Editorial

Citizen involvement in priority-setting

It is apparent that the potential for medical technologies to achieve beneficial effects for larger numbers of people with a wider range of conditions and ailments is increasing faster than the public's willingness to pay for them. This applies to the health care systems of most developed countries, regardless of the method of funding, and systems have to be devised for deciding how to prioritise, or ration, the use of health care resources. Politicians have generally been unwilling to accept a leadership role in rationing debates, preferring to propagate the idea that all demands for health care could be met if only efficiency could be increased. But numerous reorganisations have failed to solve the problem of long waiting times and inequities of access which greatly concern the public in many European countries.¹

The key issue for the future is how to ensure fair and equitable distribution of health care resources. Which essential services should be available free at the point of use or at low cost and which should not? Should all patient groups be treated equally, or are some more deserving than others? To what extent can a formula such as the quality-adjusted life-year (QALY) be used to guide priority-setting?

Decisions to restrict or ration services are not amenable to a technical fix. They can, and should, be informed by evidence on clinical and cost-effectiveness, but they also involve values. The evidence produced by experts must be weighed alongside the opinions and experience of lay people. The QALY index is derived from public valuations of different health states, but it

begs the question of whether health benefit is the only important criterion that should be taken into account? Is maximization of health gain the main purpose of a health care system, or are there other considerations, such as minimizing health inequalities or promoting a sense of security and solidarity, that could be equally or even more important?

In this issue Dolan and Shaw discuss the advantages and limitations of QALYs in the context of existing evidence on public preferences.² They call for more research into the views of different subgroups of the population about the variety of factors that could affect decisions about priorities.

The Citizens Council, newly launched by the UK's National Institute for Clinical Effectiveness (NICE), could provide a valuable source of evidence on how members of the public tackle these issues. The purpose of the Citizens Council is to 'provide advice to the Institute on topics relating to social, ethical or moral questions which arise in the Institute's work'. Membership of the group is designed to be representative of the general population and explicitly excludes people working in the NHS or private medicine, the healthcare industries, or in groups or organisations whose function is to act in support of patient or industry groups or to lobby on their behalf.

The Council's first meeting, which took place in Salford, England in November 2002, used deliberative techniques derived from experience with citizen's juries to consider the question 'What should NICE take into account when

making decisions about clinical need?"³ Among the 30 participants at the first Council meeting were an electrician, a store assistant, a make-up artist, a milliner, a scaffolder, a retired pilot, a teacher and a taxi-driver.

After listening to the views of various experts and lengthy discussions amongst themselves, Council members outlined various features of diseases and conditions (including pain and symptom severity, threat to life, availability of alternative treatments, prognosis and long-term effects, treatment effectiveness, impact on quality of life, side-effects, stigma, costs and available resources) and features of the patient (for example, their values, their ability to make an informed decision, their age, family history and health state) which they felt should influence decisions about clinical need. Factors they felt should not influence decision-making included social and economic factors, whether a disease or condition is self-induced, and how loud the 'voice' of the patient is.

The British NHS is often accused of having a democratic deficit at its heart, so the estab-

lishment of the Citizens Council is especially welcome. The next very important step will be to broaden public participation in the debate, perhaps by securing the support of the media. It will also be important to devise methods for checking that the principles elucidated by the Citizens Council have wider legitimacy and to ensure that they inform the specific recommendations arising from the NICE appraisal process.

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References

- 1 Coulter A, Magee H, eds. *The European Patient of the Future*. Buckingham: Open University Press, 2003 (in press).
- 2 Dolan P, Shaw R. A note on the relative importance that people attach to different factors when setting priorities in health care. *Health Expectations*, 2003; **6**: 53–59.
- 3 NICE Citizens Council. *Determining Clinical Need*. Salford 21–23 November 2002. London: NICE, 1. <http://www.nice.org.uk/article>.