

but is this compatible with the demand for easier and faster access—for example, via the government’s new walk-in clinics?

As O’Connor et al’s systematic review of decision aids shows, patients do not necessarily make conservative choices when they are fully informed about the risks and benefits of treatment options (p 731).<sup>15</sup> In the end the government may be disappointed if demand continues to rise despite its efforts to empower patients—but they should not be. If it increases the chance of patients being treated like grown ups, it will have been worth it.

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## The increasing importance of patient surveys

*Now that sound methods exist, patient surveys can facilitate improvement*

People often think of “exit” and “voice” as the main ways patients can influence healthcare quality<sup>1</sup>—that is, patients can leave providers they are not happy with or they can voice their opinions in an attempt to change care. A common strategy for eliciting patients’ “voices” is to conduct surveys. Clinicians have long been sceptical about such surveys, partly because they communicate regularly with their patients and saw no need for another method of hearing their concerns and partly because satisfaction surveys used to be flawed measures of healthcare quality. Now, however, that is beginning to change as rigorous methods have been applied to developing and evaluating patient surveys.

Despite numerous studies of patient satisfaction,<sup>2</sup> they have not resulted in the quality improvement that many expected. Previous satisfaction surveys had little impact because they often did not meet minimal standards of conceptual or methodological rigour and were not designed to facilitate quality improvement efforts. Responses to such surveys are subjective and difficult to interpret since they are a complex function of expectations that may vary greatly among patients with comparable care. Moreover, the questionnaires assessed things, such as quality of the food, that have little bearing on the quality of clinical care, and thus the results provided little direction to those responsible for improving care processes.<sup>3 4</sup>

It is now widely recognised that there is a need for rigorous methods, other than clinical conversations, to elicit patients’ views on such matters as treatment decisions and the quality of care received.<sup>5 6</sup> Much effort has therefore been devoted to developing and evaluating survey measures that elicit reports about specific care experiences that reflect quality of care, not amenities.<sup>7 8</sup> Such questions are less subjective and less influenced by patient characteristics, are more interpret-

able, and thus may be acted on for quality improvement purposes.<sup>9</sup>

The Picker Institute has developed and used such instruments to evaluate the quality of hospital care in the United States<sup>7</sup> and more recently, in Europe. The Consumer Assessment of Health Plans (CAHPS) project has adopted a similar approach for ambulatory care in the United States.<sup>10</sup> These newer instruments provide qualitatively better data than many earlier surveys, and the response of patients, clinicians, and others responsible for the quality of health care has been striking. One indication of the value of such surveys is the increasing public dissemination of the resulting data. CAHPS data were available to about 90 million Americans in 1999, including 39 million Medicare beneficiaries (<http://www.medicare.gov/comparison/default.asp>), 9 million federal employees, 40 million people covered by plans reporting to the National Committee for Quality Assurance, and people in plans surveyed by other sponsors.<sup>11</sup>

Regional coalitions are also increasingly coordinating data collection and dissemination. A partnership of Massachusetts healthcare, business, and government leaders recognised the need for credible, publicly available data on the quality of hospital care in the state and launched a voluntary effort to collect information using the Picker survey from 24 200 patients discharged from over 50 Massachusetts hospitals.<sup>12</sup> Those data were used to create a report that was distributed to the hospitals and made publicly available after an initial cycle of internal reporting (<http://www.mhqp.org/statewidesurvey.html>). A testament to the quality and focus of the project is the fact that participants agreed at the outset to use the data not to judge “winners and losers” but to educate and inform hospitals and consumers and to focus and facilitate quality improvement efforts. The news media generally

*BMJ* 1999;319:720-1

recognised that the important story was not that some hospitals were better than others, but that all hospitals were working collaboratively to respond to patients' concerns. Clinicians and administrators embraced the new measures as valid and important and devoted new energy to making the care of patients better, rather than criticising the message. The report stimulated numerous quality improvement activities. A similar project is under way in California with a substantially larger group of hospitals.

What are the most important lessons for clinicians from these activities? Firstly, put aside preconceptions about the value of patient surveys: there now are valid and reliable instruments that ask patients objective questions about aspects of care that both clinicians and patients think represent quality. Secondly, newer surveys and reports can provide results that are interpretable and suggest specific areas for quality improvement efforts. Thirdly, we should not worry about whether or not to release information on quality to the public and whether that impedes quality improvement. Public reporting is an inexorable trend, so our efforts should be directed to making sure that these reports contain reliable and valid indicators of quality and that their focus is not on identifying "bad apples" but on stimulating and guiding quality improvement efforts. Patients would much rather their voices be heard than exit out of frustration. Now that we have the right tools we should all work together to

hear patients' voices clearly and meet their needs better.

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## The challenge of lay partnership

*It provides a different view of the world*

Lay people have long been involved in the health service as members of governance bodies and other committees. But only recently have they been involved at the heart of professional practice and performance, working with doctors in doctor-patient groups discussing standards and guidelines, audit and revalidation. This involvement challenges doctors' belief that they can decide by themselves what patients' interests are and how they should be met. Yet when they accept this challenge and work with lay people as equals the scene is set for productive work.

For such partnership to work well we must be clear what "lay" means. Doctors share core values, norms, and skills but specialise in various ways and to different levels. Parallels among lay people are less well understood. Some lay people, usually after being a patient, develop expertise in the experiences, perceptions, and interests of patients as patients define them. These, not "ordinary" lay people, are the ones who should take part in doctor-patient groups. Among them, too, are variations in knowledge.<sup>1</sup> Patients' expertise lies in the immediacy and detail of their own experiences of health care. They cannot usually speak for other patients, partly because they seldom know what their views are, partly because their analyses are confined to their own experience. Patient groups' expertise lies in their detailed knowledge of issues that are of concern to particular groups of patients—as in maternity care. They may disagree among themselves about solutions, but their identifica-

tion of the issues is important. Patient advocates' skill lies in their ability to apply to any specific issue or situation the principles that protect patients' interests. But they may need those issues to be identified first by patients or patient groups.

These categories overlap, and much depends on individuals' ability to capture the essence of experience and generalise from that. Nevertheless, the categories bear on the selection of members for doctor-patient groups. Most groups need a mix of lay members with different skills, just as they need doctors with different skills. The exact mix depends on the purpose and level of the group.<sup>1</sup> Thus cancer patients and cancer support group members join with health professionals in local liaison groups to discuss local standards of care.<sup>2</sup> Patient liaison groups at national level discussing national standards usually include patient group members and patient advocates. The patient liaison group of the Royal College of Pathologists, for example, has a cancer support group member, a community health council member, the chair of a research ethics committee, the chair of a consumer group concerned with ethics in research, an adviser at a citizen's advice bureau, and a consultant to the World Health Organisation's international drug monitoring programme.<sup>3</sup>

In a doctor-patient group that works well differences of view among and between the lay members and the doctor members can be explored in