

# What do patients want from high-quality general practice and how do we involve them in improvement?

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## SUMMARY

*Patient involvement is being encouraged by the government and by others as a way of improving the quality of the service provided in general practice. Patients can be involved in their own individual care, for example, in treatment decision making and in disease management; or collectively, by providing feedback on aspects of practice organisation and quality.*

*Active participation in treatment decisions and in self management of chronic conditions can benefit patients in the short-term and may lead to better health outcomes in the longer term, although the evidence for this is currently equivocal. However, the ethical and societal arguments in its favour seem overwhelming. Helping patients to help themselves makes sense for general practitioners as well. Strengthening patients' coping skills could help to reduce inappropriate demands on their time.*

*Involving the public in quality improvement activities has become a key policy direction, and trusts will be required to survey their patients on an annual basis. The proposed new general practitioner contract has recognised the importance of the patient's perspective in its quality framework. Practices that want to anticipate these trends should look for patient survey instruments to obtain feedback on their organisation and the interpersonal skills of the clinicians.*

**Keywords:** quality improvement; patient involvement; self-management; shared decision making.

## What do patients want?

HEALTH professionals are being exhorted by the government and others to involve patients in managing their problems and in improving the quality of the service provided.<sup>1</sup> Many general practitioners (GPs) feel that these ideas are worthy, but impractical.<sup>2</sup> Rising expectations, technological advances, and advancing medicalisation are already placing the service under considerable strain and doctors feel embattled.<sup>3</sup> Patient involvement is often met with polite nods but little enthusiasm. But it is a mistake to assume that the seeking of patients' views and encouraging their involvement will necessarily fuel the flames even further. Indeed, it could have the opposite effect.

Expectations may be rising but they are still remarkably modest. Most general practice patients are very satisfied with the care they receive, according to the national survey of general practice patients carried out in 1998, which obtained the views of 61 426 patients in England.<sup>4</sup> Views of GPs' skills, knowledge, attitudes, and ability to communicate were generally very favourable, and those of practice nurses even more favourable. Problems identified included: access (15% of

responders said they had put off going to see their GP at least once in the previous 12 months because of inconvenient surgery hours, 37% said they had had difficulty in getting through to the surgery on the telephone, and 25% had to wait four or more days for an appointment); consultation length (12% said their consultation was too short); provision of information (14% said their GP did not give them enough information about their condition or treatment); and communication (11% said their GP did not always listen to them or take their opinions seriously).

The repeat of this national survey, due to be published shortly, will reveal whether these problems are becoming more or less prevalent. In the meantime, it is worth considering what might be done to tackle the problems identified. Studies to investigate patients' priorities in relation to general practice care have generally found that they place greatest importance on interpersonal communication and 'humaneness'.<sup>5</sup> In addition, technical competence is highly rated, as are listening and informing, taking account of patients' preferences, and involving them in decisions.<sup>6</sup>

## How do we involve them?

Conceptually, interest in involving patients in healthcare processes occurs at two levels: those processes that are based on the care of individuals, such as treatment decisions and disease management, and those that are concerned with collective issues, such as practice organisation and policy development. There is scope for quality improvement at both of these levels.

### *Involvement in treatment decisions*

It used to be assumed that doctors and patients shared the same goals and that only the doctor was sufficiently informed and experienced to decide what should be done. Nowadays, patients are much more likely to challenge the notion that 'doctor knows best'. Most patients expect to be given information about their condition and the treatment options and they want clinicians to take account of their preferences. Decision making in cases of serious illness can be a protracted process. Patients require time to come to terms with the choices facing them and seek support when uncertainties become additional burdens.<sup>7</sup> Some may prefer to leave the final decision about treatment choice to the doctor, but they still want to be involved

in the process.<sup>8</sup>

Some clinicians have argued that the desire for greater involvement is restricted to a minority group of young, white, middle-class patients, but the evidence does not support this. Despite a clear association between age and decision-making preferences,<sup>9-11</sup> age on its own is not a reliable predictor of a patient's preferred role. For example, a study of older patients with coronary heart disease revealed considerable dissatisfaction about the fact that they were given very little encouragement or opportunity to participate in decisions about their care and little attempt had been made to inform them about the treatment options.<sup>8</sup> They felt that this implied a lack of respect for their views. Trials of decision aids to inform patients and enable them to play a more active role have revealed strong support for this approach among patients in all social groups.<sup>12,13</sup> People's preferences may vary according to the stage in the course of a disease episode and the severity of their condition and their views may change when they experience examples of effective participation.

Many clinicians are attracted to the idea of a participative decision-making style in theory, but find it difficult to put into practice. Time constraints inhibit information provision and it is sometimes quite difficult to discover what the patient already knows and how much they want to be involved. Some clinicians fear that encouraging patients to choose between competing treatment options will place an additional burden on people who are feeling unwell and lead to unnecessary anxiety and distress.<sup>14</sup>

Although the evidence that involvement in decision making leads to sustained and significant benefits to patients is equivocal,<sup>15,16</sup> the ethical and societal arguments in favour of patient involvement, understanding, and participation in the choice of interventions seem overwhelming. When patients are fully aware of the 'pros' and 'cons' and uncertainties of treatment effects they often opt for a conservative approach.<sup>16</sup> This can lead to difficulties when individual choice is at odds with public policy; for example, with respect to the immunisation programme. However, in other circumstances it can result in fewer people being subjected to the risks of unnecessary treatment. There is little doubt that current medical practice does not achieve much in the way of patient involvement in decision making, often termed 'shared decision making'.<sup>17</sup> Even under professional examination conditions, general practice registrars fail to exhibit this facet of the consultation<sup>18</sup> and it is apparent from qualitative studies, that there are significant barriers that need addressing before a philosophy of partnership becomes second nature.<sup>14</sup>

### *Involvement in disease management*

It is often forgotten that most health care is self care. In looking after themselves and their family members, lay people provide a far greater quantity of health care than do health professionals. Hannay used the metaphor of an iceberg to illustrate the point that health professionals, even those working in 'first contact' care such as general practice, see only a small fraction of the afflictions that could potentially trigger a consultation.<sup>19</sup> Some estimates have suggested that a majority of medical care (perhaps 85%) is self care.<sup>20</sup> There is a wealth of lay knowledge about illness and how to treat it and many people prefer to consult family and friends before going to see a

health professional.<sup>21</sup> Nevertheless, GPs often feel besieged by patients who don't really need their help. There is a vicious cycle at work. Struggling to cope with the large numbers of patients who queue in their surgeries every day, few GPs have the time — or perhaps the inclination — to help their patients help themselves. The extent to which patients feel enabled following GP consultations appears to be related to the duration of the consultation, yet pressures to reduce waiting times mitigate against a shift to fewer, longer appointments.<sup>22</sup>

Interest in involving patients in the management of chronic illnesses predates interest in patient participation in treatment decision making. Whether patients have the same enthusiasm for self management, as advocated by many experts on this subject, is debatable. Taking asthma as a specific example, where guidelines specify the need for self management approaches,<sup>23</sup> and a Cochrane review concluded that there was evidence of benefit,<sup>24</sup> there remains debate about the most appropriate design of self-care programmes and whether patients and professionals have realistic expectations of each other in these areas.<sup>25,26</sup>

Nevertheless, it remains transparent to everyone who has ever suffered a chronic illness that it is the patient who has to manage (or not) the emerging problems; the real epiphany is the realisation that all patients self manage, all the time. If health professionals act in a way that undermines people's coping skills, then they can expect to see patients calling on their services with increasing frequency.

The challenge for clinicians is to make the two essential stages of this process as easy as possible to achieve. The first is the educational steps necessary for individuals to become 'expert patients', fast tracking a process that happens to all patients, albeit slowly, as they learn how to deal with their illnesses. Lorig's work on patient education shows how best to accelerate the learning needed, as individuals begin to tackle the implications of their illnesses.<sup>27</sup> Secondly, self-management programmes have to be designed so that they are flexible and capable of being tailored to individual needs and preferences. Not all patients are able (or wish to) monitor their illness in great detail. Although new technologies will enable more vigilance over issues such as, for instance, blood glucose levels, there is a fine balance that needs to be struck between the attention needed to maintain a reasonable health status and the opportunity costs of having to be one's own physician. Ensuring that health services are easy to access and use is another area that receives far too little attention. Getting hold of repeat medication, for instance, can be a time-consuming, frustrating task for many patients and one that causes tensions throughout the system.

### *Involvement in practice improvement*

Involving the public in healthcare processes has become a key policy direction in the United Kingdom (UK).<sup>28,29</sup> The Department of Health in England proposes to replace Community Health Councils with statutory Patient Forums, to strengthen the patients' voice, and to establish a new independent statutory national body, the Commission for Patient and Public Involvement in Health, supported by Patient Advisory and Liaison Services (PALS) in each Trust (primary and secondary). In addition, all Trusts will be required to survey their patients on an annual basis and the General Medical

Table 1. A selection of patient-based survey measures.

Name	Description/topics covered	Sample
National Survey of General Practice Patients <sup>4</sup>	Access, interpersonal relations, out-of-hours care, use of other health services, referrals	Designed as a postal survey. First mailing achieved a response rate of 64% from sample of 100 000 ( <i>n</i> = 61 426). Results available for each health authority in England. Now being repeated to produce data for each PCT. <a href="http://www.doh.gov.uk/nhspatients/">http://www.doh.gov.uk/nhspatients/</a>
General Practice Assessment Survey (GPAS) <sup>37</sup>	Includes ten subscales: access, receptionists, continuity of care, communication, interpersonal care, doctor's knowledge of the patient, enablement (see below), specialist referral, nursing care, and overall satisfaction	Designed as a postal survey. Comparative data available. <a href="http://www.gpas.co.uk">http://www.gpas.co.uk</a>
EUROPEP <sup>38</sup>	Short version includes 23 items for self-completion by patients. Available in 15 different languages.	Comparative data available from many European countries. <a href="http://www.equip.ch/groups/europep.html">http://www.equip.ch/groups/europep.html</a>
DISQ <sup>39</sup>	Patient evaluation of doctor's interpersonal skills	Patient questionnaires at exit from consultations. Comparative data available
Enablement <sup>40</sup>	A six-item questionnaire to measure the degree to which patients feel 'enabled' by the consultation	Patient questionnaires at exit from consultations. Comparative data available
Recertification patient survey <sup>41</sup>	A patient survey developed by the American Board of Internal Medicine for use in the US for recertification. The GMC is developing a similar instrument in the UK	Thirty patients are asked to complete the survey. <a href="http://www.abim.org/cpd/cpdhome/index.html">http://www.abim.org/cpd/cpdhome/index.html</a>
Satisfaction with surgery and consultation <sup>42,43</sup>	Asks patients to indicate their extent of agreement/disagreement with various statements about general practice	Designed for self completion after the consultation
Picker Patient Experience preferences; (including primary care) <sup>44</sup>	Includes eight dimensions: access; respect for patients' preferences; coordination and integration of care; information, communication and education; physical comfort; emotional support; involvement of family and friends; transition and continuity	Designed as a postal survey. Comparative data available from Europe and US. <a href="http://www.pickereurope.org">http://www.pickereurope.org</a>

Council wants doctors to seek their patients' views on the quality of interactions. These measures are designed to ensure that local concerns are provided with a coherent feedback system.

Systems to involve the public and patients do, however, run into three perennial problems. First, the main difficulty of avoiding tokenism, where a lone lay voice is difficult to hear above a cacophony of competing interests.<sup>30</sup> Second, it is difficult to achieve a balanced viewpoint that reflects the interests of a representative group, rather than the views of a vociferous minority. Third, most systems are reactive and fail to include the public in the healthcare planning and design phases.<sup>31</sup>

### What can be done in practice?

Translating these ideas into practical steps in general practice is a perennial challenge, especially in areas where socioeconomic contexts and cultural diversity challenge an organisation's capacity to respond. Nevertheless, the impact of patient feedback should not be underestimated. By way of an example, a practice in a deprived urban area reacted to the results of a waiting room survey requested by the Commission for Health Improvement by making significant changes to their access system. They decided to modify the obligations placed on reception staff to 'triage', unofficially, patients' appointment requests. The reception staff had been doing this to survive the angst placed on them by the clinicians (their employers) on the one hand and a 'demanding' public on the other. This example of organisational responsiveness to patient feedback is salutary. We feel that patient engagement is necessary, to prevent public service organisations becoming complacent or immune to changing needs.

The proposed new GP contract has recognised the impor-

tance of the patient's perspective in its quality framework.<sup>32</sup> Three elements are outlined:

1. clinical quality standards (for example, national clinical priorities, locally determined clinical priorities);
2. organisational standards (for example, human resources, health and safety, premises, practice management, information management and technology, clinical governance, prescribing, appraisal, adverse incident reporting); and
3. patient experience (for example, patients' views on doctors' communication skills and attitudes, opening hours, access to doctors and nurses).

At the time of writing (late April 2002), details about criteria, standards, and how the patient's experience is to be measured were not available. Practices that want to anticipate these trends in quality improvement should look for tools to conduct patient surveys, to obtain feedback on their organisation and the interpersonal skills of the clinicians. Table 1 indicates some of the instruments that have been used in primary care and where comparative data exist.

### Conclusions

Gathering the perspectives of service users has been a key feature of recent developments in society, but it is only over the past decade or so that the healthcare sector has identified methods to assess the views of patients. Although there are increasing numbers of examples where patients are being actively involved in quality improvement,<sup>33</sup> clinical policies,<sup>34</sup> and guidelines,<sup>35</sup> the methods are largely unevaluated. If these

methods are to be extended then they should be assessed in terms of their effectiveness, efficiency, and maybe even safety.<sup>36</sup> Patient involvement is largely underdeveloped, particularly in general practice.<sup>31</sup> An overview showed that contributions can include preferences (ideas about what should occur), evaluations (reactions to aspects of care) and reports (observations on the organisation or process of care).<sup>36</sup> So, although we understand that many will think it impractical to involve patients in quality improvements, perhaps, ironically, the reverse is the smart way forward.

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