A Handbook on Citizens' Juries

with particular reference to health care

Gavin Mooney

A Handbook on Citizens' Juries

with particular reference to health care

Gavin Mooney

Honorary Professor, University of Sydney, Australia; Honorary Professor of Health Economics, University of Cape Town, South Africa; and Visiting Professor, Aarhus University, Denmark and the University of New South Wales, Australia

Acknowledgement

I am most grateful to all the citizens who have taken part in the Citizens' Juries reported on in this book. Apart from anything else you have restored my faith in the idea of citizenship.

Please cite as:

Mooney G (2010) A Handbook on Citizens' Juries. Available at www.gavinmooney.com

Contents

1. *Introduction*

This explains the need for and the purpose of the book and provides a short outline of the book’s contents.

2. *To Consult the Public or Not?*

The question of whether to consult the public on health care matters remains a subject of some debate.

3. *What is a Citizens’ Jury?*

The chapter ‘tells the story’ of citizens’ juries, setting out the pros and cons of this specific form of deliberative democracy.

4. *Running a Citizens’ Jury*

This provides detailed guidelines on how to arrange a citizens’ jury.

5. *A Citizens’ Jury in Primary Health Care*

In this chapter there is a report on one citizens’ jury in a primary health care organisation.

6. *Eliciting Citizens’ Principles*

Here the emphasis is on principles as identified by one particular jury.

7. *Eliciting Citizens’ Claims*

This chapter examines how ‘claims’ can be elicited in a jury and what such claims might comprise.

8. *An Aboriginal Community Controlled Health Organisation's Members' Jury*

This chapter reports on what is believed to be the only 'members' jury' ever held in an ACCHO in Australia.

9. *Conclusion*

The intent of this chapter is to encourage the use of citizens' juries in health care.

References

Appendices

A. Comments In-Advance to Experts

B. Surveys

C. Evaluation Form for a Citizens' Jury

Chapter 1

Introduction

This book is aimed primarily at health service staff in Australia interested in running a citizens' jury in health care. It will also be of value to similar people in other countries and students both of health care and of deliberative democracy. The techniques and processes involved are however relevant to other areas of society beyond health care such as education, the environment, etc.

I am a health economist who believes very firmly that informed citizens do not have a great enough say in how health services are funded, run and planned. I have run seven citizens' juries in health care in Australia and have lectured on these experiences both in Australia and in other countries. I am an advocate for citizen and community power in health care, believing that in most countries the extent to which 'the people' have a say in such matters is all too limited.

The book is being made available free on the web to encourage the use of citizens' juries in health. It is not an academic book but more a 'how to' book. The only "cost" to those who choose to use it is that they are requested to report to me on how any attempts to run citizens' juries went. Please email g.mooney@gavinmooney.com

Relevant Background of Author

I have had a distinguished academic career as a health economist in several countries – starting in Scotland, then Denmark and Scandinavia more generally, New Zealand, Australia and South Africa. In June 2009 I was awarded an Honorary Doctorate by the

University of Cape Town ’as one of the founding fathers of health economics’.

Over the years I have been increasingly concerned at the emphasis within my own discipline of economics (at least the economics of the neo classical kind) of the values of individuals. While living and working in Denmark in the eighties, I met Uffe Juul Jensen, Professor of Philosophy at Aarhus University. Uffe introduced me to communitarianism which is a philosophy which (roughly) emphasises community values over individual values and where community per se has a value in its own right. For more – and various references - see my *Challenging Health Economics* (Mooney 2009). That introduction from Uffe to communitarianism radically changed my thinking.

In the early nineties, in Australia I was a member of the Pharmaceutical Benefits Advisory Committee which deals with inter alia the price subsidisation of pharmaceuticals. In that capacity I was asked to look at the sorts of principles that the committee was using in reaching its judgments and I set up a rough process with the committee to do this. The details of that process do not matter but what stuck me when asking members of the committee about some issues – such as whether an extra year of life was to be valued the same no matter if it were at age 20 or age 80 - was that they quickly and I think reasonably they suggested that such judgments were not for them to make but for the community at large. The question that arose in my mind was then how to get at such community values.

Since then, additionally, I have become more and more interested in the idea of the health care system as a social institution and of bringing citizens’ (as opposed to consumers’ or patients’) values into play in health care. To that end I have been involved in facilitating seven Australian citizens' juries in health, six of these in Western Australia and one in South Australia over the period 2000 to 2008. Two of these were state wide (in WA), two were for Divisions of General Practice, one for an Area Health Service, one for a 'GP+' Clinic (the last in South Australia) and one in an Aboriginal Medical Service. I have thus more experience in running such juries than anyone else in Australia.

I have also recently written an academic text on the theory and practice of bringing community or communitarian values into health care: *Challenging Health Economics*, Oxford University Press, 2009. This is useful but not essential reading for those considering running citizens' juries in health.

This Book

The book is a mini text in citizens' juries in health in Australia. It is both a handbook for those wanting to know how best to organise and conduct such juries and a brief introductory text on citizens' juries which can be used in various health, social admin and political science courses which cover issues surrounding deliberative democracy. The focus is health care but the processes are relevant beyond that.

While there is growing interest in these matters, there is no book in Australia and very little written elsewhere on the pros and cons and modus operandi of deliberative democracy techniques and, more specifically, citizens' juries in health care in Australia.

The aim is to provide a short accessible text for those interested in such juries and particularly those interested in *organising* such juries. The book thus aims to meet the needs of two markets. First it provides a useful guide for practitioners who seek to set up such juries. Second it is a short introductory text for students on MPH and other similar health courses, as well as those courses such as social admin and political science where knowledge of the workings of deliberative democracy need to be exemplified. It is thus both practical and pedagogical.

There is a burgeoning interest in the use of citizens' juries in health in Australia. I know this because as I talk about them at health and medical conferences, there are lots of questions about these. The National Health and Hospitals Review Committee (NHHRC 2009) also recommended their use. It is because of this interest that I decided to write this book.

I have attempted to make the book light and accessible. While written by an economist it is largely free of economic jargon. There is some economics here in these pages although many may see the discussion of values and whose values as being more about philosophy than economics. So be it; but economics does need values. I believe that in health care the extent of the use of and appreciation of the need to use citizens' values is all too limited. Yet whose health is it we are dealing with? Who is paying for health care? Is health care not first and foremost a social institution?

Chapter 2

To Consult the Public or Not?

There is an ongoing debate over what role the general public should play in health care planning. Sceptics of public involvement have expressed concerns over the limited knowledge, interests and expertise of the public. Advocates have argued that, regardless of the problems involved, it is ultimately society's resources that are being allocated and therefore society's preferences that should count.

To get the citizenry heavily involved in health care planning is just not practical. Athenian democracy has its appeal but the opportunity costs are just too high. We need to devise and adopt a set of principles for social choice – a 'constitution' - for health services.

With Virginia Wiseman we developed the idea of a constitution (Mooney and Wiseman 2000; Mooney 2009). This involves a set of principles on which policy and actions might be based: such as equity, how important it is and how it might be defined. Is there to be concern only with horizontal equity, the equal treatment of equals, or also vertical equity and the unequal but equitable treatment of unequals? A constitution might cover issues of respect for individual autonomy, of ensuring the freedom of individuals to refuse treatment, of the extent to which only outcomes matter or whether processes (such as decision making per se) are also to be valued. It might even state in which contexts in public health the community's preferences should count and when valuation issues might be left to the experts.

The idea of stepping back and thinking through the principles on which societies seek to build their health services is a simple one. Questions of the appropriateness of health care, of evidence bases, of health outcomes measurement – all potentially laudable – cannot satisfactorily nor comprehensively be addressed until there is clarity with respect to the values that do and should drive the health care system. That set of values in my view has to come from the community.

What is possible is to bring public preferences into health service decision making without all the complexities and costs of Athenian democracy. This involves using the community voice to establish the underpinning values and leave the 'experts' to operationalise the constitution.

Duane Blaauw and colleagues (2003 pp39-40) suggest: 'Health systems are complex social systems. This seemingly obvious observation is curiously absent in much of the current discourse about health systems and health sector reform.' They claim that this is in part due to the 'economic biases of the field' (p 39). They go on to say that '[b]ecause health systems are social systems, health system researchers and reformers need to pay much more attention to social theory … It is necessary, not only to pay more attention to the socio-cultural dimension of health systems, but also to ensure that existing interventions do not undermine the development of more humanistic approaches. Our understanding of the complex social world of health systems is limited and fragmented. Current perspectives rely on simplistic assumptions about human behaviour but we lack the methodological tools to develop more complex insights.'

They argue that there is a need to ‘focus on priorities such as developing shared goals, promoting organisational values, creating supportive work environments, influencing informal social networks, building trust, and improving organisational learning’. They accept that ‘[p]ractical health system researchers and reformers may be sceptical that such an approach is too complex or too normative’.

These authors thus get us part of the way to valuing health care systems *per se,* even if they do not go far enough in seeing health care as a social institution.

Looking to health services as social institutions means that they become more akin to social services where the inputs are not simply the resources of the health services but involve also the resources of the citizens. This is most obvious at the level of the patient and his or her carers in the community. But citizens can also be involved as a resource in health care in the sense of their time and effort in offering their informed preferences for the procedural foundations of health care i.e. the constitution for health care.

Freedman (n.y.) argues that too infrequently is the issue of a health care system as a social institution addressed or taken into account in health policy making. She makes this point in the specific context of the Millennium Development Goals (MDGs) but it has wider relevance. She argues (p 1) that the way that the goals are framed ‘invites a technocratic, largely top-down approach with a familiar sequence of steps: determine the primary causes of the MDG diseases/conditions; measure the incidence and prevalence; identify the medical interventions to prevent or treat these causes; determine the most cost-effective delivery systems for those interventions; calculate the costs; advocate for ‘political will’ to get the job done.’

Lucy Gilson (2003 p 1461) argues that health systems 'are not only producers of health and health care, but they are also purveyors of a wider set of societal norms and values'. They are thus social institutions in the sense that they help to mould and are moulded by the nature of the society in which they operate. There is a two way interaction between the health care sector and the population and not the unidirectional emphasis that health policy tends to assume or adopt. The health services are technocratic organisations, there to serve the health of the people. But they are more. They are also social institutions, a part of the social fabric and having the capacity to be a major player in influencing the nature of society. Thus they need to take their place alongside other major institutions such as the education sector, corporations, the courts and the public service. How people react to and respect these institutions can in turn influence the make up of society and have an effect on individuals' perceptions of their position in society.

The health care system thus has a value of its own independent of or at least additional to what it produces by way of outputs such as improved health to individuals. This value takes the following forms: a social institution which contributes to the health of the population as a whole and not just the individual's health; a social institution which by being accessible to all contributes to the idea of living in and helping to build a caring society; and a social institution which, in being amenable to the preferences of citizens, enhances democracy. These features together we may label under the heading of building social decency.

Let me give an example. If a primary care organisation wishes to set up some strategic planning exercise, this will most often be goals focussed. It may be no more than a description of how decisions are to be made. Often this process ignores the issue of establishing the foundation of principles on which that planning is to be based. Debate about what the values base might be may well be bypassed.

Instead, if there is a recognition of the need for a constitution on which to plan the functionings of the organisation, that in turn requires discussion as to how this is to be done and according to whose values. Again many answers might be given to these questions but the key point is that, asking these questions, they now need to be answered. If there is a further recognition of the idea of health services as social institutions that will point in the direction of using community values. Again if there is an acknowledgment that the players who are around for the long haul are the community who are served by these services then citizens are the people who are most likely to provide what Stephen Jan calls ‘credible commitment’ (Jan 2003) to the social institution that is health care.

Chapter 3

What is a Citizens' Jury?

In recent years there has been increasing interest in involving communities in decision making in health and health care through various forms of 'deliberative democracy' (Davies, Wetherell and Barnett 2006). These usually involve a selection of people or a community or a meeting of citizens who are asked about certain issues.

I have experimented with citizens' juries (Mooney and Blackwell 2004) as one form of deliberative democracy that might serve as a vehicle for the purposes of setting principles and priorities, and establishing communitarian claims (see chapter 5). These bring a random selection of citizens together, give them good information and a chance to quiz experts; and thereafter allow them to discuss and reflect on certain questions, against a background of resource constraints.

What 'vehicle' is used to get at citizens'/community values will depend to some extent on what is sought. Thus: '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' (Mooney and Blackwell 2004). Apart from citizens' juries, other approaches are focus groups, opinion polls and conjoint analysis.

Whatever process is used for eliciting community values it should seek to reflect as well as possible the preferences of the relevant citizens qua citizens, provide sufficient information for the preferences to be meaningful (because the exercise of preferences must be well informed), an opportunity for respondents to reflect and deliberate, and a recognition of the scarcity of health service resources (because preferences are truly revealed when one is required to make a choice).

What sorts of issues might citizens address? It is likely that '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"' (Mooney and Blackwell 2004).

It is important at a broader level not to lose sight of the issue of citizen engagement in social institutions and building such social institutions, the idea of fostering democracy and democratic governance. While this can be restricted to being instrumental, the idea that it might be seen as a valued benefit of the process is acknowledged by some writers (see for example Kashefi and Mort 2004) who argue for this as an outcome, consequence or benefit in its own right. Kashefi and Mort warn against some of the problems of settling for instrumentality. 'Incidental' consultations are deeply mistrusted and can be seen as 'social control disguised as democratic emancipation' or 'simply … ways of deflecting criticisms of mainstream (un)democratic practice'. Certainly, there are risks associated with public consultation. It can result in a cynical response in attempting to build democratic governance, and I have experienced such cynicism in facilitating citizens' juries, albeit from a small minority of jurists. Most enthusiastically endorse the process and express positive feelings (even delight!) at being involved, some very readily arguing that such deliberative processes ought to be extended to other areas of social life. Beyond the anecdotal however, research is needed to show that citizens do value their health care system as a social institution. This in a sense is self-evident but it does need to be supported with good quantified evidence regarding the nature and extent of this value.

Citizens' juries have their genesis in the UK (see for example Davies, Wetherell and Barnett 2006) but more recently I have been involved in facilitating seven of these in Australia (see for example Mooney and Blackwell 2004). That first hand experience has been partly responsible for my being persuaded that citizens are well able to provide these values.

What is sought is to establish what values drive citizens' wants from these social institutions. There are three key objectives. First there is the desire to establish which factors citizens want to be taken into account when scarce resources for health care are being allocated. These might be simply and only health or health need. They might be more concerned about addressing problems, thereby focussing on health needs as sickness rather than about looking to see what difference the resources might make i.e. their capacity to benefit. They may seek extra resources for particular issues conditions or disease – for those suffering from mental illness, for example.

Second there are issues around equity where the citizens seek to determine what they mean by equity, for example whether to opt for equal access for equal need or equal health and for horizontal equity (the equal treatment of equals) or vertical equity (the unequal but equitable treatment of unequals). Weights may also need to be attached to different characteristics, such as for vertical equity for benefits to say poor people. They have to decide which people merit having above average weights and why. Is this to be based solely on disadvantage and what in their view constitutes disadvantage - the poor, the elderly, Aboriginal people, those who are mentally ill? Which groups in this context are most disadvantaged and is this a criterion for yet greater weights to be attached to any benefits to them?

Third there may be considerations around organisational issues such as the existing balance in resource use between say prevention and cure; between the community and hospitals; and between curative and palliative care. There may also be other organisational issues which merit additional funding such as seeking to ensure efficiency and transparency in decision making; providing adequate information to the public on what services are available and when; and ensuring there are safeguards in place to promote quality of care.

To propose that the community get more involved in health service decision making is not new. WHO (1954), more than half a century ago, proposed a move to have citizens' values drive health service decision making. That idea has been around since (see for example the World Federation of Public Health Associations in 1984, Vuori 1984) and more recently the Romanow Commission in Canada (Romanow 2002).

Chapter 4

Running a citizens' jury

Introduction

Citizens' juries are not difficult to set up. They do however need to be set up well. This means following a few basic guidelines as outlined in this chapter.

What Are We Seeking?

What we are seeking in organising any citizens' jury are the views of the informed citizenry on some issue or issues. There is a need for clarity as to what precisely the issue is that is up for discussion and also how the views of the citizens might or might not affect the decisions surrounding the issue. Are the citizens' views to determine the decision? Will the decision makers be looking to take account of the citizens' values in making a decision? Will the decision makers simply want to know the citizens' values in, thereafter, reaching their decisions?

There are different views on this! I think it is important that in advance of getting into their deliberations, the citizens are made clearly aware of the nature of their tasks and what the impact of their deliberations might or can be. Good to be able to say: "your values as citizens will be taken into account in any decisions taken"; even better "your values will serve as the basis of any decisions taken". Whatever, there needs to be some straight talking on what and what not the citizens can affect – and how. The risks here are obvious. Many of the public have become rather cynical about "consultation" and members or potential members of a jury may be somewhat reluctant to be involved or to become energised regarding their tasks if they feel that they are wasting their time or this is all some public relations whitewash job so that the organisers can say “oh yes, we consulted the public”.

A second issue is that members of the jury need to have drummed into them that they are there as citizens and that they have been randomly selected to represent the citizenry or community of Newtown or Area South or Region Blue. They are not there as users of health care but citizens, tax payers and potential users of health care. Also they are not from Bonnington, Binnington or Bunnington but as citizens of Region Blue. Of course they may be influenced by the fact that they themselves or someone near and dear has cancer or lives a long way from hospital or has had a bad experience with the mental health services or they do come from Bunnington. They should not however talk directly of their cancer or Bunnington’s hospital.

Background

I have been involved with seven Citizens’ Juries in Australia. These have been quite varied in nature. The first was in 2000 organised by the Medical Council of Western Australia, a group of progressive doctors, and covered the whole state. The emphasis was on setting principles and priorities for the state as a whole.

In 2001 the Medical Council of WA picked up one of the key themes from 2000 and organised a jury around equity with three strands Aboriginal versus non-Aboriginal; elderly versus non elderly; and Perth (the state capital) versus rural/remote.

The 2002 Osborne Division of General Practice citizens' jury considered the principles that the citizens wanted to underpin that division's activities. (Divisions are geographically based primary care networks which are primarily GP-focussed and which can influence GPs in how they practice.)

The citizens' jury for the South West Area Health Service in Western Australia in 2005 which covers a population of approximately 110,000 people was a particularly interesting event. The results of the jury's deliberations which covered both principles and priorities were fed into a large public forum of various stakeholders. This latter addressed more operational issues but did so on the basis of the results from the jury.

In 2007 the Perth Primary Health Care Network, a division of general practice, held a jury which again looked at both principles and priorities for their network.

Again in 2007 I facilitated a jury in South Australia in Marion GP Plus which is a primary care organisation.

Finally, thus far, the 2008 South West Aboriginal Medical Services held what was not strictly a citizens' jury but a members' jury where participants were drawn from the SWAMS membership. That deliberated over both principles and priorities.

Selection of Jurors

In selecting jurors, the key idea is to try to bring together a group of people who are able to represent the community involved. Thus ideally they should not self select or be invited through say an advertisement in a local paper. Rather, best, is some randomisation process say from the relevant voters' roll. In some instances those selected may be topped up with some people from minority groups who may be otherwise missed, such as youth and Aboriginal people.

The process at this level may vary but that adopted should try to stick to the idea of representation and randomness as far as possible but recognising that no process will be perfect. Writing out to people with some simple basic information about the purpose and process to seek expressions of interest is where to start. Of those who say yes – and this is now no longer a random group - they then need to be examined to try to ensure a good mix, by say gender, age, location, income or SES and any other factors that are seen as being potentially relevant.

About 15 are then asked to attend, keeping perhaps 3 or 4 as reserves in case any then say no or drop out later because of sickness. The optimal number for a jury is between about 12 and 20. The number needs to be big enough to allow representation and give the occasion the sense of an event. Too big and the 'conversation' across the jury that is necessary may not happen and not everyone may have an adequate chance to say their piece. (When people feel they have to compete to get their voice heard, the process is in danger of breaking down.) From my own experience with jury numbers from 10 to 19, I would suggest that 15 is about right – 19 was too many to keep everyone in the conversation (and overstretched my facilitation skills!).

There is something of a debate about whether to give out information about health and health care in advance or just leave this to the experts on the day (see below). My feeling is that since the jury is an attempt to obtain the preferences of a community *qua* community it is better that the learning process is also a joint one.

Further giving information in advance may mean that some read it and some do not. There is however no uniquely correct answer to this question. What may be relevant is that in only one instance of the juries that I have facilitated has there been in the evaluation any strong view for having more information in advance. (This was for a division of general practice jury. What the jury felt would have been useful was information in advance not about health and health services but about divisions as organisational entities. The public in general do not understand what divisions are so here there may well have been a stronger case for more information in advance.)

Format

The cases that I have been involved with have had a fairly steady format but there is no single uniquely correct way to do this. The initial approach to potential jurists is accompanied by a brief statement of what is involved, the arrangements, the purpose, etc. They are also told that they will have their expenses paid and will receive a fee. (This has normally been about $300 each.) They are asked to attend from about 5pm on Day 1 to about 4pm on Day 2. The main purpose of the first evening is to break the ice, give them a bit more information about what is involved, etc. but in particular just to get them to begin to know one another and the facilitator (and vice versa) – but the key is to get them to relax together as a group.

The information they get in their letter of invitation will not have gone into detail on what is meant by principles. So, this first evening is a good time to pursue that. Best I think to give examples from other sectors than health to reduce the risk of leading jurists. I have found education a good one (about training for jobs, for being good citizens, equity, etc.) and one that the members of the jury can readily relate to.

It is also to remind them quite strongly that their role is one of citizenry and that they are there to represent the community. The intent is to have them ready for the next morning to be citizens on “citizen jury duty” knowing a little of each other. Getting them together over a dinner on that evening before is I think important. I have not facilitated and would not like to facilitate a jury that did not have this evening before get together. It adds to the costs but I am clear that the benefits are much greater.

At the start of day 2, it is worth repeating briefly the intent of the process and that they are there as citizens. Beyond that the rest of the morning or at least most of it will be taken up with experts presenting relevant information to the jury and the jury having the opportunity to quiz the experts.

What that ‘relevant information’ comprises is clearly a function of whatever issues are to be discussed but is likely to cover demographics and epidemiology giving a picture of the relevant population and its health problems, including for example risk groups; what services are available and where; resources current and future; what the authority can control or influence and what it can’t; what constraints on actions it faces; etc. Such information should be presented as factually as possible. Any questions that cannot be answered at the time need to be addressed by the end of the morning if at all possible.

Juries can be quite tough on experts. They also can see through any attempts to pull the wool over their eyes. Such a lay audience is perhaps one of the most difficult for ‘experts’ to address as there is a need to avoid jargon, not to talk down, not to talk over their heads – and experts need to be warned to be well prepared. Ideally I think rehearsals of experts’ talks should be held but as a minimum it is important that draft statements are prepared of each talk, sent to the facilitator and the final version circulated to all the experts so each knows what the others are covering. (See Appendix A.)

After the experts have presented and been quizzed, they leave the jury alone with the facilitator (but are available, by phone say, if any additional questions arise later in the day). It is then that the deliberation stage starts. This can be tricky as it is important not to lead the jury. Pre-prepared questions are better avoided beyond an opening gambit of: “Well what did you make of all of that?” or “OK in terms of principles and priorities what are your thoughts on what you have heard?”

Here there is no set format but getting some opening statements and then seeing whether these can be grouped under certain headings – maybe efficiency, accountability, etc. – may well be useful. Clarification may be needed (from them) as to what they mean as a group by certain terms e.g. equity. Once these statements begin to be developed there is then a need to see to what extent there is consensus across the group and at what level. While this can be tricky, I have never found a group unable to reach a consensus, although sometimes this will be stated in rather broad terms.

Later chapters give examples of the sorts of principles and priorities that have emerged from citizens’ juries. There is no template for what will emerge; and nor should there be.

On priorities it is important to convey to the members of the jury that they cannot or at least should not indulge in wish listing and that resources are limited. Thus (as is most likely) they can readily come up with ideas on where services should be expanded, they then need to be asked what services they will drop or reduce to pay for that expansion.

An example of this (see chapter 6 below) is the SWAHS jury. Their priorities were greater equity and more to be spent on mental health services and prevention. They then had to be asked; "OK but what will you give up?" and they plumped for fewer hospital beds and a reduction in small Emergency Departments.

The use of "communitarian claims" can also be of assistance in establishing a citizens' jury's preferences (see chapter 7). These reflect the idea that it is the community who have the task of deciding what constitute claims, the duty to allocate claims and to decide on the relative strengths of different claims. More details are given in Chapter 7.

Are Citizens Up to It?

This is in the end a matter of opinion. To some extent it depends on what is at stake. My own view is that when issues of principles and broad priorities are at stake there is no one better placed ethically to judge on such matters. Think of the possible alternatives - and remember that we are talking here about social values and social value judgments – doctors, nurses, administrators, patients, politicians? The only two real possibilities here are patients and politicians. Patients as patients are inevitably and rightly interested only in their own wellbeing and not that of the community. Politicians are clearly a possibility but the issues involved are often too detailed or too local for politicians to be the best people to use to this end. However it is clear that in most instances it will be they who decide how, if at all, citizens' preferences are to be used.

Are the values citizens come up with "reasonable"? Much depends on quite what is meant by "reasonable". But in this context let me mention two examples from my own experience.

For the 2001 WA jury, in advance, when the Medical Council were planning the equity event and choosing Aboriginal versus non-Aboriginal as one dimension of possible inequity, there was concern that the jury might turn out to be racist.

In the event the Aboriginal person who presented the information on this was subjected to some racist comments by two members of the jury. Beyond that however the rest of the jury in essence argued strongly against these two members to the extent that when a decision had to be made as to what was the top priority for addressing inequity was between Aboriginal versus non Aboriginal; Perth versus rural/remote; or elderly versus non-elderly, the jury agreed unanimously that the top priority was Aboriginal health. It was citizens' juries as representing the community at their best! (It is also the case of course that over such a question as racism there is no gold standard. The WA health service, as it stands, is not devoid of racism – see Henry and colleagues 2004).

The other experience was at that same jury and addresses the question of how reasonable are the thinking powers and the values of citizens. At this jury which, as mentioned, was about equity, it was necessary to get the jury to come to some agreement on what they meant by equity. What they came up with was as follows:

Equal access for equal need, where equality of access means that two or more groups face barriers of the same height and where the judgment 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.

As it happens I have researched into equity in health care a lot in my career and seen definitions of equity from all sorts of health authorities, Ministries of Health, WHO, etc. I have never come across a more sophisticated definition than this one – from a bunch of "ordinary" citizens!

Citizens in my experience show great ability to handle questions of setting priorities and principles and to wrestle with difficult concepts like equity. And they do so with great enthusiasm! They come to these tasks with fewer vested interests than most and as a result I guess are actually better equipped for these tasks than many others.

Finally it is clearly important to get feedback from the members of the jury on their experience. (See Appendix C.)

Chapter 5

A Citizens’ Jury in Primary Health Care

Introduction

In this example the key tasks of the citizens’ jury were two. First to set the principles (or values) they wanted to underpin Marion GP Plus Centre. Second to indicate what their preferences were for prioritising the services at, or with the resources available to, Marion GP Plus.

These GP Plus Centres (Government of South Australia 2007) have been set up in South Australia to ‘provide a focal point within the community where a range of primary health care service providers work together to enable improved coordination and delivery of care’. The philosophy underpinning these GP Plus Centres ‘is one of collaboration with local general practitioners to complement the services provided by general practice and to make it easier for the local community to access a broader range of allied health, mental health, drug and alcohol, nurse practitioner, counselling and other support services closer to home.’

The following are the principles that emerged from the jury on Marion GP Plus. They are listed in terms of logicality rather than any weighting by way of the importance of the principles. Thereafter the three key priorities are set out.

Good Management

Good management was seen as an important principle on the basis that both the establishment of Marion GP Plus and its operation would involve some rather tricky issues, particularly with respect to coordination of services but also of clients. It was also important simply because all the other issues of principles and priorities might fall apart if there is not good management.

Components of good management included

- An appropriate referral system which is knowledge-based with respect to both the health of the community and community attitudes and values.
- Transparency in decision making in service provision and resource use; especially being transparent to the community.
- Being accountable to the community on an ongoing basis but also with regular reviews, using citizens' juries to allow reflection on changing demographics, illness patterns and community attitudes but also to monitor the progress of management in promoting the principles established and in pursuing the priorities of the jury in practice. This clearly would involve some form of feed back, an evaluation process and possibly establishing research priorities.

Safety

The principle of safety covered primarily the safety of any treatments or procedures but also the safety of potential clients in using the services.

Access

The principle of access is closely related to equity but since both were seen as important and had a number of different facets, they have been listed separately.

Access had a number of components

- Entitlement. All citizens in the catchment area should be entitled to use Marion GP Plus
- Good knowledge in the community. Efforts need to be made to ensure that there is good knowledge available to the local community about Marion GP Plus and the services it provides in the relevant community.
- Affordability. Services should be affordable where possible free for all but especially for those most at risk
- Language and culture. Barriers created by these factors need to be addressed
- Cultural safety/ security. This is required for all cultural groupings but especially Aboriginal people
- Ease of access. Having services close to the people with good parking and transport, to provide ease of access geographically.
- Timeliness of service. Services need to be timely in the sense of being available when people need them
- Availability. This is not required 24/7 but access should be arranged to cover times when other facilities are busy or closed.
- Information on other services. Marion GP Plus should act as a 'hub' where clients can go to get information about service availability and not just health services but also others, such as social security or housing, which can have an impact on health. Ideally referrals to other services should have a named contact at these services.

- Case management. Services where necessary should be 'individual-focussed' with care available and structured in ways which facilitate access to suitable 'packages' of care, often from multiple-providers.

Equity

This principle was seen in terms of both horizontal equity where clients with the same problems get access to the same care, treatment or management; and positive discrimination (vertical equity), based on the principle of the greater the risk the greater the positive discrimination; and the worse the health status the greater the positive discrimination.

This means greater priority for some social groups including the following:

- Aboriginal people
- Those on low incomes
- Those who have language barriers
- Those who have cultural barriers
- High risk groups

Additionally services should be made more 'male friendly' to overcome men's reluctance to attend for care – for example having easily accessible check ups for men.

Efficiency

There were two key principles of efficiency

- Value for money or 'best buys'
- Doing things as well but cheaper and thus freeing up money

Together these were summed up as ‘the right care, in the right place, at the right time’.

As a part of this efficiency principle, identifying gaps and advocating for new services was seen as a sub-principle.

Whose values?

The citizens very much welcomed the opportunity to be able to offer their preferences on principles and priorities. A key principle for them was that it be the preferences of the community which underpin Marion GP Plus.

Health promotion/prevention

The citizens took very much a social determinants of health stance in considering health promotion and prevention.

Marion GP Plus should be based on a holistic construct of health – embracing not just health care but food, exercise, lifestyle, etc. and, where appropriate, complementary health services.

Such a holistic construct would involve advocating for the involvement of other (non-health) services in promoting health (through making them more aware of their potential health role) – for example, teaching health issues in schools on, say, drug problems.

In adopting a holistic approach there remains a need to avoid duplication with other services.

Management of Expectations with Staff

Education of clients in changing roles of health professionals (e.g. nurse rather than doctor in some settings) and managing the changed expectations of clients

To support this principle the jury proposed a “duty officer”, receptionist, gate keeping role for Marion GP Plus.

Priorities

The citizens emphasised three facets that they saw as priorities at Marion GP Plus.

- Equity, with positive discrimination for disadvantaged groups and with the degree of positive discrimination being a function of either the level of risk or the extent of health need.
- Good management since, without that, all else fails.
- Point of contact for assistance in gaining knowledge of where to go with particular problems. This would involve establishing information about and linkages with other services (both health and non-health), identifying gaps and seeking to fill these and advocacy with other (non-health) services to be more cognisant of their potential health role.

Chapter 6

Eliciting Citizens' Principles

Introduction

A group of citizens was randomly selected from the electoral roll from the health service area concerned, the South West AHS (SWAHS) in Western Australia. Of these, initially 30 people expressed interest in being on the jury. These were then whittled down to 13, that process trying to ensure a good mix of age, gender and geographical location. The purpose of the jury was to allow the SWAHS to tap into the community's preferences for the set of principles they wanted to underpin SWAHS' decision making.

The jury were asked to consider themselves as being citizens of the South West – not from any specific town in the area and not bringing their own personal baggage with them. They were told that what they came up with would be used as the values foundations on which SWAHS would plan in future.

They were then presented with information by 'experts' (senior health service staff) on the health of the people in the area and relevant demographics; the services currently available; the resources available and their current deployment; safety and quality issues; and the organisational and other constraints that the health service faced. They were also given the opportunity to quiz the experts who presented the information.

Thereafter they were given time to reflect and discuss as a group what principles and values they wanted to underpin the decision making of SWAHS. Finally they came up with a list of the following set of principles.

The Principles

Fairness

The principle on which the citizens placed most weight was fairness (equity). They defined this as equal access for equal need, where equal access involved equal opportunity to use health services. The barriers to using health services were many, including financial cost, distance, racism, etc. Equal access was where people perceived the barriers they faced to be equally high; need was taken to be capacity to benefit (i.e. how much good can be done?) and disadvantaged people were to be weighted more highly (e.g. higher weighted health gains for Aboriginal people).

In general they had a particular concern for the most disadvantaged, especially the health of Aboriginal people.

At the same time the jury acknowledged the “trade-off” or competition between equity and efficiency.

Efficiency

Efficiency was seen by the jury in two ways: first in terms of doing things as well but more cheaply or doing more with the same resources; and second it is about doing as much good as possible (benefit maximisation) with the resources available.

The citizens were of a view that the second type of efficiency needed more emphasis i.e. there should be more consideration given to priority setting across different programs. For example should the health service spend more on maternity care even if that meant less on care of the elderly?

With one notable exception they were not inclined to argue for higher priorities/ increased spending for certain specific areas. They did want to ensure that such priority setting was done explicitly. The exception was services for the mentally ill.

Where they wanted to make savings to pay for the extra services they sought was through hospital rationalisation. They believed that the existing deployment of resources to and in hospitals and Emergency Departments was inefficient and asked that SWAHS examine ways to rationalise these. They suggested for example that some of the hospital buildings might be converted into aged care facilities or to provide services for the mentally ill.

Trust with respect to safety

A third set of principles related to quality, safety and risk management. In this context their strategy was one of trust. They trusted SWAHS to ‘take care of’ these issues on behalf of the community.

Prevention

The next principle was prevention. They wanted a higher priority for prevention but were concerned with ‘value added’. By this they meant that, where other organisations (e.g. the Cancer Council, Heart Foundation) were already involved in prevention, SWAHS should avoid duplication and concentrate on prevention that would not otherwise be pursued.

In discussing health promotion within the context of prevention they saw the objective as being about promoting informed choices about health issues.

Self-sufficiency

The area was such that some patients went to Perth, the capital city of WA and 2 to 3 hours drive away. On the principle of whether SWAHS should aim for greater self–sufficiency in treating patients, the jury had no strong views but felt that total self–sufficiency did not make sense. The extent of self–sufficiency must and should vary by condition.

Holistic care

The jury expressed concerns about ‘body parts’ medicine and saw an increasing role for holistic health.

Transparency and accountability

The citizens supported transparency in decision making in SWAHS as exhibited in the holding of the citizens’ jury.

Community values

Finally they endorsed the principle of the community establishing the principles and values on which SWAHS should base its decision making.

Chapter 7

Eliciting Citizens' Claims

A citizens' jury was held for the Perth Primary Care Network (PPCN) which is a Division of General Practice i.e. a geographically based primary care network which is primarily GP-focussed and which can influence GPs in how they practice. The jury consisted of 17 members, 14 drawn randomly from the relevant electoral registers; two selected Aboriginal people; and one selected youth. The jury were addressed by experts and had the opportunity to question them on any issue they wished.

This jury was asked to consider the idea of 'claims' on resources. It was put to the jury that, in thinking about factors which they might want to take into account in deciding how to allocate any additional monies that might be available to the Network, the idea of such factors being seen as the bases of 'claims' on resources might be useful. This is based on the idea of 'communitarian claims' These reflect the fact that it is the community who have the task of deciding what constitute claims, the duty to allocate claims and to decide on the relative strengths of different claims. There is value in being part of the process of arbitrating over claims. An atomistic, individualistic society will be slow to recognise that the community does have a duty with respect to meeting such claims. The more embedded individuals are in a community and the greater the recognition of such embeddedness, the stronger will be communitarian claims in that community.

The strength of a claim is not a function of an individual's ability to manage to feel harmed. Harms and the strengths of these harms are for the society to judge. Strictly, with respect to claims, the bad feelings arising for the person harmed are only relevant in so far as the society deems them to be relevant. They are a matter for "community conscience" (Mooney and Jan, 1997 p 85).

There are parallels between claims and rights. Claims can be seen as a sub-set of rights. The word "claim" is perhaps an unfortunate one in this context as in everyday usage it tends to require an active role for the person who is to benefit from the claim. "I claim" and "you claim" is standard usage where this is shorthand for "I claim on my behalf" and "you claim on your behalf". Here we *the community* determine how resources are allocated on the basis of how we *the community* determine first what constitute claims – what are deemed relevant criteria for allocating health care resources – and how we *the community* see various different groups' or individuals' strengths of claims for the resources involved. It is *our* preferences, the community's preferences, for *their* claims, the various groups' claims, that determine how the resources are allocated. It is *we the community* who also decide what is relevant in identifying and weighting claims in terms of the characteristics of the different potential recipient groups and the community as a whole (Mooney and Russell 2005).

The question to the members of the jury was then: what characteristic of a group of people might justify providing more than average resources to that group? Thus someone having blue eyes was unlikely to affect the citizens' judgement as to that person's claims on the Network's resources – but their poor health might.

A full listing of the initial bases of claims (in no particular order) that the jury came up with is as follows (see Appendix B):

- Poor health

- People who have had a raw deal
- Being poor
- Rural areas
- Elderly
- Children
- Aboriginality
- Overweight/obese
- Vulnerable/marginalised groups
- Poor access
- Feed back to the community
- Unemployed
- Mentally ill
- Chronic disease
- Prevention/health promotion

There are thus many bases for claims. The key ones were:

- Poor health

- Marginalised/ vulnerable populations, especially Aboriginal people and mentally ill people

- Poor access for a range of reasons, but especially poverty and geographical i.e. rural

The source of high or strong claims on resources can be summarised largely as disadvantage, with poverty, Aboriginality and mental illness being the factors where the PPCN might best devote its energies and resources.

With respect to the relative strengths of claims, poverty emerged as the strongest claim, ahead of both poor health and Aboriginality.

The aggregation of claims was not possible but the strength of claims of poor, Aboriginal people, in poor health, would clearly be high.

Strengths of claims were also elicited (see Appendix B). For poor people (average household income of $30,000 pa) compared to rich (average $100,000 pa) the weight was over 4. For poor health (life expectancy of 60) versus better health (life expectancy of 80) the ratio was 2:1. For Aboriginal versus non Aboriginal the ratio was just under 2. Additional 'strengths of claims' established were 2:1 children to adults; 1.5: 1 elderly to adults; and 1:1 men to women.

For this jury the set of principles included:

Accessibility

This was an important principle on two fronts – availability of GPs by time of day and day of week.

Equity

This was also a major principle and was seen as best described as equal access regardless of ability to pay, defined broadly.

Universality

While universality (of access) might have been included under equity, the jury saw it as sufficiently important to list as a separate principle.

Quality of service

The principle of high quality was readily agreed. Components included more holistic care but linked to the idea of a duty of care on the part of the doctor to the patient as a whole; GPs running on time; better referral systems, especially for mental illness; and improved doctor patient relationship, with greater transparency on a number of fronts, particularly: 1. Influence of pharmaceutical companies on GPs practice; and 2. greater shared decision making in general but also for example on choice of specialist that patient referred to. The jury also established a principle of greater sensitivity and responsiveness to patients' wishes by GPs.

Emphasis on lifestyle

The principle of emphasis on lifestyle was very real but was tempered by a recognition that the Network's budget was small and GPs in general could not be expected to do everything. Therefore these issues might be better addressed elsewhere in the health system. This was a conclusion reached with some reluctance and was a change of heart along the way.

Value for money/efficiency

The principle of value for money was endorsed for the PPCN.

Transparency of and accountability in decision making

These two but related principles focussed on transparency and accountability with respect to the patient doctor encounter. They were discussed against a background of a concern regarding the extent to which the patient could always trust the doctor to do what was best in the interests of the patient, these interests being defined, or as a minimum agreed upon, by the patient. Examples of lack of trust were raised in the context of the pressures doctors face from pharmaceutical companies and the lack of transparency in choosing to refer a patient to a particular specialist without adequate explanation as to whether and why that specialist is the best for that patient.

Greater sensitivity on the part of GPs

Again this related to the behaviour of doctors towards their patients and the need for the doctors to be more ready to recognise the inequality in the relationship between doctor and patient. In doing so the doctor needed to acknowledge better the sensitive nature of the encounter and involve the patient more in the decision making process through providing adequate information and respecting patients’ desires for autonomy. The jury wanted to see the PPCN take positive steps to make doctors more aware of the need for such sensitivity and provide guidance or training as to how the GPs might do better on this front.

Chapter 8

An Aboriginal Community Controlled Organisation's Members' Jury

Introduction

This was an unusual jury. It was the first time as far as is known that something of this ilk has been used in an Aboriginal Medical Service. The 'citizens' in this case were 15 members of the South West Aboriginal Medical Service, selected to represent a cross section of the membership. The jury came together in Busselton over dinner on Wednesday May 14 and then all day on Thursday May 15, 2008.

I facilitated the jury both because of my experience in running citizens' juries in health but also because I research on the economics of Aboriginal health. It was emphasised from the word go that the jury were there not as individuals *per se* and not as patients but as representatives of the SWAMS membership as a whole. They were asked by me to bear that role in mind during the whole occasion. I also emphasised that, in considering issues surrounding SWAMS, their task was not to indulge in wish listing all the services they wanted SWAMS to provide but to accept that resources were limited and any additional activities would need to be paid for by cutting back elsewhere.

The jury was charged with looking at two key issues. First what values or principles did they want to underpin the SWAMS activities? Second what priorities did they want to see SWAMS pursue?

These issues were tackled against a background of the jury being addressed by three experts from SWAMS. The first provided an overview of the services provided by SWAMS; the second spoke about the SWAMS budget and finance; and the last expert gave an account of the SWAMS region and clinic. Each expert was quizzed at length by the jury members.

The experts took their leave and the jury was left with the facilitator to discuss and agree upon principles and priorities.

Principles (in no special order)

Members' principles

The values of the members (as in this members' jury) should form the basis of the principles on which SWAMS operates. It was however recognised that it is the task of the officers and not the members to operationalise these principles.

Access

This principle has a number of dimensions which revolve around barriers to use of SWAMS services. These barriers include money fees; geographical location and hence distance; information (about the availability of services); and culture (especially regarding the barriers to access if services are not culturally secure). Problems of access for certain specific groups – men, youth and elderly - were specifically identified.

Equity

Services must be provided on an equitable basis. This was defined as “equally accessible to all with similar needs but with priority to be given to those with greater needs”.

Transparency

Transparency was identified as an important principle of governance in three contexts: SWAMS decision making generally; more specifically SWAMS decision making in employment policies; and in the availability of SWAMS existing services i.e. members having adequate information about what, when and where SWAMS services are available.

Relations with other services

This principle incorporates the notion that, accepting that SWAMS’ resources are limited, SWAMS should both facilitate access to other health and non health services and more generally liaise with other relevant organisations.

Advocacy and empowerment

As an Aboriginal organisation SWAMS is to act as an advocate on behalf of the Aboriginal community in general and not just in the context of health.

Funding

An important principle is recognising and acting upon the fact that for the tasks they face SWAMS is seriously under funded. It is thus a principle that SWAMS devote some of its resources to trying to increase its funding.

Prevention

The prevention of disease is an important principle.

Drug and alcohol

SWAMS can play an important role in facilitating liaison, cohesion and cooperation across the various agencies in the South West who are attempting to assist with drug and alcohol problems.

Confidentiality

All patient records must be treated as confidential.

Aboriginal Control

SWAMS is an Aboriginal organisation and must give priority to the needs of Aboriginal people, while at the same time accepting that (a) legally, wadjellas* cannot be and, morally, should not be denied treatment; and (b) treating wadjellas does bring in money to SWAMS which can then be used for services for Aboriginal people.

* non Aboriginal people

Priorities

The Members' Jury came up with eleven priorities in three 'tranches'. Within each tranche there is no particular order.

Three top priorities

- SWAMS must make members more aware of the services available, those provided not only by SWAMS but also by other agencies which SWAMS' members can also access.

- Recognising the serious under funding that currently exists at SWAMS as compared with the problems and needs their clients face, SWAMS should give greater priority to fundraising.

- Prioritising patients by need/urgent/emergency is important and the current system, which gives the impression of being confused and confusing, needs to be improved, perhaps through some form of triage. The Membership then need to be informed as to what the system is so that they can then use it in an appropriate manner.

Next priorities

- Accepting that SWAMS resources are limited and that the organisation is but one of many seeking to assist those with drug and alcohol problems, SWAMS should facilitate cooperation and coordination across these different agencies, starting with organising a workshop of all relevant parties.

- Given the lack of knowledge in the general community of the nature and extent of Aboriginal health problems, SWAMS should move to improve awareness, e.g. through the media, of the extent and nature of the problems of Aboriginal health.

Other priorities

- Many elderly members are looked on by the community to assist in caring for others. SWAMS could do more to support these members.

- Post operative care

- A bus for the disabled

- Population groups identified as not getting adequate support from SWAMS at present include men, youth and the elderly.

- Promotion and protection of culture, especially in the context of healing.

- Reducing “scariness” in those who are about to undergo some procedure e.g. a surgical operation or dialysis.

Chapter 9

Conclusion

How can the senior managers of health services learn what people want from their health care? How do political parties work out what citizens want from their health services? The answer, as I have tried to show in this book, lies in citizens' juries. These involve bringing together a random sample of the relevant population; asking them to put their citizens' hats on; giving them good information on the issues for debate; encouraging them to question experts to clarify that information or seek more information; and then giving them time to reflect on some appropriate issues and make recommendations.

These ideas formed the basis of the seven juries with which I have been involved in a facilitating role. It is from the experiences of working with these 'ordinary' citizens that I have prepared this book. It is written in the hope that others may seek to set up such juries and help to 'democratise' the health services. After all, they *our* health services, the community's health services.

The big advantage of citizens' juries over most other methods of deliberative democracy is that they embrace all of the key features of random selection of participants, ensuring they are informed and they are asked to act as citizens. The Canadians and the British have both engaged in such participatory democracy in health care.

The process is not difficult and, in my experience, people love to be involved in this way.

Notably these are not ‘decision-making’ bodies. Their task is purely to recommend the principles and broad priorities that the citizens believe should underpin their health services. It remains for ministers (and others) to make decisions.

For example, in a jury in WA in October 2005, the citizens identified as priorities the principles of greater transparency in decision making, greater equity, more prevention and increased resources for mental health. To achieve this, they were willing to give up some small inefficient hospitals and Emergency Departments. The decision making that follows juries' recommendations however remains where it is now; with politicians and policy makers.

It is of note that in each of the citizens' juries I have facilitated, greater equity has been identified as a priority. The citizens consistently want a better deal for the disadvantaged, especially Aboriginal people. They also have some concerns for other disadvantaged groups and want a shift to more prevention and away from cure.

Citizens appear also to want to bear what might best be described as the moral responsibility for setting principles. For example I have witnessed jury participants puffing out their moral citizens' chests when reporting on their recommendations. They respond positively to the idea of being asked to act responsibly on behalf of their community.

Equity as a health care principle is especially interesting. There is a possible vacuum in equity policy in Australia and in other countries. Who currently in health care nationally or at a state level or in a hospital or in a general practice is responsible — morally responsible — for equity policy; for its formulation and for its deemed importance (relative for example to efficiency, with which it may sometimes conflict)? Oddly, at none of these levels is the answer clear. One answer — the citizens' answer — is that it should be citizens!

The other key principles that juries might get into — what the objectives of the health care system might be (is it just improving health?), transparency in decision making, etc. — can be looked at in similar terms. In terms of moral responsibility in the community, these issues may not carry the same weight as equity but some such responsibility is still likely to be present.

There is no threat here to our parliamentary democracy from these citizens' juries. Having ‘citizen ownership' has its advantages as the community is better informed and more aware of the problems of running a health service within a constrained budget. Citizens at the first jury with which I was involved in 2000 remarked on how, after being on the jury, they better understood the system and were more sympathetic to the problems faced by those who had to decide how to spend the health dollar.

There is so much to be said for these juries. To anyone reading this book I encourage you to try to set one up. They are potentially so important in bringing health services and the community back together again and stopping health care from becoming a technocratic or ‘medocratic’ organisation. Citizens‘ juries can help to make health services the social institutions which they need to be.

Organising them is also fun – and my impression is that being a member of a jury is also fun!

References

Blaauw D, Gilson L, Penn-Kanana L and Schneider H (2003) Organisational relationships and the 'software' of health systems reform. Johannesburg: Centre for Health Policy, University of Witwatersrand.

Davies C, Wetherell M and Barnett E (2006) Citizens at the Centre. Bristol: Policy Press.

Freedman L (n.y.) Achieving the MDGs: health systems as core social institutions. http://ipsnews.net/indepth/MDGGoal5/MDG5%20Freedman.pdf Accessed January 2010.

Gilson L (2003) Trust and the development of health care as a social institution. Social Science and Medicine 56 1453-1468.

Jan S (2003) A perspective on the analysis of credible commitment and myopia in health sector decision making. Health Policy 63 3 269-278.

Kashefi E and Mort M (2004) Grounded citizens' juries. Health Expectations 7 1-13.

Government of South Australia (2007) GP Plus Health Care Strategy http://www.publications.health.sa.gov.au/cgi/viewcontent.cgi?article=1028&context=spp Accessed January 2010.

Henry B, Houston S and Mooney G Henry B, Houston S, Mooney G (2004) Institutional racism in Australian healthcare: a plea for decency. Medical Journal of Australia 180 10 517-520.

Mooney G (2009) Challenging Health Economics. Oxford: OUP.

Mooney G and Blackwell S (2004) Whose health service is it anyway? Medical Journal of Australia 180 76-78.

Mooney G and Jan S (1997) Vertical equity: weighting outcomes? or establishing procedures? Health Policy 39 1 79–88.

Mooney G and Russell E (2003) Equity in health care: the need for a new economics paradigm? In Advances in Health Economics. Eds. A Scott, A Maynard and R Elliott. London: Allen and Unwin.

Mooney G and Wiseman V (2000) Mooney G and Wiseman V (2000) A constitution for health services. Journal of Health Services Research and Policy 4 1-2.

NHHRC (2009) A healthier future for all Australians - Final Report. http://www.nhhrc.org.au/internet/nhhrc/publishing.nsf/Content/nhhrc-report Accessed January 2010.

Romanow R J (2002) Building on Values: The Future of Healthcare in Canada http://www.hc-sc.gc.ca/english/care/romanow/hcc0086.html Accessed January 2010.

Vuori H (1984) Overview — community participation in primary healthcare: a means or end? IV. International Congress of the World Federation of Public Health Associations. Public Health Review 12 331-339.

World Health Organization (1954) Report of the Expert Committee on the Health Education of the Public. Technical Report Series 89. Geneva: WHO.

Appendix A

Some Comments In-Advance to Experts

While I recognize that as a bunch of experts you are well nigh perfect for this and will be very professional, nonetheless I want to emphasize a few things. (And if you think: “Oh dear this guy Mooney is just so patronizing” – well sorry but I’ll take that risk!)

First you must *keep to time*. That means being on or even better under15 minutes. Do not go over. It is quite likely that the citizens will respond at greater or shorter length to some presentations than others so the timetable may not be as neat and tidy as it is currently set out. So the amount of time for the citizens to quiz or comment on what you each say may vary but your presentation must be no more than 15 minutes. If you can all be there for the whole morning that would be great or at least from the beginning until you are finished your presentation. That allows you to get a ‘feel’ for how things are going (except poor Judith who is on first!).

Second there is a need to talk at *the right level*. I do not want to tell my granny (presumably these days nor my grandpa - although strictly I think this was the role of women) how to suck eggs but talking to a group like this (i.e. 'ordinary citizens') is for most of us THE hardest bunch to get messages over to - neither over their heads nor talking down. No acronyms; no jargon; no "cardiothoracics"; no prevalences; no incidences - sickness is better than morbidity; etc.

Third try to be as *factual* as you can. You are not selling anything other than information. Inevitably you will be somewhat subjective in for example what you choose to present but the style of presentation is as far as possible objective and factual. Interpretation can come in questioning and answering.

Fourth I think *power point* is good to give a second dimension to your presentation. But try to present in such a way that your presentation can be followed without the slides. Keep them few and with little information on each. No masses of numbers and graphs VERY simple and well labeled. Keep both *the font and your voice up* as some of the citizens may otherwise struggle.

Fifth attention spells may be shortish so best probably to *end* with a slide (or comment) on your *5 (at most) key points*.

Sixth the *jury may be quite challenging* of your expertise and your presentation. As may I! – and while the situation is not adversarial, if there is any difficulty here I must be perceived by them to be on their side not yours. They may think that the wool is being pulled over their eyes or some spin is being attempted or that you are deliberately biasing things. You just have to take that and come back with some defence as best you can.

Seventh best that you are *not around in the afternoon* but if possible contactable by phone if the citizens want clarification on something (but not crucial).

Eighth please feel free to *give me any advice* on the day.

Ninth *enjoy* this – ‘twill be fun!

If any of you want to run anything past me in advance, feel free Email is XXXXX or phone XXXXX.

Appendix B

Claims

In completing this you are asked to act as a representative of the community – a citizen. You should assume that your answers could influence how the Perth Primary Care Network (PPCN) might spend any additional money they might get to improve health care (but only outside hospitals, NOT in hospitals).

1. Assume they have an extra $10 million to spend. Please allocate the $10 million across those groups/policies that YOU would want them to spend extra money on. (For example you might allocate $6 million to elderly people; $3 million to people with drug problems; and $1 million to prevention and health promotion.)

	$
○ Aboriginal people	
○ Children	
○ Disabled people	
○ Elderly people	
○ People with drug problems	
○ People with mental illness	
○ Poor people	
○ Prevention and health promotion	
○ Providing better access to services	
○ Other(s) please specify ______________________	
Total	$10 million

2. In making the judgments in 1., tick below which factors you took into account

   - ○ Low income
   - ○ Lack of existing services
   - ○ Perceived poor health
   - ○ Poor quality of existing services
   - ○ 'There but for the grace of God'
   - ○ They have had a raw deal generally
   - ○ Too little spent on this/these currently
   - ○ Unfairness of existing services
   - ○ Other(s) please specify _______________________________

3. Which one factor had the greatest influence on you?____________________
4. Which one factor had the next greatest influence?______________________

Appendix B

Strengths of Claims

You have to allocate resources in the Legoland Health Authority across a number of health promotion programs. You have an ***additional*** $1 million to spend.

NOTE CAREFULLY! ***These programs are all equivalent in terms of improving health per dollar spent. Your concern is restricted to health.***

You have to decide how to allocate the extra $1 million across different groups, remembering that ***the total impact on health will be the same.*** All you affect is the distribution of health gains.

$

(i) Program A aimed at 1,000 children
Program B aimed at 1,000 working age adults
Program C, aimed at 1,000 elderly people ___________

Total **$1 million**

(ii) A, aimed at 1,000 people with average household income of $30,000 pa
B, aimed at 1,000 people with average household income of $100,000 pa ___________

Total **$1 million**

(iii) A, aimed at 1,000 people with average life expectancy of 60
B, aimed at 1,000 people with average life expectancy of 80 __________

Total **$1 million**

(iv) A, aimed at 1,000 Aboriginal people
B, aimed at 1,000 non Aboriginal people __________

Total **$1 million**

(v) A, which provides 10 units of health gain to each of 10 people
B, which provides 1 unit of health gain to each of 100 people _________

Total **$1 million**

(vi) A, aimed at 1,000 women
B, aimed at 1,000 men __________

Total **$1 million**

Appendix C

Evaluation Form for a Citizens' Jury

First many thanks for your attendance at and contributions to the Citizens' Jury.

The management of Legoland Health Service would very much like to get the impressions of the jurists to the event and to that end you are requested to complete the questions below and return this form in the stamped addressed envelope to ……. if possible by ……. Your answers will be treated in strict confidence and no individual citizen's responses will be identified to management. This will be used to plan future juries. A copy of the report will also be sent to you.

Please answer all the questions (even if just to say 'Don't Know'). It should only take you 15 or 20 minutes to complete.

For questions 1. to 3. you are asked to indicate what you think on a scale of 1 to 10 where 1 is strongly disagree and 10 is strongly agree.

1. Overall the jury was something that you felt was successful in allowing citizens' views to be fed to Legoland Health Service. Number: ___________

Comments:____
____
____
____
____

2. Overall the jury was something that you were happy to have been involved in. Number: ___________

Comments:____
____
____
____
____

3. The facilitation process and the facilitator (Gavin Mooney) were good Number:___________

Comments:____
____
____
____
____

For questions 4. to 6., circle your preferred answer.

4. Was it useful to come in on the Wednesday evening ie. the evening before? Yes No
Comments:

5. Was the jury given adequate information for its tasks? Yes No
5.a If no, what changes would you suggest for a future jury?

6. Was the time available (one day): Too long About right Too short
Comments:

7. What was the best aspect of the whole process?
Comments:

8. What was the worst aspect of the whole process?
Comments:

9. What changes would you suggest if the jury were to be held again?
Comments:

10. Other comments: