health professionals, that they will be given the help they need to help themselves, that they can access reliable information about their condition and the treatment options, and that they won't have to worry about the financial consequences of being ill. They also want to be sure that these benefits are equitably distributed and that public resources are being used efficiently for the good of all. Social solidarity and trust will continue to be the essential underpinnings of a sustainable health system.

Summary points

The UK government wants its reforms of primary care to reflect public priority

Research shows the patients want fast access to good care

They want to have a say in their care and be helped to help themselves

Free and equitable care is also important

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