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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it can be complex, of limited effectiveness, and expensive.[4] The report on cervical screening from Bristol showed that new abnormalities were found in 15 551 of 225 974 women tested: 6000 were referred for colposcopy.[5] The numbers were excessively high compared with the incidence of malignancy that could possibly be prevented. The study concluded that, despite being well organised, much of the effort was devoted to limiting the harm done to healthy women.[5]

Because of the combination of benefit and harm in all procedures the individuals being screened must receive full and accurate information about the procedure and give their informed consent. When uncertainty exists it should be discussed, not omitted or glossed over, and advice should be explicitly supported by the best available evidence.[6] Coulter has criticised patient information materials for emphasising the benefits of interventions, glossing over the risks and side effects, and rarely mentioning scientific controversies. Too many, she says, adopt the paternalistic view that patients cannot cope with bad news and must be kept ignorant of medical uncertainties.[7]

Evidence-informed patient choice involves providing people with research based information about the effectiveness of healthcare options and promoting their participation in decisions about their management. Yet the processes and outcomes of evidence-informed patient choice are poorly understood and need to be carefully evaluated.[8] Very little is known about the effects of sharing research based information about healthcare effectiveness with patients and involving them in decisions about their care.[9] In order to facilitate informed choice, it is not clear what information should be given, how much information should be given, and how this should be framed. The same information may be provided using a range of media—in writing or verbally, face to face or over the telephone—in varying amounts of detail, and at different times in the process of screening. The effectiveness and efficiency of these different ways of presenting information requires research.

Moreover, tension may exist between the aims of promoting effective forms of health care and promoting patient choice. In a recent review of informed consent in cervical cancer screening Anderson and Nottingham highlighted the tension between those wanting "more honest" information to be available to women invited for screening and the medical experts running the screening programmes, who were worried that such information would discourage people from attending.[10] They claimed that the failure to be honest about the uncertainties perpetuated public misperceptions and put laboratories in an impossible position that led to more and more defensive medicine and "overcalling." Along with others,[11] they comment that target payments for cervical screening for general practitioners work against the spirit of enabling women to make an informed choice on whether or not they want to be screened. As Anderson, herself a general practitioner, said, "We are rewarded for the number of women we persuade to be screened, not for the quality of information we give."

Failure to obtain truly informed consent for many current preventive interventions is clearly unethical. Indeed, the General Medical Council's recent guidance on seeking patients' consent makes it clear that doctors must make sure that patients are provided with all the information they want or ought to have to make a properly informed decision.[12] The guidance on screening spells out what this should include: the purpose of the screening; the likelihood of positive and negative findings and possibility of false positive/negative results; the uncertainties and risks attached to the screening process; any significant medical, social, or financial implications of screening for the particular condition or predisposition; and follow up plans, including the availability of counselling and support services.

However, many impediments exist to obtaining such consent. Anderson and Nottingham emphasise the importance of providing information to general practitioners and other health professionals if they in turn are to communicate effectively with those invited for screening about the limitations and risks of screening. They also need time to explain and answer questions. Doctors themselves need to be aware of an immense amount of complex information; patients may find it difficult to assimilate this information. Clinical practice guidelines may be helpful, but not all are based on evidence, and recommendations are often conflicting.

Nevertheless, although uncertainties complicate the process of achieving informed consent, they underscore the importance of conducting research and taking care to ascertain what people believe about the disease and its causes, what they understand, and what they want to know. Ultimately informed patient choice, particularly about interventions that are both offered and delivered by health professionals, should take place in the context of shared decision making between the patient and health professional.[9] Above all we need to respect patients' autonomy—and that includes their right to decide not to undergo a screening intervention, even when refusal may result in harm to themselves.

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