Citizens’ Juries - A Model for Involving the Community in Health Policy

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Increasingly, consumer participation in treatment decisions has become a focus of health care management. Interest is now shifting to models of participation by consumers not just as patients but as citizens with a right to participate in resource allocation and other health policy concerns. This article examines a Western Australian attempt to adapt the concept of citizens' juries as a model to broaden the range of consumers engaged in policy development in Australia.

Entering the new millennium, the Australian community is faced with the question of responding to an increasingly complex society. As the trends of globalisation seem to imply the end of local control, we are confronted with questions about the role and nature of government, and with increasing concerns about the meaning and practice of democratic participation. At every level of Australian society, people are concerned with allocation of scarce national, local and personal resources, with establishing priorities for needs, and with how to ensure we all have a say in the making of decisions about such issues. Australian people are grappling with the question of how best to achieve the outcomes they hope for and with improving the general well being of individuals and communities.

As the area of health becomes more fraught with issues and concerns of what can be afforded and who should receive which services, ensuring access to adequate and appropriate health services becomes even more crucial. Access to health care enables people to participate and to meet their obligations, it encourages and supports the development of social harmony and social inclusion.

Consumer participation in decisions about their own health care and the services and options available to them, has developed in recent years into a more central part of health care management. Due to an increased focus on consumer involvement as patients in their own health treatment, members of the broad community are often now called on to participate as citizens. For example consumer representatives may be sought to participate in reference groups when research activities are proposed by a health agency or a new service is being developed. The recent HEALTH CARE NETWORKS REVIEW carried out by Stephen Duckett and others in Victoria, has recommended that broadly-based community advisory groups be set up for each of the new health service networks and that consumers are represented on the boards of these service groups. These activities meet the criteria outlined by the COUNCIL OF EUROPE, Committee on Local and Regional Authorities, for examples of democracy at the practical level.

The COUNCIL OF EUROPE, Committee on Local and Regional Authorities defines democracy at the procedural level as dependent on the inclusion of consumers in decisions of policy and principle. Critically, these sorts of decisions are those that usually take place prior to the development and delivery of services. This type of consumer and citizen involvement has tended to be less visible in Australia. In reality, the involvement of consumers whether at the service delivery level or at the procedural level of policy is at best occurring incrementally. Systematised and transparent processes for including consumers, at all levels of the health system in Australia still need to be consciously developed and supported. As commentators and researchers such as the COUNCIL OF EUROPE, Committee on Local and Regional Authorities note, participation doesn't happen of its own accord, least of all amongst those least predisposed to take part. Nonetheless, as consumer involvement has become more
common, the question of which values, and whose values, do these members of the community bring to healthcare decision-making has come more to the fore.

Making Decisions about Health Care

The economics of health care forms a large part of the context and topical discussion about health care and policy. There is a particular focus on the setting of priorities for health care spending and deciding on forms of rationing. Yet there is concern that in this procedural policy area there has been a lack of a mandate from the community for decisions that amount to rationing and for the sorts of principles used in making decisions about health care. Adrian Towse, in his article INTRODUCTION TO PRIORITY SETTINGS, reiterate this point, together with concerns about how choices are made in prioritising which outcomes will be encouraged. Where community views have been sought, the tendency is towards almost exclusively using deterministic methods and approaches such as quantitative economic research methods like strength of preference, opportunity cost and marginal approach methodologies. This tendency has been described by Mandy Ryan in her paper ECONOMIC APPROACHES TO GETTING PUBLIC PREFERENCES.

Using these sorts of methods without reference to social context and with no attempt to understand the values that participants bring to the process of making decisions, leaves recommendations made in this way vulnerable to the charge that health care is about service planning and not about those in need. Interestingly, the English experience described by Paul Dolan, THE NEED FOR QUALITATIVE APPROACHES, also suggests that if consumers are asked questions and to assign preferences, the process of elicitation becomes critical to helping them think through ideas and issues and form opinions. It also suggests, that ordinary people bring a range of contextual factors to bear on abstract choices.

People who are not health care providers often focus more on quality of life when considering treatment success, in contrast to say, life years of survival. This is illustrated by the concerns of one community in the HERTFORDSHIRE CASE STUDY carried out by Chris Heginbotham and others, which placed priority on rehabilitation services and support for disabled people. These are aspects of care traditionally less valued and resourced in the health care system, that are about life as it is lived and experienced by the ordinary person. The focus of consumers on quality of life is also an emphasis on those factors which enable people to continue to be included in and to participate in the mainstream of community life. If choices must be made about health priorities and in determining what forms health outcomes, then these differences of standpoint must not only be accommodated but the intended outcomes addressed.

Citizens' Juries

Drawing on this background, Health Issues Centre recently participated in the development of a conference on resource allocation organised by the Western Australian Medical Council. The Conference Health and Economics - Bridging the Abyss, was a one day program primarily for health professionals. The aim was to discuss and develop their ideas about resource allocation in health and ...develop a list of principles to be considered when making decisions about money and health.

Our role was to facilitate the input of 20 members of the broader Perth community through a process described as a citizen’s workshop. The citizens' workshop was an iteration of the British development of the citizens' jury concept as a way of involving the general public and democratizing health policy development.
Citizens’ juries build on the idea of legal juries and how ordinary citizens participate in legal decision making by hearing court cases. In the case of health, the *jurors* are citizens selected to participate in a policy development exercise on behalf of a particular community. Participants in citizen’s juries are invited through a process of random selection from the electoral roll. In the West Australian example some 200 letters of invitation were sent out and approximately 30 people initially agreed to participate. This number was reduced to 20 as health service providers were excluded, work commitments excluded some others and an attempt was made to include a balance of age groups and ethnic backgrounds.

Since they are in essence self selected participants, these consumers are no more *representative* than many other processes of engaging the community. For example, no consumers identifying themselves as indigenous accepted the invitation to participate in the West Australian citizens' workshop and one woman dropped out after the first meeting because she had difficulty completing a self administered questionnaire.

The process of citizens’ juries revolves around what Coote and Lenaghan describe in *Citizens’ Juries: Theory into Practice* as *skilful moderation* and allowing space for *deliberative reflection* by the participants who are provided with information and supported by *expert witnesses* who can provide further information on the spot about the issues under discussion. In the British examples, the juries operate as a kind of standing committee and may deliberate over some months.

In the West Australian case study we recruited people who were asked to attend a concentrated workshop on the health system. At this workshop they were given an overview of how the health system works from the perspective of the WA Health Department including a briefing on some of the critical issues. This was supported by written information. The workshop was held the night before the Conference proper. The citizens attended the workshop alongside health service providers, receiving the same information. Following the plenary sessions the consumer participants broke into two groups at which they deliberated on a number of scenarios dealing with resource allocation issues.

The critical feature of the citizens’ juries convened in Britain, according to Coote and Lenaghan, is that their recommendations are intended to be acted upon. Thus the commitment made by ordinary citizens of their time and energy has an outcome. The jury's verdict is not binding nor does it need to be unanimous. The report of findings must be publicised and the recommendations responded to within a specific timeframe. Explanations must be provided of the decision to follow the recommendations or take another course of action. The British experience suggests that citizens juries are *appropriate for choosing between clearly defined options or for developing guidelines for decision-makers* rather than *producing detailed plans or considering abstract ideas*.

The recent Australian workshop and the more practiced British experience with citizens’ juries suggests that they could be a powerful and systematic way of connecting health care policy with the concerns of the broader community and for ensuring that there is ongoing dialogue between the many stakeholders in Australian society. The recorded experience of citizens’ juries also contradicts the view that according to Coote and Lenaghan is often held, that members of the public are unable to grasp complex issues or to develop broad enough views. The quality of the citizen feedback to the Medical Council of Western Australia conference certainly occasioned comment. The consumers who participated in this conference were convinced that community participation in health care decision-making is crucial. They made challenging comments such as *...[we] need to look at our objectives for the future and work back to ensure we have the infrastructure in place....*
Community Participation and Sustainable Health Policy

Health policies stand as indicators of the social values and preferences operating in Australian society. When policy decision-makers develop arrangements for distributing health resources without including consumers they miss out on a major source of assistance in creating sustainable health policy. They also artificially separate their activities from the outcomes for the broader Australian community generated by health policy.

Similarly, a focus on including only those consumers who are currently dependent on the health system whether as patients or carers, may not capture the diversity of views and values amongst other citizens whose support is also crucial for the sustainability of health policy decisions. This affects the capacity of health policy to take a long term view and leaves a focus on reactive choices and decision-making, on tussles over priorities and monitoring of services, not on change and innovation. Methods like citizens’ juries offer the potential to provide a critical benchmarking process for health decision-making and greater acceptance by the broader community of those benchmarks.

The key limitations of this approach are cost and the self selected nature of participation, primarily making it attractive to those who are relatively articulate and educated. It is an approach that therefore needs to be supplemented by more targeted approaches to consumer involvement. Nonetheless it provides a useful addition to current thinking about how to promote democratic participation by the community in health policy development. All policy is only as good as the community ownership and outcomes it achieves.

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A report of the Health and Economics - Bridging the Abyss Conference is available from the WA Medical Council Ph: (08) 9222 2174.

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