

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.¹ 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.¹ Thus cancer patients and cancer support group members join with health professionals in local liaison groups to discuss local standards of care.² 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.³

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

depth. Listening to different viewpoints, reconsidering, and negotiating can lead to consensus on difficult issues.⁴ Sometimes the consensus reached would satisfy the most radical patient or patient group. For example, the patient leaflets drawn up by the patient liaison group of the Royal College of General Practitioners give explicit advice about choices of treatment or how to decline having a medical student present during a consultation.⁵ Such matters are not usually touched on in leaflets written by doctors.⁶ At other times the consensus reached will not change professional standards for practice as much as some patients and patient groups would like. Thus the same group's guidance on removing patients from general practitioners' lists does not say that patients should never be removed against their wishes. But it restricts the number of reasons that may justify removal and recommends steps to be taken by the doctor to reduce the likelihood of removal and the ill feeling that accompanies it.⁷

Occasionally consensus cannot be reached—but even then issues are raised and may be revived later. In the early 1990s the doctor members of the same patient liaison group resisted a suggestion from the lay members that pamphlets by patient self help groups should be available in surgeries.⁸ But in the leaflets produced by the group in 1997 patients are encouraged to look for leaflets and to contact patient organisations.⁹ The climate of professional thought changes; and doctor-patient groups can help influence the nature and the pace of change. Discussion can alter the way doctors look at issues. Or it can strengthen a position that protects patients' interests and weaken one that threatens them.

For doctor-patient groups to work well, other aspects of their composition need care.

- The suitability of doctor members as well as that of lay members should be considered. Some professionals are readier to dismiss lay people as “unrepresentative” than to apply the same nebulous criterion to themselves.
- Though both medical and lay members should have relevant expertise and links to their peers, they should

be appointed for their personal contribution and not as representatives-delegates of any group.

- It takes time to build trust and mutual understanding, so groups should avoid erratic changes of membership.
- For most groups, the numbers of lay and medical members should be equal, as they are in some of the medical royal colleges' patient liaison groups. Where a working group's remit is narrow fewer lay members may do. But richness of discussion will suffer if the number is too low. The same is true if there are too few doctors.¹⁰
- Members should not be in clinical relationships with each other.¹ Working relationships of equality are different from clinical relationships with their complex feelings and vulnerabilities.

These are early days for such groups, and the exact part they should play in relation to standard setting, audit, and revalidation is only partly clear. But they hold out the promise of helping medicine meet its own aspiration to offer effective care that both patients and doctors judge good.

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Gaining informed consent for screening

Is difficult—but many misconceptions need to be undone

“By offering screening to 250 000 we have helped a few, harmed thousands, disappointed many, used £1.5m each year, and kept a few lawyers in work.”¹ This conclusion, by one of the authors of a report on cervical screening in Bristol, illustrates that screening, like most medical interventions, has harms as well as benefits. All the more reason therefore to ensure that patients undergoing screening are fully aware of both the benefits and the harms. Yet there are many barriers to seeking truly informed consent, and we know surprisingly little about effective ways of doing so.

The detrimental side effects of screening include anxiety, false alarms, false reassurance, unnecessary biopsies, overdiagnosis, and overtreatment. Some people have a disease detected on screening, receive

treatment, yet still develop recurrent disease: we have made no real difference to their destiny, just prolonged the period they are aware of their disease. False positive results can cause major distress as well as prompting further investigations, often invasive, before the patient can be cleared. A recent study of mammography in the United Kingdom found that anxiety in women requiring further investigation because they were false positive on initial screening was still significantly higher 11 months after their recall appointment than in women who received negative results at initial screening.²

There are misconceptions among the public about the purpose of screening and the accuracy of screening tests.³ In pursuit of good uptake or population coverage the proponents of screening often state that screening is simple, effective, and inexpensive. In truth

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