expertise."³ However, they made few practical suggestions as to how this was to be done.

The publicity surrounding the Child B case brought health care rationing to public attention and highlighted (with occasional dissent on this point) the fact that the NHS cannot afford to provide every possible medical technology to everyone who wants it. Again, there were few constructive suggestions as to how decisions should be made about whom to treat. A selection of comments about the significance of the Child B case in this respect is provided in box 5.

Towards an informed public debate?

Decisions about the treatment of seriously ill children and the rationing of health care are both complex and emotive. This study examined the extent to which the media informed the public about the various issues associated with a particular case. Although many issues and arguments were discussed in one or other newspaper article, people who dipped into or read only one newspaper would only have found a very partial view. Publicity brought the case and some of the issues it raised into the open, but it did not necessarily leave people well informed. In particular, the question of whether the treatment was in the child's best interests was relatively neglected. Child B became "the girl refused treatment on the NHS" and her case was quite clearly associated in early media coverage with health care rationing.

Journalists have to work within severe time and space constraints and must write entertaining stories that sell newspapers.¹² We should not expect them to provide a comprehensive and detailed analysis of all the relevant aspects of a case like this. The current climate, in which the NHS is highly politicised, means that even cases that are primarily about clinical effectiveness and a patient's

best interests come to be seen as examples of rationing.

Public participation in debates about health care rationing is increasingly seen as desirable.¹³ However, given the limitations of the media, other means will need to be sought if the public are to participate in an informed way.

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- 1 Sheldon TA, Maynard A. Is rationing inevitable? In: *Rationing in action*. London: BMJ Publishing, 1993:3-14.
- 2 Entwistle VA, Watt IS, Bradbury R, Pehl LJ. How did the media cover the child B case? In: Marinker M, ed. *Controversies in health care policies: 2*. London: BMJ Publishing (in press).
- 3 Weighing health costs. *Daily Telegraph* 1995 March 13:20.
- 4 Care in the courts. *Times* 1995 March 11:17.
- 5 Prayers for the dying. *Daily Express* 1995 March 11:8.
- 6 Stuttaford T. Success of earlier treatment makes for poorer prognosis. *The Times* 1995 March 13:3.
- 7 Weale S. Dying girl is denied treatment. *Guardian* 1995 March 10:1.
- 8 Palmer J. Final hurdle for cancer experts. *Daily Mirror* 1995 March 13:4.
- 9 NHS Executive. *Priorities and planning guidance 1996/97*. London: NHS Executive, 1995.
- 10 Allen D. Did they let our little angel die too? *News of the World* 1995 March 12:20-1.
- 11 Le Fanu J. Who'll have the last word? *Daily Telegraph*; 1995 March 11:23.
- 12 Entwistle V. Reporting research in medical journals and newspapers. *BMJ* 1995;310:920-3.
- 13 Smith R. Rationing: the debate we need to have. *BMJ* 1995;310:686.

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Setting priorities: is there a role for citizens' juries?

Jo Lenaghan, Bill New, Elizabeth Mitchell

Citizens' juries are an attempt to meaningfully involve members of the public in decisions which affect them in their own communities. The Institute for Public Policy Research and Cambridge and Huntingdon Health Authority have recently piloted the first jury in the United Kingdom. Sixteen jurors sat for four days, hearing evidence from a number of expert witnesses. The jurors were asked to consider how priorities for health care should be set, according to what criteria, and to what extent the public should be involved in this process. This pilot was also an attempt to assess the process itself, and our initial evaluation indicates that, given enough time and information, the public is willing and able to contribute to the debate about priority setting in health care.

One sixth of health authorities are now explicitly excluding certain treatments from public provision.¹ Who is making these decisions, and according to what criteria? What opportunities do the public have to challenge or be involved in these decisions? As Anne Bowling has pointed out, obtaining a representative view from the public can be difficult, and the methodology of ranking lists of treatments and services can be criticised as superficial in relation to the complexity of the decision to be made.² The Institute for Public Policy

Research in partnership with Cambridge and Huntingdon Health Authority has recently piloted the first citizens' jury in the United Kingdom in an attempt to develop a more sophisticated technique for involving the public in these difficult decisions.³

Methods

Professional recruiters (Opinion Leader Research) were given a demographic breakdown of the Cambridge and Huntingdon area, and 16 people were selected by stratified random sampling to represent their community. The jury sat for four days, and during this time the members were presented with information to help them to reach a number of decisions. Jurors were asked to consider how priorities for purchasing health care should be set, according to what criteria, and what role, if any, the public should have in these decisions. Expert witnesses gave evidence, and jurors were given the opportunity to question them before debating the issues among themselves. All of their discussions were recorded, and jurors were asked to fill in questionnaires before and after the event on issues of health policy, both as individuals and as a group, so that we could obtain some quantitative and qualitative data.

Results

The citizens' jury heard evidence from Ron Zimmern, director of public health at Cambridge and

Institute for Public Policy Research, London WC2E 7RA
Jo Lenaghan, health policy researcher

King's Fund Policy Institute, London W1M 0AN
Bill New, senior research officer

Cambridge and Huntingdon Health Authority, Fulbourn Hospital, Cambridge CB1 5EF
Elizabeth Mitchell, communications officer

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Huntingdon Health Authority, who explained how the health authority currently sets priorities. The jurors developed their own criteria for purchasing health care and debated whether quality was more important than quantity in the context of finite resources, after hearing evidence about single and dual chamber pacemakers in order to help them address the issues. A majority (12/16) felt that quantity was more important than quality in the context of a finite budget. The jurors were also asked to consider whether a health authority should give priority to effective treatments for minor problems or to treatments of unproved effectiveness for life threatening conditions. To help them decide about this issue, jurors heard evidence from doctors' and patients about deviated nasal septa. The majority of jurors favoured giving greater priority to effective treatments for minor problems but were keen for health authorities to continue to fund treatments of unproved value in the interests of medical research and progress.

On the third day the jury considered whether priorities should be set at a local or a national level. Professor Maurice Lessof gave evidence on behalf of the Royal College of Physicians and outlined the case for creating a national council for priority setting.⁴ Philip Hunt, director of the National Association of Health Authorities and Trusts, argued that priority setting should be left to the local health authorities, and Frank Honigsbaum, a health economist, explained what strategies other countries used to deal with these issues. After much discussion and debate, at the end of the day all 16 jurors agreed that there should be a national council for priority setting. Thirteen of the jurors thought that the role of this body should be to set guidelines for decision making at the local level; two jurors thought that a national body should be proscriptive, defining what is and isn't available on the NHS; and one juror felt that a national council for priority setting could do both. This finding was repeated in a questionnaire which each juror was given at the end of the fourth day to fill in privately.

Most of the jurors (15/16) thought that there should be an element of public involvement in developing guidelines for priority setting at a local and national level, although most thought that public opinion should only be taken into account along with other interests. Some jurors were keen to see lay representation on the national council for priority setting, but others thought that a body like a citizens' jury could scrutinise the work of this council and inform it of the public's opinion on specific issues. All of the jurors pointed out that if the public were to be involved in the decision making process then people would need a lot more information about the issues concerned. There was a strong feeling that the national council for priority setting should not be political—most jurors thought that doctors, ethicists, health economists, lay people, and even health managers should sit on the council, but nobody voted for the involvement of politicians.

At the end of the citizens' jury, jurors were asked to reach a number of decisions, and their recommendations are currently being written up in a report that will be submitted to Cambridge and Huntingdon Health Authority for consideration. The commissioning authority is not bound by their decision as the aim is to enrich rather than replace the existing decision making process. However, the authority should take the findings of the jury seriously, and if it does not follow the recommendations of the jurors then it must set out its reasons for this.

Discussion of the process

This pilot jury was also concerned with evaluating issues of process: how did the jury cope with the questions; how were its deliberations managed; how much

information should be provided; and how should jurors be recruited and reimbursed?

CHOOSING A QUESTION

The crucial issue is the choice of question that the jury is asked to address. In Huntingdon, the jury was given a broad set of questions concerning how decisions relating to priority setting in the NHS should be made. Initially the jurors found this difficult. It was hard for them to assimilate all the information necessary to address these issues, and they were not clear what, precisely, they were required to answer. One interesting aspect of the jurors' reaction was their initial nervousness about whether, in this context, they ought to be involved in making decisions on public policy. They asked why the elected or appointed bodies were not making these decisions and whether members of the public were competent, technically or otherwise, to do so in their place.

Over the course of the jury, the jurors gained in confidence, but clearly the more broad and open ended the question, the longer the jury will need to sit and the more difficulty it will find in suggesting concrete proposals. When the jurors were presented with a choice between a clear set of options, such as whether priorities should be set at local or national level, they found it easier to deliberate and reach a conclusion.

There are two models for citizens' juries: a "deliberative" model involving broad, open ended questions where the jury is engaged in a process of guiding policy makers and offering feedback and opinion from the local community; and a "decision making" model, where the jury adjudicates on a "live" issue involving a clear set of options and where a statutory body has found it difficult to reach a decision using standard procedures. Both models could improve the democratic process; the latter might also improve the legitimacy with which controversial decisions are made.

JURY DELIBERATION

Another important issue was the organisation of the jury's deliberations. The central problem was one of group dynamics: how might the moderators ensure that all the members of the jury have adequate opportunity to express their opinions? Not surprisingly, some jurors were more articulate, confident, and experienced and better educated. They tended to dominate the discussions when all the jurors were present. To address this issue, the jury was split into two smaller groups, one of men and one of women. As a simple expedient, this worked well—those who were quieter in sessions involving the whole group gained confidence in a smaller group, although other methods of organising small group discussions need to be explored.

In managing the jury's deliberations, the role of the moderator is crucial. The moderator acts as a kind of chairperson, ensuring that discussions run on time, that all jurors have a chance to participate, and that witnesses keep to their brief and answer the questions that are put to them. Moderators also need to ensure that the discussion stays on the chosen topic, while at the same time allowing opportunities for jurors to suggest their own witnesses and questions. Clearly this is a skilled job: the approach in Huntingdon was to use moderators with no experience or knowledge of the subject matter; an alternative would be to use a neutral "expert." The problem with the former strategy is that witnesses may be able to manipulate the jury by using their specialist knowledge; with the latter, the danger is that bias may creep into the proceedings.

INFORMATION

There is a question about how much background information to provide, and how to deal with "points of

fact." Jurors felt they would have benefited from background briefings, both relating to the overall question at stake and the individual witnesses' presentations. There may be a case for supplying the jury with a briefing paper from a neutral expert before the jury convenes, and encouraging witnesses to supply a one page summary of their argument, also in advance. The difficulty is ensuring that this information is neutral.

Clarifying questions from jurors about points of fact is even more problematic. There could be an "expert" on hand to provide this information, but no individual is all-knowledgeable, and having a single person undertaking the role might introduce bias. However, some procedure for dealing with factual inquiries is necessary.

RECRUITMENT AND REIMBURSEMENT

The jurors were selected at random to represent the sociodemographic characteristics of their community. Although this did not present problems in Huntingdon, in other areas there may be a need to resolve difficulties for jurors for whom English is not their first language.

It was felt that significantly more than the 16 jurors who were recruited would have made the sessions hard to manage; however, more experience is needed of other jury sizes. To retain impartiality it may also be necessary to vet jurors to ensure that none has a vested interest: for example, should a clinician be allowed to take part in a jury discussing issues of priority setting when he or she

might stand to benefit from a particular decision? Jurors were reimbursed with £250 for the four days. They seemed satisfied with this payment—no juror dropped out and attendance was almost 100% over the period the jury sat.

Conclusion

The Cambridge and Huntingdon citizens' jury has shown that, given enough time and information, the public is willing and able to contribute to the debate about priority setting in health care. We are hopeful that this method, in conjunction with the more traditional techniques, may offer us a meaningful way of involving the public in decisions about priority setting in health.⁹ Decision makers at a local and national level should seize this opportunity to show that they are willing not only to listen to but to act on the voice of the public.

- 1 Redmayne S. *Reshaping the NHS: strategies and priorities and resource allocation*. Birmingham: National Association of Health Authorities and Trusts, 1995.
- 2 Bowling A. Health care rationing: The public's debate. *BMJ* 1996;312:670-4.
- 3 Coote A, Kendall L, Stewart J. *Citizens' juries*. London: Institute for Public Policy Research, 1994.
- 4 Royal College of Physicians. Setting priorities in the NHS: a framework for decision making. *J Coll Physicians Lond* 1995;29:379-80.
- 5 Cooper L, Coote A, Davies A, Jackson C. *Tackling the democratic deficit in health*. London: Institute for Public Policy Research, 1995.

The rationing agenda in the NHS

Bill New, on behalf of the Rationing Agenda Group

The Rationing Agenda Group has been founded to deepen the British debate on rationing health care. It believes that rationing in health care is inevitable and that the public must be involved in the debate about issues relating to rationing. The group comprises people from all parts of health care, none of whom represent either their group or their institutions.

RAG has begun by producing this document, which attempts to set an agenda of all the issues that need to be considered when debating the rationing of health care. We hope for responses to the document. The next stage will be to incorporate the responses into the agenda. Then RAG will divide the agenda into manageable chunks and commission expert, detailed commentaries. From this material a final paper will be published and used to prompt public debate. This stage should be reached early in 1997.

While these papers are being prepared RAG is developing ways to involve the public in the debate and evaluate the whole process.

We present as neutrally as possible all the issues related to

rationing and priority setting in the NHS. We focus on the NHS for two reasons. Firstly, for those of us resident in the United Kingdom the NHS is the health care system with which we are most familiar and most concerned. Secondly, focusing on one system alone allows more coherent analysis than would be possible if issues in other systems were included as well. Our concern is with the delivery of health care, not its finance, though we discuss the possible effects of changing the financing system of the NHS. Finally, though our position is neutral, we hold two substantive views—namely, that rationing is unavoidable and that there should be more explicit debate about the principles and issues concerned.

We consider the issues under four headings: preliminaries, ethics, democracy, and empirical questions. Preliminaries deal with the semantics of rationing, whether rationing is necessary, and with the range of services to which rationing relates. Under ethics and democracy are the substantive issues of principle and theory. The final section deals with empirical questions and those relating to the practicality of various strategies.

"rationing" relates to individual cases

- "Priority setting/resource allocation" tends to entail value judgments; "rationing" tends to be more technical, based on effectiveness (or vice versa).

We believe these semantic distinctions are merely variations on the same fundamental question relating to the allocation of NHS resources. How do we choose which beneficial services should be offered to whom and which should not? The question of benefit is analysed further below. However, we consider that health care services that are not regarded by anyone as beneficial under any circumstances are not relevant to this topic. In short, the empirical quest to establish which medical interventions have no benefit is not a question of rationing.

King's Fund Policy Institute, London
W1M 0AN

Bill New, senior research officer

Rationing Agenda Group
Members of the group are listed at the end of this report.

Correspondence to:
Mr New.

email: inbill@kehf.org.uk

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Preliminaries

How does rationing differ, if at all, from priority setting or resource allocation?

The terms "rationing," "priority setting," and "resource allocation" are often used interchangeably, but in some instances specific meanings are implied. These other interpretations include the following:

- "Rationing" implies exclusion or denial of a service
- "Rationing" refers to withholding, without consent, potentially beneficial treatment or to any non-market allocation of resources (this interpretation is common in the United States)
- "Priority setting" relates to services or client groups;