



Australian Health Care Reform Alliance

Action Plan for Health Care Reform in Australia

Paper IV: Community Consultation and Engagement

One of five papers forming a submission to the
Council of Australian Governments

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The Australian Health Care Reform Alliance is made up of 53 consumer and professional organisations. A full list of AHCRA membership is at the end of this document. For more information see our web site.

www.healthreform.org.au

Community consultation and engagement

The need for dialogue with citizens and consumers about the future of the Australian health system

Introduction

This paper argues that in order to create a sustainable Australian health system of the future, which is both more integrated and can meet the myriad of consumer and financial pressures on it, there needs to be a meaningful (and we use that term carefully) national dialogue with citizens and consumers. At what we see as a crucial turning point in health policy, such a national process could create a common set of values, principles and priorities - the first national vision and framework for health care that could inform all governments in Australia.

In making this proposal, we wish to present:

- **What we mean by citizen and consumer engagement**, the type of process we suggest for such a dialogue.
- **Why** such a deliberative and informed exercise is of value to Health Ministers, to the health system nationally and to the Australian population.
- **What kind of consultation** (because we are not talking about the usual run of the mill consultation dominated by organised interest groups) and the principles underlying such an engagement with citizens and consumers.
- **Some potential methods** that have been developed and tested to achieve this, and some evidence of their value.
- A list of the **potential problems** with this approach and **some solutions**.

Context

The Alliance and many other commentators have documented the multiple pressures placing the Australian health care system in an increasingly vice-like grip. These will not be reiterated in detail here, except to say that the key issue is to how to manage increasing demand in a sustainable way in the face of other exponentially rising cost or resource pressures. There is little doubt that the system cannot continue as it currently is, even into the medium term. Serious reform of the health system is on the agenda at both the state and national levels.

Few would be more aware of these pressures than those sitting in the ministerial hot seats who are increasingly required to make complex and difficult resource allocation decisions with long-term implications.

Often this may mean having to prioritise:

- some care approaches over others (more prevention or more treatment)
- some treatments over others (i.e. more high technology interventions over low-tech)
- some conditions over others (those easily treatable vs. expensive to treat, especially with medications)
- some populations over others (well-off vs. poor, younger people vs. older people).

Of course these decisions are already being made. Sometimes Ministers make these decisions, but in many cases clinicians and health managers are being forced into making

such decisions every day. Who should receive the next hip replacement, a very old patient or a younger one desperate to get back to work? Should the hospital buy more neo-natal cribs or invest in more education for young mothers?

Such decision-making occurs by definition in a highly piecemeal fashion, patient-by-patient, program-by-program, and service-by-service.

This is an unsatisfactory and totally unsustainable means of managing the present and facing the future. Given the significant challenges our system is facing, crucial medium and long-term decisions that apply across the **whole** system are required.

Defining citizens and consumer engagement

What do we mean by citizen and consumer engagement? The Health Canada Policy Toolkit describes citizen engagement as the *“public’s involvement in determining how a society steers itself, makes decisions on major public policy issues, and delivers programs for the benefit of the people. Citizen engagement is closely linked to the concept of social cohesion. Social cohesion refers to the building of shared values, reducing inequities, and enabling people to have a sense that they are engaged in a common enterprise and face shared challenges as members of a same community.”*¹

The future of health care, and the big-picture resource allocation and priority decisions required, are clearly such major public policy issues.

The Alliance agrees that citizens, all of whom potentially may require health care and preventive and acute health interventions, do need to be involved in such decisions. So the engagement process we are proposing would involve citizens in a structured, transparent, information-rich, deliberative and meaningful process (described in more detail below). This contrasts with the more common policy development processes, which privilege the organised stakeholders; for example peak bodies of providers, professional associations, commercial interests, lobbyists, and other interest groups.

Further, in order to get a balanced picture from the community, citizens’ perspectives need to be augmented by the extra insights of two other groups: those who use the system the most (e.g. consumers with chronic conditions) and those who often miss out on sufficient care. Participation of health consumers is clearly not new and is becoming increasingly accepted as part of the modern approach to the planning, evaluation and quality improvement of health care. Many policies exist to support it at government and agency level, and its benefits are being increasingly recognised. It needs to be extended into the bigger policy questions and resource allocation problems.

This approach has already been used successfully in various contexts in Australia. Lessons can certainly be learnt from their application in a variety of fields, including health. For example, the Royal Women’s Hospital in Melbourne had an extensive deliberative process involving hundreds of women from across the state that provided the crucial information that enabled it to make a sustainable decision about its future location and services.

Finally, and very importantly, the results of such a process -- some building blocks for the future Australian system - would provide a common tool for **all** governments, rather than the myriad of state and federal visions and frameworks we currently have. The Alliance considers that we are at a critical juncture in our national health policy debate (witness the creation of the Alliance itself and similar recognition by many governments). Nationally, such

¹ Health Canada (2000), Policy Toolkit for Public Involvement in Decision Making, prepared by the Corporate Consultation Secretariat, Health Policy and Communication Branch, Ottawa.

a consultative approach is not only highly desirable, but essential to create the building blocks for any meaningful change to occur.

The need to consult the community

There are several simple reasons for consulting the community.

First, as noted, this is a key turning point in health policy requiring some high impact decisions. Citizens / consumers have a right to have a say at such a moment: *“it is their health and their money”*.²

Second, we believe that some informed and deliberative advice from citizens and consumers, especially about the underlying principles, values and priorities for the future system, will be of **great value to you as Health Ministers** in making sense of the more technical and sometimes vested interest advice you will receive from those within the system.

Third, there are some significant broader benefits in such an approach.

Let us provide more detail.

First, big decisions demand consumers' and citizens' input. It has been commonly argued that such citizen and consumer engagement is needed when public policy is at a key turning point.³ This usually occurs when a society is reassessing its options, setting priorities, mapping the boundaries of where major change is possible. Citizen engagement helps to clarify how deeply held values are evolving with changing circumstances:

“The values we hold play a central role in defining how we view the critical issues facing the future of health care. They play a central role in deciding which problems should have the highest priority, which options are acceptable, and in shaping the solutions we choose to adopt”.⁴

Given that much of the required decision-making has a strong value base, we suggest that some strategic consultation in very specific and credible ways nationally (described below) would give you some valuable criteria -- some useful tools to apply in addressing these difficult but far-reaching questions.

Further, the timing is right for developing such nationally applicable tools. We argue strongly that the Australian health system is at a key turning point today.

There is an unusually widespread agreement by most major stakeholders and governments that some big, critical decisions are required about the shape and priorities of our future health system. At such an important moment, many more people than the 'usual list of suspects' (and that includes the Alliance members) need to be involved.

We think that means giving a voice to the largest group of stakeholders: the citizens and health consumers of Australia who are probably those that health ministers hear least from.

² MacFarlane, D., (1996), *Citizen participation in the reform of health care policy: a case example*. Healthcare Management Forum, 9(2), 31-35.

³ Maxwell, J. et al (2002), *Citizen's Dialogue on the Future of Healthcare in Canada*, Commission on the Future of Healthcare in Canada. Accessed at www.healthcarecommission.ca

⁴ Romanow, R.J. (2002), *Building on Values: The Future of Health Care in Canada- Final Report*. Canadian Government Publishing, Ottawa. Accessed www.healthcarecommission.ca

It is significant that today a broad alliance of stakeholders (providers, researchers and consumers) is saying that these voices need to be heard.

The **second** rationale is that the results from this process will not only be informative but also useful to health ministers and senior officials. Ministers do, and will, receive much input and lobbying over these critical decisions by organised health interest groups, some of whom of course are part of our own Alliance.

However, we argue that at a policy turning point like this, a mixture of representative citizen and consumer perspectives about underlying values and priorities will be highly valuable in making sense of and reality-checking the diverse range of expert (but often conflicting) advice.

As you are aware, any system designed only by experts and interest groups will be skewed. Although the technical knowledge of experts and stakeholders is an essential ingredient in public policy development, they often make incorrect assumptions about what citizens and consumers want and value. A review of public values in the health care system concludes that the public may be a 'critical ideal resource' of identification of values to guide the health care system.⁵

Further, as Garland and Stull point out:

*"providers of special expert information, however, do not constitute the appropriate source for the articulation of community values. As members of the community, these technical experts represent only a narrow segment of the population. They are not a representative group. They tend to define problems from the perspective of their specialized field. This leads to putting the perspective of the special field ahead of the values of the community. Priority should be given to articulating the social goals valued by the community. With a clearer view of these values, the experts can help leaders find the most effective or efficient way to achieve society's goals".*⁶

John Menadue, who headed inquiries in health reform in SA and NSW in 2000 and 2003, put the point this way:

*"Unless the Commonwealth and State governments involve the community in setting priorities in health spending, we will not make real progress in systemic reform.... Unless the community is locked in through appropriate structures and processes, health reform will not happen. The public must be connected".*⁷

Further, making the decisions is only half the battle. Ensuring they are implemented can be just as difficult, if not more so. We argue that policies and changes based on the transparently garnered values of the public will be much easier to put into practice.

As Maxwell has noted, *"the legitimacy and sustainability of our most important public policies depend on how well they reflect citizens' values".*⁸

Governments in many other countries (Canada, Sweden, France, NZ, UK) have acknowledged the benefit of involving citizens in collaborative efforts of health reform, including Canada's recent major review of their health care system. The input from the extensive community engagement strategy of the Romanow Commission significantly shaped the final report and recommendations made to the Canadian Government.

⁵ Abelson, J., Eyles, J. (2002), Discussion Paper No.7: Public participation and citizen governance in the Canadian health system. Accessed at http://www.healthcarecommission.ca/Suite247/Common/GetMedia_WO.asp?MediaID=975&Filename=7_Abelson_E.pdf

⁶ Garland, Stull, 2003, Public Health and Health System reform: Access, Priority Setting and Allocation of Resources. Accessed at <http://www.asph.org/UserFiles/EthicsCurriculum.pdf> on 11/11/05

⁷ Menadue J, 2003, *Health Reform; Possible Ways Forward*, MJA 179(7) 367-369.

⁸ Maxwell J et al, 2003, *Giving Citizens a Voice in Healthcare Policy in Canada*, BMJ; 326:1031-1033

Nearer to home, a Western Australian health authority very recently has used citizens' juries to ask some key questions of its population. South Australia has reviewed its health service and included consultative processes as part of this. Victoria too has rapidly growing expertise in consumer participation across its system.

Third, there is also a broader set of benefits from such an exercise:

- It will give Australian citizens and consumers a variety of opportunities to become involved, and help provide a citizens' vision for health care.
- It will enable citizens and consumers to make thoughtful and productive contributions that can act as building blocks to shape the future of public health care.
- It will increase public awareness about the difficult choices of health prioritising in a cost-constrained environment, and tap the public's ability to give meaningful information to policy-makers about their important underlying values and principles.
- It will increase social cohesion by ensuring that diverse voices can be heard.
- It will increase understanding among those involved about how deliberations with government proceed, and what is possible and not possible to achieve in a representative democracy.
- It will build some consensus and greater community trust and hence decrease the fear factor when change is implemented.

The type of national consultation proposed

We are proposing that the federal and state governments jointly run a national engagement process with citizens and consumers, aimed at eliciting some consensus on the main values, principles and priorities for the future of the Australian health system. This process would be based on a set of principles, described below, so that it was legitimate and credible, transparent, meaningful, information-rich for participants and deliberative. These principles are described more fully below.

Who to consult

The process would be strategically aimed at involving:

- Random samples of citizens drawn from the general population (enough to be significant but probably less than several thousands).
- High users of care who have considerable experience of how the system does, or does not, meet their needs (e.g. those with chronic conditions).
- Traditionally hard-to-reach groups, including those with special vulnerabilities (i.e. the homeless, people with disabilities) who have special prevention and care needs.

The involvement of a sample of citizens will give a sense of the views and priorities of ordinary Australians. However, this sample of general citizens may not appreciate the special needs of those forced to use a lot of health services because of their chronic conditions. Similarly, the needs of minorities may not be sufficiently understood by the citizens, especially as experience shows that such groups are often under-represented in mainstream exercises. Involvement therefore of these three groups will provide a more balanced set of outcomes.

Numbers consulted do not need to be large if some of the random sampling methods proposed are used and the findings from the various methods are triangulated. However, they do need to be enough to be defensible and legitimate or the exercise may be considered futile.

How to consult

We are proposing consultation based on a number of essential principles. The methods proposed are those that would meet such principles, which are as follows:

- The approach must be seen as **non-partisan and legitimate** by the key stakeholders, especially funding governments, before the process starts (otherwise it will be of limited value).
- The process should be **transparent**, accessible and accountable and run by an independent organisation.
- Participants will need to be **well informed**, for example provided with good quality information on which to offer opinions and to share their values. This stage might also include a public awareness campaign to stimulate interest in the consultation, including a website where such factual information about all sides of the issues is accessible, and information about how participants are to be selected or accessed.
- The process should be **deliberative**, that is people will get the chance to discuss the information provided, ask questions, put forward their own views and listen to those of others before being asked for their views. Typically they may be given concrete problems, with resource and other constraints to solve and make decisions on (i.e. not just produce a wish list), and then be asked to analyse the underlying principles and values used to make their final decisions.
- The process should be **meaningful**, that is linked to a genuine policy development and decision-making process.
- The process should use a **variety of methods** and triangulate findings, that is seek the common themes and positions found across all methods, so that different populations or methods do not bias results.
- The process is sufficiently **resourced and well facilitated** so that it can be organised properly and generate good quality results.
- People's contributions are respected and participation is **non-burdensome**.

We believe that genuine community consultation is democratic -- the source of good ideas that can become the basis of good public policy, empowering for those involved, and in some circumstances a fair way to ration public policy attention and resources. We consider this approach meets those criteria.

However, we recognise that community consultations, as often undertaken, can also be:

- Time consuming and expensive (particularly for those who have poor communications with established authority and systems)
- Liable to be corrupted by those who manage it – so that it becomes bad community consultation or tokenism
- Able, in some circumstances, to be dominated by the best resourced, loudest and most skilled advocates (which makes it 'not genuine').

We consider these traps can be avoided but they should be openly addressed in any exercise developed.

What questions to pose

One of the more challenging aspects of this whole process will be to gain agreement on what it is we want to know from the community. Firstly, this involves defining the issues and their scope. Secondly, it involves 'framing' the actual questions to be asked and explored that will elicit valuable responses to the overarching issue. Most of the methods we propose seek in-depth responses to very concrete problems, as these are easier for the average - person to answer. Such problems should involve prioritising benefits/outcomes so as to be realistic and provide information useful to decision-makers. However, as noted, the processes will also explore the underlying values and criteria that participants use to come to their decisions. **The latter information is likely to be the most valuable to decision-makers.**

So, for example, one might give a group of parents the issue of deciding how to allocate a budget for a paediatric service, where they need to choose between various services (e.g. education and support for young mothers vs. increased technology in childbirth). Once they have discussed it and made a decision, follow-up questions would ask them how they made the decision — what values and criteria were important to them in making choices between competing priorities. Such values and priorities may then be able to be applied to other issues. This project has actually been undertaken successfully in Adelaide.⁹

Below we list some of the broader issues that could be addressed using the methods outlined in this paper. As noted above, the specific concrete problems one would pose to participants would need to be developed as a second step:

- What are the values and principles you believe should underpin and drive funding and services of the Australian health care system?
- What is the right balance between health spending on treatment as against prevention?
- Should health care in Australia be universally and freely accessible on the basis of need, "adequately" funded by tax dollars, or should there be a two-tier health system that includes both a public system restricted to only the very poor and a separate private system for others who pay a private fee for service?
- If we do not have adequate supplies of health professionals for our current configuration of services and roles, how should we address this?

The questions could also be both positive and negative, that is it might be useful in some contexts to seek from participants what they would and would not tolerate in how the health system was organised in the future.

Methods

No one consultation mechanism is perfect and each method has its bias, and hence both the literature and experience recommends the use of a complementary combination of methods, say, three or more. Further, new mechanisms for community consultation and participation have emerged and been developed in recent years. Unlike the more traditional mechanisms they provide the opportunity for people to engage in representative, well informed, deliberative processes that lead both to recommendations on specific issues for the common good and underlying values and principles.

⁹ Alexander, K. M. and Hicks, N. (1998) *Sailing Without Radar: An Excursion in Resource Allocation*, Australian Health Review 20:2, 76-99

Such methods include citizens' juries, citizens' deliberative councils or citizens' assemblies, consensus conferences, deliberative polls and televoting. All rely on talking to a cross-section of people, the provision of good quality information to participants, and a deliberative process. For example, citizens' juries (CJs) are one of the more widely practised of the new techniques worldwide and have been used in Australia and extensively overseas. A CJ brings together a group that is representative of the profile of a local community or the population as a whole (ideally chosen at random). Participants are asked to consider an issue of local or national importance, usually involving a matter of policy or planning.

Although participants are called 'jurors,' they also serve as lawyer and judge during the process. Information is presented in a quasi-courtroom setting, and jurors are asked to reach consensus on the issue as representatives of a collective public voice, and not out of self-interest. The CJ process is designed to allow decision-makers to hear directly from citizens, to learn about their values, concerns and ideas regarding an issue of public importance. The great advantage of the CJ is that it yields citizen input from a group that is both informed and (relatively) representative of the public at large.

ChoiceWork Dialogues (used by the Romanow Commission in Canada) engage representative groups of ordinary "unorganised" people to work through a complex problem and make value-based choices. The challenge is to identify how those opinions are likely to evolve as people learn. The key insight behind this method is that the public needs the opportunity to "work through" conflicting values and difficult choices in order to reach judgments on an important issue. ChoiceWork provides an opportunity for people with differing views to find common ground and move forward together.

Televoting is a less participative process and allows citizens to cast ballots on specific issues, but differs from conventional polling in a number of significant ways. Televoting provides a randomly selected, statistically significant sample of respondents with balanced, factual background material on an issue before they are polled. The Televote allows easy access to more detailed information, and time to consider the information and issue/s before making a decision. It is a useful follow-up when more in-depth methods have identified some key values or principles and confirmation is needed from a larger group of citizens or consumers.

A list of possible methods is given in Appendix A. The exact combination of methods will depend on the scope and budget for the exercise. Clearly there is a wide range of other more widely used consultative methods available -- although many do not meet all the criteria set out above, and have well-known biases. The exact purpose of the exercise would clearly drive the choice of methods used.

The information that would need to be made available

We consider that the proposed process would need to include provision of the same good quality easy-to-read (avoiding acronyms and jargon) information to all participants. Such information would need to be agreed by all stakeholders. They should include non-political, unbiased and factual background papers on the pros and cons of each position. They should be available in paper form, on the web, and translated where necessary.

Potential issues

Cost

We acknowledge it will require a reasonable budget. However, it will be a very modest investment if it can help create nationally accepted building blocks that all governments can use to develop integrated, sustainable and acceptable reforms.

Political risk

The dialogue may reveal a consensus around values and principles that differ from party ideology or established 'flagship' policies. This is a clearly a possibility but one that all organised interests face when asking the citizens and consumers. The outcomes may not fit with some AHCRA members' policies either. However, if the results are credible, they provide good quality information to update policies.

Who should run the process?

We propose it is run by an independent organisation that is acceptable to all funders and key groups.

Reaching agreement on the information provided to participants

It will be a challenging task to develop information with the necessary content for participants that is acceptable to the main stakeholders. However, if we agree on the broad themes to be explored and then select concrete examples of real choices for participants to deliberate upon, the background information should relate to that concrete example.

How is it linked in with broader reform processes?

This must be agreed upon very early on in this exercise in order to make it meaningful. If this is not straightforward, there are examples of reform processes overseas (UK and Canada) that may provide useful models.

Risks of not doing anything

Although there are risks associated with the proposed exercise, there are clearly also risks in not attempting to engage with a broader constituency when facing key decisions about something as important to Australians as their health system. An obvious risk is that as the pressures rise, and governments are forced to make difficult decisions that have long-term effects, they will do so in a way that fragments the overall system and increases community dissatisfaction.

Next steps

We trust that our argument for engaging ordinary Australian citizens and consumers in health reform at this time has struck some resonance with you today. We want to propose a way forward.

First, we would appreciate your considered response to our proposal in the very near future.

Second, we are seeking an invitation from you to work together on this consultative agenda.

Third, we propose that some representatives of ACHRA, together with those of national and state governments, could meet in the near future to start collaboratively exploring the parameters of a plan for a meaningful engagement process that could be of crucial value to both you, the health sector, and indeed to all Australians. We have already given considerable thought to feasible options that we would be very happy to share with you.

AHCRA recommendations on community consultation and engagement:

1. Establish a national consultation process

- 1.1 Federal and state governments should jointly resource a community consultation process to enable community input into the values, principles and priorities that should underlie the health system.
- 1.2 An independent organization should be selected to run the process.

2. Involve a range of citizens

- 2.1 The process should engage a range of people: the general population; high users of care with considerable experience of the system; and traditionally hard to reach groups (i.e. the homeless, people with disabilities) who have special prevention and care needs.
- 2.2 Numbers up to several thousand would suffice with random sampling amongst target groups.

3. Use a combination of consultation methods

- 3.1 The followed methods are highly recommended:
 - Citizens' Deliberative Councils/Citizens' Assemblies
 - Citizens' Juries
 - Round Tables
 - ChoiceWork Dialogue
 - Televoting

4. Act now to collaborate on the consultative agenda

- 4.1 We propose representatives of AHCRA, together with state and federal governments meet to plan a meaningful engagement process that will be of crucial value to all Australians.

Range of Consultative Methods (Appendix A)

Those marked ** are seen as particularly useful for the process proposed.

- Level Five: Citizen Engagement
- Citizens' Deliberative Councils/Citizens' Assemblies**
- Citizens' Juries**
- Consensus conferences
- Deliberative Polls
- Search Conference
- National Discussions

- Level Four:
- Charrette
- Round Tables**
- ChoiceWork Dialogue **

- Level Three: Consultation
- Computer-assisted participation
- Interactive www/e-conferencing
- Televoting **
- Workshops

- Level Two:
- Community or public meetings
- People's panel
- Polling
- Focus Groups

- Level One: Communication
- Open House

A full description of these methods can be found in Health Canada, Policy Toolkit for Public Involvement in Decision Making, prepared by the Corporate Consultation Secretariat, Health Policy and Communication Branch, 2000

AHCRA Members

Australian College of Midwives, Australian Consumers' Association, Australian Council of Social Service, Australian Healthcare Association, Australian Health Promotion Association, Australian Nursing Federation, Australian Rural Health Education Network, Australian Salaried Medical Officers Federation, Australians for Native Title and Reconciliation, Catholic Health Australia, Centre for Clinical Governance Research (UNSW), Centre for Health Services Research: Sydney West Health and USYD, Combined Pensioners and Superannuants Association of NSW Inc, Continenence Foundation of Australia, Council of Remote Area Nurses of Australia, Country Women's Association of Australia, Doctors Reform Society, Frontier Services of the Uniting Church, Health Consumers Association,(The) Health Consumers' Council WA Inc, Health Consumers Network, Health Issues Centre, Health Professions Council of Australia (comprising Audiological Society of Australia, Australasian Podiatry Council, Australian Association of Social Workers, Australian Institute of Radiography, Australian Orthotic and Prosthetic Association, Australian Physiotherapy Association, Australian Psychological Society, Dieticians Association of Australia, OT AUSTRALIA, Society of Hospital Pharmacists of Australia and Speech Pathology Australia), Maternity Coalition Inc, Health Reform SA, National Aboriginal Community Controlled Health Organisation, National Council on Intellectual Disability, National Public Hospitals Clinicians' Taskforce, National Rural Health Alliance, NSW Council for Intellectual Disability, NSW Nurses Association, Public Health Association of Australia, Public Hospitals, Health and Medicare Alliance (Qld) , Services for Australian Rural and Remote Allied Health, Royal Australian College of General Practitioners, Royal Australasian College of Physicians, Rural Doctors Association of Australia, South Australian Salaried Medical Officers Association, Tasmanian Medicare Action Group, The Chronic Illness Alliance, Victorian Medicare Action Group.