Whose health service is it anyway? Community values in healthcare

Gavin H Mooney and Scott H Blackwell

ABSTRACT

- There is growing interest in involving the public in decisions about healthcare provision.
- Citizens' juries, whose members were randomly selected from the electoral roll (rather than derived from consumer interest groups), have been trialled in Western Australia.
- When asked to take a community focus, presented with balanced evidence and given time to discuss and deliberate, the juries were able to identify and debate issues of broad principle, such as equity. Such issues seem to be best handled by referring to community values.
- Any public consultation process should provide sufficient information, opportunity for reflection and deliberation, and recognition of the scarcity of resources.

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WHO INFLUENCES THE SHAPE of our health services? Many Australian citizens seem to want more health services than are currently available. There may well be many other "stakeholders" — politicians, doctors, nurses, patients, patient advocacy groups, or the media — who agree with this wish, but this doesn't stop governments holding a tight rein on health spending. Furthermore, healthcare spending decisions made within budgetary constraints are not generally made in close consultation with the community. Here we examine the arguments for drawing the community into the decision-making process. How can we elicit community values (drawing a distinction between the community and consumers) and at what level and over what issues might the opinions of the community be used to guide decisions?

Citizens' juries

Citizens' juries are one way of introducing greater democracy into health service decision making. In 2000 and again in 2001, under the auspices of the Medical Council of Western Australia, citizens' juries were trialled in Western Australia .[1,2] To date these are the only two instances when such juries looked at health issues in Australia.

The principles underpinning the citizens' juries were:

- random selection — of citizens of WA without any specific "axe to grind", drawn randomly from the WA electoral roll
- being community focused — jurors were asked to deliberate and make decisions for the whole community, not just themselves as individuals
- balance — the witnesses giving evidence to the jury have to provide a balanced view
- deliberation — time to discuss, ask questions and make decisions.

The first jury met in March 2000 in tandem with a health industry conference on health and economics and its recommendations were that there be:

- greater priority setting in health
- equity, based on equal access for equal need
- positive discrimination for disadvantaged people
- more spending on prevention and public health ahead of treatment of disease
- more spending for rural and remote health ahead of urban health
- more of a focus on community based health services.[1]

The second jury met in February 2001 and focused on equity, one of the priorities identified by the 2000 jury. The citizens on the 2001 jury began by deliberating on a concept of equity in health services. This was agreed to be equal access for equal need, where equality of access means that two or more groups face barriers of the same height and where the judgement of the heights is made by each group for their own group; and where nominally equal benefits may be weighted according to social preferences, such that the benefits to more disadvantaged groups may have a higher weight attached to them than those to the better-off groups.

The jury then applied this principle to three areas of inequity in WA health services:

- Aboriginal versus non-Aboriginal healthcare
- rural and remote healthcare versus urban healthcare
- aged versus other healthcare.

The jury was then given a nominal sum of money and, on the basis of their deliberations and listening to and questioning of the experts, were asked to allocate this money across the three identified areas. This they were able to do, giving greatest priority to reducing inequities in Aboriginal health.

The jury procedure is a way of discovering community values in a context that supports informed decision making (unlike, for example, opinion polls). In eliciting these values, there is an important distinction to be drawn between the community and consumers of healthcare services. The former involves citizens; the latter largely patients. Clearly, individuals can be, and often are, both. Citizens include patients, potential patients, taxpayers and insurance premium payers. Citizens' values are more likely than patients'

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values to embrace interests in others in the society. Equity, for example, may be of little concern to the patient; it is more likely to figure in the mindset of the citizen.

Thus the input of citizens' juries is different from "health consumer" advice, which usually comes with a specific focus or "axe to grind". Consumer input is best applied to diabetic care or timing the opening of the GP surgery. The community has a broader vision — more detached, more social, and more considerate of the needs of others.

"Community" is a term that can embrace different groupings. These will normally be geographical (eg, town, state, nation) but can also be socially defined (eg, the Aboriginal community, the gay community). An individual can belong to more than one community. Which community to select when eliciting preferences will be a function of which decisions are being analysed and who is affected by these decisions.

Two clear messages arise from the experience with citizens' juries. Firstly, that through this process the community can give meaningful advice on broad issues underlying health resource allocation. Secondly, that citizens' juries are capable of dealing with some big issues conceptually (the sophistication of their equity definition is testimony to that!) and practically.

Since these jury events, the Osborne Division of General Practice in Perth has sought the community view using a similar process.

Some milestones in public participation

1954: WHO recommends involvement of the general public in health education policy making[5]

1977: UN report sees public participation as a central tenet of primary health care[6]

1984: World Federation of Public Health Associations calls for public participation in primary health care to build on local knowledge[7]

Early 1990s: Public involvement in setting health service priorities in New Zealand[8]

1994: Oregon makes first explicit attempt at health care rationing in the US[9]

1995: WHO reaffirms the importance of community participation in health promotion[10]

1990s: Citizens' juries in the UK[11]

Means of public participation

Mort and Harrison suggest that "being in favour of public participation is rather like being against sin; it is hard to find disagreement".[3] While in recent years there has been growing interest in involving the community in health service planning and decision making, such participation has a lengthening history dating back for at least half a century. One might argue that the idea goes back much further, to the age of enlightment, when Rousseau wrote of his ideal society: "Bands of peasants are seen regulating affairs of state under an oak, and always acting wisely."[4]

Scarcity of resources is a fact of healthcare. This needs to be recognised by the potential respondents to any community survey, thereby avoiding "wish listing" in an environment where the opportunity costs of choices are not apparent. The sorts of choices they should face are those that health service planners face: whether to spend more or less on interventions in maternity care or the mentally ill; more or less on urban, rural or remote healthcare; on the young or the old; on Aboriginal or non-Aboriginal healthcare.

In the literature there is little discussion on what approach to use in eliciting community preferences. Is the intention to obtain community values by aggregating the preferences of individuals concerned for themselves? Or by asking individuals to put themselves in the position of planners acting on behalf of a community such as, say, the Perth community or the Australian community? Or are community values best discovered by allowing a communal discourse that gradually reveals a consensus? Each approach is likely to reveal a different set of community preferences. The usefulness of each approach will be partly dependent on what kind of decision making the results are intended to guide.

Dolan et al consider three perspectives:[12]

- personal — value to the individual self
- social — value to others
- socially inclusive personal — value to others plus self.

A fourth is the "communitarian" perspective,[13] where the community and not an aggregation of individuals might be the focus. The Perth citizens' juries, where consensus was sought rather than the sum of individuals' votes, might be seen in these terms.

There are various techniques available for finding community values. In addition to citizens' juries, these include deliberative democracy, focus groups, opinion polls, conjoint analysis and several others.[14-17] There is too little evaluation of these to judge which is best. Such a judgement may not be possible: each technique may have its place.

We recommend that any process for eliciting community values should provide:

- sufficient information (because the exercise of preferences must be well informed)
- opportunity for respondents to reflect and deliberate
- recognition of the scarcity of health service resources (because preferences are truly revealed when one is required to make a choice).

Expert views or medical specialist knowledge may be important inputs, providing information that is then filtered through a random group of citizens engaged in deliberation and reflection. Such a process allows the social context to be added to medical science.

Many decisions in healthcare are complex and technical. At the clinical level, society trains doctors to act as patients' agents to allow the patient (or sometimes the doctor on behalf of the patient) to make decisions that are more informed than those of the patient alone. Above the level of individual clinical decisions, there are questions of resource allocation and policy that are very much social choices. They still have to be informed by technical information. In between, doctors are faced with many decisions where it is less clear which values should apply. Partly this is because it is difficult to decide where the dividing line should come between professional and social value judgments; partly because some decisions are so technical and complex that citizens cannot make truly informed choices. However, citizens may accept their limitations in some areas of decision making, while insisting on their right to decide in others. Citizens may choose the issues for which they want their preferences to be counted. They may thus have "preferences for preferences".

This last issue has received less attention than it merits. In a study in Australia, Wiseman et al showed that citizens were keen to be involved in healthcare decision making,[17] but saw this as "involving other groups, namely clinicians, health service managers, and patients and their families". The desire to be involved varied with the type of decision (eg, citizens were less inclined to want to be involved in decision making "concerning specific medical procedures").

We would argue that the sorts of decisions for which health services should seek to discover community preferences are those:

- for which citizens can be given adequate information at not too high a cost
- in which they themselves have a preference for being involved.

These principles point to more community involvement at the broader level, such as in determining the principles that underlie healthcare services in general, or what has been called "a constitution" for health services.[18]

Conclusion

There are various problems with seeking community preferences to guide healthcare: the time taken to achieve consensus, the difficulties in establishing informed choice, the tendency for pressure groups and interested parties to outweigh the silent majority, and so on. None, we believe, is insurmountable. There are issues of broad principle (such as equity) that do seem to be best handled by referring to community values. How best to elicit such values remains subject to debate and requires more research. Exactly which decisions, to what extent and in what way, should be influenced by community values will (we suspect) always be a contentious question and will not necessarily be answered in the same way in all health service jurisdictions. Citizens' juries are one way forward. The best approach will vary depending on the questions being asked, the community concerned and the resources available. However, we would submit that the need for good information, choices constrained by resources, and time to reflect are requirements of any process for eliciting community values.

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