The Health Rights of Rural & Remote Communities

Addressing the challenges

For better health - -

- Our bottom line is health outcomes for people in rural and remote areas.
- We value our consumers, and recognise their greater difficulties (inc.cost) of being engaged –
 - poor phones, no public transport, less connected to information sources - -
- Investment in country health is justified by human rights, equity, and productivity.

Core Principles

- Regardless of income, education, culture or geographical location, Australians have a right to accessible health services according to need.
- Rural and remote communities in Australia are extremely diverse.
 - A 'one size fits all' approach will be ineffective, costly and treated with skepticism by the locals whose ownership and support is essential.

Core Principles

- Rural and remote areas are taking the lead in breaking down a 'silo' approach to health –
 - including in workforce education and training (UDRHs, Rural Clinical Schools), funding (MPS, Regional Health Services, More Allied Health Services) and across jurisdictional boundaries (Broken Hill-Adelaide, the Top End).
- R&R people would be major beneficiaries of national reform including a single government and/or a regional approach.
- Safety and quality remain paramount

The Current Situation

- It's a great life but:
 - we're sicker and older than city folk
 - we have more health risk factors and disability
 - it costs more to deliver us a given level of health care
 - our professionals are stretched, getting old
 - we haven't bumped into a psychiatrist 'out bush' for years
 - Nevertheless we are still optimistic and organised!

Indigenous Health

- 2001: 410,003 people identified as of Aboriginal and Torres Strait Islander origin (2.4% of the Australian population).
 - NSW had 29% of the total, Qld 27%, WA 14% and the NT 13%. NT: more than one-in-four people are of Indigenous origin.
- 54% of the total live in non-metropolitan areas, and in remote areas 25-30% are Indigenous.
- Communities on Lands have serious infrastructure and cultural challenges
 - ¼ of all Aboriginal and Torres Strait Islander peoples live in discrete Indigenous communities.

Life Expectancy

- Life expectancy for Aboriginal and Torres Strait Islander people is the same now as it was for the total Australian population 90 years ago (for men) and 80 years ago (for women).
- Their life expectancy is 20-21 years less than for the total population. Indigenous babies die at the same rate as in some of the most impoverished countries in the world.

History of Concern

- In response to George Robinson's advocacy in the 1830s, Earl Grey of the Colonial Office in London asserted that "the very *first* use of revenue generated from the land should be for the amelioration of the Aboriginal condition".
- A similar goal to "improve highest priorities first" is endorsed by the Australian Government under Healthy Horizons.

Indigenous health workforce -

- Health care provided by Indigenous people to Indigenous people is one strategy to improve access and health status and life expectancy.
- Currently a very low proportion of the Indigenous population work in health
 - and the number is minimal if Aboriginal and Torres Strait Islander Health Workers are not counted

- eg we have 76-90 Indigenous doctors

Answers - -

- Need to develop services that are locally effective and provide access to the full potential of the Australian health service
- Support for the community-controlled health sector as a key part of the system
- Need culturally appropriate education and training for all health professionals
- Focus on chronic disease care and public health policies

It's about outcomes

- What does it all mean for consumers and patients in rural and remote areas?
 - The CWA was formed in New South Wales in 1922. Over the next 14 years, each State and the Northern Territory formed an association.
 The Federal body was formed in 1945 and its first annual conference was held here in Adelaide in 1946.

Who Are We?

- 30% of Australians in rural Australia, inc.3% in remote regions.
- Many of us have poorer health outcomes and a higher incidence of cigarette, drugs and alcohol abuse
 - a man born in far western NSW can expect to live 13 years less than one born in Mosman, Sydney. (RACP)
- Access includes timeliness: later = poorer prognosis.

Healthcare Funding

- Medicare deficit in rural and remote Australia:
 - "No Doctor: No Medicare"; "No Pharmacist: No PBS".
- Deficit estimated at \$400 million (\$4 million in one semi-rural Electorate in NSW)
- Some of it does come back in special programs: Rural GP Strategy, RHS, RFDS etc. (We are grateful but more needs to be done.)

Complexity - -

- Productivity Commission: improved remuneration and working conditions are key factors in attracting and keeping more doctors and other health professionals in rural and remote areas.
- Rural and remote health workers face enormous clinical challenges in their everyday working lives.

Education and Training

- Healthcare workers in rural & remote health are 'specialists' in their field
 - Which means they have to maintain skills across the breadth of practice.
- Need more rural and remote specific education and training across all health professions to enable them to deliver essential services for rural communities.

Education & Training Placements

- Need more education and training places for all healthcare disciplines.
- Sufficient positions must be quarantined for rural origin students
 who are more likely to return to the bush to work.

Rural Scholarships – Welcome Initiative

- Australian Government: new funding for rural allied health undergraduate scholarships for eg physiotherapy, occupational therapy and speech therapy.
 - This initiative comes on top of existing scholarships to assist students from rural backgrounds to study medicine, nursing and pharmacy - essential to maintain our rural workforce.

Community and Service Recognition

- Health professionals must be recognized for the professional, family and community roles they play
 - Yes everywhere but in rural and especially remote areas we are especially visible (= vulnerable, powerful, potentially stigmatised).

Consultation in SA

- 2005: SA Health Dept, Rural Doctors Workforce Agency and practising rural docs. to 37 locations to seek out important issues facing rural docs.
 - key strategies were identified and initiatives developed to attract new doctors and to support those working in rural South Australia.
- This consultation and its proposed strategies for retention have set a benchmark for other States
 - roll out the evidence-based solutions.

The Health Team

- In times of workforce shortage and difficulty in accessing health services it is essential that health workers embrace the team approach to healthcare.
- Integrated models of care have been found to be most effective in many areas of healthcare provision.
 - Eg maternity services -

Appropriate use of professional skills

- Many birthing centres in rural and remote Australia have been deliberately closed in the past 15 years
 - despite evidence of the devastating community effects (cf banks, schools)
- Many women then must travel great distances at great cost and at a much higher medical risk to obtain essential birthing services.

Health Teams: eg Maternity & Birthing Services

- Many rural areas have developed high standards of care by a cooperative approach involving rural obstetricians, proceduralists, midwives, specialists and multi-skilled rural nurses.
- This teamwork model of care must be encouraged to enable women and their babies to receive the optimum level of care in their local communities close to family and home support.

Local Midwife = Local Service

- Rural women unsafe (eg enforced full-term travel) and communities suffering.
- Local Midwifery clinics could provide safety and better outcomes for women who would otherwise have to leave their home area.
- 99% of Australia's midwives do not work to the capacity to which they are educated/ registered.
- Midwives are an appropriate carer for pregnant women who are healthy.

Change in a Changing Landscape

- Overseas evidence shows that in the right conditions primary midwifery units play an important role: should be further investigated in Australia.
- Innovative funding models should be developed for midwifery maternity care.
- Midwifery clinics would increase access to maternity services for some women.

Consumers and Maternity Services

- Extensive consultation (community members, service providers and Governments) must occur.
- Consumers will be central to the return of rural maternity services.
- Direct health benefits and savings for rural families.

Mental Health Services

- One: strengthen the capacity of mainstream rural and remote health to address mental illness.
- Two: build mental health teams in R&R areas through an integrated team approach: adequately trained and resourced MH workers, psychologists, rural doctors, video-conference links and specialist support.

Medical Records

- Maximize the potential health professionals have been trained for.
- Support them with integrated e-health records and access to IT connection etc.
- Already a major area of expenditure but fragmentation of R&R services leads to interruptions in the legitimate flow of clinical information.

Practice Nurses

• Practice nurses alongside rural doctors play an essential role in team healthcare and rural practice: in primary healthcare, health prevention, health screening, emergency care and chronic disease management.

• Practice nurses must be supported with adequate training, financial support and opportunities for career pathways.

Peter's Summary

- Focus on solutions to well-known challenges.
- Models of care must enable equity of access for rural and remote communities.
- · Rural and remote health workers face many challenges in their working lives
 - must be supported with specialist-generalist status, adequate remuneration and retention packages and training pathways, and adequate professional support.

Workforce

- Shortages for all health professionals
- National registration or at least mutual recognition of registration is a must the rural & remote workforce (including locums) crosses borders
- Multidisciplinary teams
 - communication systems
 - IT support and training
 - integrated records
 - intersectoral

Flexibility + assured quality & safety

- 'workforce redesign' a conversation we must have but we must protect the quality and safety of service and health outcomes
- Done well it could enhance recruitment, retention and job satisfaction
- Still paramount are best practice and the evidence base
- Flexibility the key to provide services that enable equity of access to health care for R&R communities

Case study: Allied health

- Involves State programs, Australian Government programs and private sector
- Implementation in 'silos' of funding
 - duplication of services
 - withdrawal of similar services by another provider leaving access similar or worse then prior to new program coming on board (MAHS; RHS)

Success in allied health

North West Queensland Primary Health Care Association

- Sustainable model for the delivery of allied health services (Mount Isa)
 - gap analysis and community consultation
 - management and planning
 - operation and service provision
 - recruitment and retention of allied health staff
 - evaluation and review

Healthy people and communities

- Allied health professionals valuable contribution to all aspects of human services health, welfare, disability and education
- Much more than therapy and rehabilitation
- A continuum from the cradle to the grave

Case study: Remote Area Nursing

- 50% of health workforce are nurses; ageing
 A crisis needing urgent attention
- 1034 nurses per 100,000 persons in R and 959 in VR, cf 130: and 134: docs.
- PC: 2.2% nursing shortfall by 2006
- Need to train for Australia and the region

Nursing initiatives

- Nurses and allied health need financial incentives similar to those available for medical students
- Nursing education needs a remote/rural focus and culturally sensitivity to world cultures as well as Indigenous
- Abolish single nurse posts in R and VR as a safety and retention strategy

®evolution

- New funding and service delivery models
 - Evidence based and best practice
 - Safety and quality of care
 - Most appropriate service provider
 - Maximise health outcomes
- Roll out more advanced practice nurses and nurse practitioners RANs have been doing it for 200 years already!
- Will enhance the range of services to remote and very remote people

Remote areas

Strengthen the AMSs

- Some are well funded, others not

Broaden the funding base to a region rather than an individual service

The Health Rights of Rural & Remote Communities

- adequate funding will increase accessibility and community involvement
- provide for more viable, flexible service, employment on regional basis
- Back to basics: comprehensive primary health care, health promotion, prevention, early diagnosis, build capacity to maintain good health, food security

Micro thoughts -

- Design services with individuals in mind:
 - the woman from a remote area having someone with her when she travels to town to give birth
 - the man who has to wait for a shorter time for his knee operation so he can get back to work on the farm more quickly
 - the locum RAN who can be a locum where she is needed, moving across borders, feeling safer and more supported working with another nurse, and staying longer

And so...

- The consumer and health outcomes are paramount
- Health services must be
 - evidence-based
 - best practice
 - fFlexible -
 - and must use the most appropriate skills mix

Finally....

Whether reform is ®evolutionary or evolutionary, rural and remote health requires specific recognition and resources.

The R&R health community is helping lead reform in the sector.

THE NEED FOR DIALOGUE WITH CITIZENS AND CONSUMERS ABOUT THE FUTURE OF THE AUSTRALIAN HEALTH SYSTEM

Consultation/Communication Working Group Draft 10 November 2005

This paper is a draft of the paper to be given to the Health Ministers and their senior officers on Thursday afternoon. It will be discussed on Thursday morning during our onehour session on this proposed national dialogue, and amended in light of our discussions before being printed off and handed out to Ministers. This paper has therefore only been distributed to AHCRA members to date. It was developed by the Working Group consisting of Greg Perry, Gregor MacFie, Gordon Gregory, Gordon Renouf, Viola Korczak, Kathy Kendel, Tim Woodruff and Tony McBride.

Comments in advance are welcome: please send to t.mcbride@healthissuescentre.org.au

1. 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; a 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 you as Health Ministers, to the health system nationally and hence 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.

2. Context

The Alliance and many other commentators have documented the multiple pressures placing the Australian health care system increasingly in a vice-like grip. These will not be reiterated in detail here, except to say that the key issue boils down 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 you, sitting in the ministerial hot seats and 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 lowtech)
- 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 these are made by you, but in many cases thousands of 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 decisionmaking occurs by definition in a highly piecemeal fashion, patient-by-patient, programby-program, and service-by-service. This is a 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.

3. What is 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 and consumers 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. those 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 which 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 of your governments). Nationally, such a consultative approach is not only highly desirable, but essential to create the building blocks for any meaningful change to occur.

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



Draft Paper: Need for dialogue with citizens and consumers

4. Why do we need to consult the community?

There are several simple reasons for consulting the community. **First**, as noted above, 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 tease these out in 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 you, as health ministers, hear least from. It is significant that today a broad alliance of stakeholders (providers, researchers and consumers) are 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 you as health ministers and senior officials. You 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



² MacFarlane, 1996

³ Maxwell J et al. 2002

⁴ Romanow, 2002, Commission on the Future of Health Care in Canada

HAILING Draft Paper: Need for dialogue with citizens and consumers

concludes that the public may be a 'critical ideal resource' of identification of values to guide the health care system.^{5,6} 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".⁷

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".⁸

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*".⁹

It is worth noting that 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. Nearer to home, for example, the Western Australian Government 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.

⁵ Ableson

⁶ Eyles 2002

⁷ Garland, Stull, 2003, Public Health and Health System reform: Access, Priority Setting and Allocation of Resources, accessed at <u>http://www.asph.org/UserFiles/EthicsCurriculum.pdf</u> on 11/11/05

⁸ Menadue J, 2003, *Health Reform; Possible Ways Forward*, MJA 179(7) 367-369.

⁹ Maxwell J et al, 2003, *Giving Citizens a Voice in Healthcare Policy in Canada*, BMJ; 326:1031-1033

- 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.
- There may be some economic benefits from such an approach, for example through allocative efficiency.

5. What type of national consultation are we proposing?

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?

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 defendable and legitimate or the exercise may be considered futile.

How?

We are proposing a 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.

6. What questions would we pose?

Of course one of the more challenging aspects of this whole process will be to gain agreement on what it is we want to know from citizens. Firstly, this involves defining the issues and their scope. Secondly, it involves 'framing' the actual question/s to be asked and explored that will elicit valuable responses to the overarching issue. Most of the methods we are proposing seek in-depth responses to very concrete problems, as these are easier for the average citizen to answer. Such problems should involve prioritising benefits/outcomes so as to be realistic and provide information useful to decisionmakers. However, as noted above, the processes should 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.

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 value 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.

7. 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 citizens to engage in a representative, well informed, deliberative processes that leads both to recommendations on specific issues for the common good and underlying values and principles.

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 (perhaps 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" citizens 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 such as health, 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.



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8. What information 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.

9. What are potential problems with this?

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 any 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 as proposed, there are clearly also risks in not attempting to engage with a broader constituency when facing such 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.

10. What needs to happen next?

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.

Thank you for your attention.

APPENDIX A – RANGE OF CONSULTATIVE METHODS

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