



Conversations with Australians: the first step

*"This is OUR health system, not the government's, the Minister's or the providers'.
The system must be consumer-centred with decisions made from this perspective."*

Summary Report on a pilot consultation May-June 2007

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NEED FOR A DIALOGUE

The Australian Health Care Reform Alliance (AHCRA) believes that we are at a crucial moment in the history of Australian health care. Australia has a highly complicated and fragmented health system. It has areas of excellence alongside appalling gaps, and has a very fragmented structure that is a mystery to most Australians. The 'system' (or systems as they really are) are funded by a multitude of sources and are subject to ever-increasing pressures (financial, workforce, technology) as well as rising consumer demand and expectations, and not to mention an ageing population. Doing nothing will not avert the coming crisis.

AHCRA is a coalition of over 40 organisations representing consumers and health care providers advocating for a fairer and more effective health care system. AHCRA considers that at such a critical turning point for our health system, there needs to be a meaningful national dialogue about this with citizens and consumers. Such a national process could create a common set of values, principles and priorities for the health system of the future. It could assist in creating the first national vision and framework for health care that all governments in Australia could use as the basis of a sustainable future system, based solidly on the values of its citizens.

This report summarises a process undertaken by AHCRA that aimed to start such a conversation with Australians, albeit it in a modest way, but with the hope that others, especially governments, would take up and enlarge upon this approach.

INTRODUCTION

This summary report details the process and key findings from a pilot, small-scale consultation with 180 Australians on the future of the health care system. The consultations were conducted between March and June 2006 and preliminary findings presented at the Australian Health Care Reform Summit in July 2007.

The consultations were initiated, designed and conducted by the Community Engagement Working Group (the Working Group) of AHCRA.

The consultations and reporting were managed by Health Issues Centre. Health Issues Centre is a member of AHCRA and is an independent health policy research and action centre that has been promoting consumer perspectives in the Australian health system for over 22 years.

The consultation was substantially self-funded by member organisations of AHCRA, but crucially assisted by small grants from the Toowoomba Hospital Foundation (for rural consultations) and Public Health Association of Australia (Victorian Branch).

This report was written by Tony McBride and Lauren Cordwell from Health Issues Centre on behalf of AHCRA. They wish to thank the many people involved in the design and implementation of the consultations. A fuller version of this report will be available later in July 2008 on the Centre's website www.healthissuescentre.org.au.

APPROACH

Literature Review

A brief literature review was undertaken to assist the AHCRA Community Engagement Working Group prepare questions for the consultation. The aims of the review were to identify common principles, values and criteria emerging from previous consultations with consumers and communities (i.e. areas where there was no further need to explore in depth) and to identify obvious gaps in topics (i.e. fruitful areas to explore).

Consultation strategy

Given the limited budget but the willingness of AHCRA members, it was decided to pilot one method: structured facilitated consultations. To ensure some consistency across multiple facilitators, and to increase the volume of data, the chosen method involved a series of consultation meetings where individuals discussed key questions in small groups (to stimulate thought and widen participants' appreciation of relevant factors), and then recorded their own personal responses in a workbook. This provided detailed data that was quantitative and qualitative. Three questions in the workbook required individuals to nominate key actions or criteria and then to prioritise them.

Consultations with consumers and citizens were conducted across Australia between April and June 2007. The consultations were organised by ten AHCRA members. A total of 12 consultations were run by AHCRA members in four states. 160 people participated in the consultations with participation numbers at each consultation ranging from 5 to 23 people.

There were some passionate individuals (about 20) who were unable to attend the consultations but who had expressed interest in participating in the process. They were sent a copy of the workbook with an invitation to complete and then return the workbook to Health Issues Centre. Table 1 provides a list of the groups that participated in the consultation.

Table 1: Consultations

- 1 Choice members (Sydney)
- 1 ACOSS network members (Sydney)
- 1 Public secondary school parents group (Melbourne Girls College)
- 1 Health Consumers Network members (Sunshine Coast)
- 1 Health Consumers Network with homeless people (Sunshine Coast)
- 1 Health Consumers Network with consumers with chronic disease (Sunshine Coast)
- 2 Health Consumers Council WA members (Perth)
- 1 Victorian Council on the Ageing members (Melbourne)
- 1 Chronic Illness Alliance members (Melbourne)
- 2 Frontier Health Services local community members (Far West and Far North Queensland)
- ~ 20 other individuals

Literature review

The brief literature review identified a small number of Australian examples where citizens and consumers had been consulted on issues relating to future health care and their role in priority setting. The studies suggest there is clear citizen support for consumer and citizen participation in health particularly as it relates to decision-making and priority setting.

The review found that citizens have identified equity and access as issues of significant importance for future health care. Furthermore, when citizens have been invited to make suggestions on future health care they have been able to identify a range of relevant strategies and key principles. AHCRA was keen to facilitate the development of consumer-developed criteria for a health system, but no previous studies were identified that included this aspect.

Consultation

As noted, a total of 180 people from around Australia participated and completed a workbook. The majority of participants (87%) were aged over 40. Six people (3%) identified themselves as Aboriginal and Torres Strait Islander and 12% identified themselves as being of a culturally and linguistically diverse background. Twenty one people (12%) indicated that they were a health professional although they answered as users of health services. Although the consultations were primarily aimed at consumers, the relatively small percentage of health professional was not seen as biasing the findings in a way that was sufficient to exclude them.

Judging a health system

Participants were asked 'If you had to judge the health system in another country, what would be the **five** main criteria or standards that you would use to assess how well it worked overall for the people of that country?' (This was phrased to try and help people answer more broadly, rather than from just their own circumstance.) These we see as useful yardsticks for judging system reform initiatives in Australia.

Accessibility, in one form or another, was the most important criteria by a long way, mentioned on average by 80% of participants. This included equity, affordability and geographic accessibility, as well as timeliness. This was described as '*access when people need it*' or not waiting so long that care is compromised. Most people saw these aspects of access as applying to all services, although some identified access to a GP as critical (as the entry point to the system no doubt). Services more often mentioned specifically were ambulance services (especially for rural Australians) and dental services. Typical criteria articulated by participants included the following:

Equity:

- Equitable, fair system for all Australians, city or country, regardless of race
- Equitable – treatment should be available to all members of society, and should not depend on ability to pay

Affordability:

- Service should be affordable' (many thought 'free')

Whilst a common sentiment was:

Patients should not have to "go private" to get services.

Geographic access was naturally a particular concern to participants from rural Australia. This included access to specialists. The need for private health services or private health insurance was mentioned by only a handful.

Access was also seen more broadly by a considerable number as being accessible in a cultural and social way. These included the need for services to recognise people's cultures, the availability of interpreters, and caring for people with respect and compassion. Several people identified a crucial indicator of a good system as being how well it cared for its most disadvantaged clients.

Continuity of care was seen as an important criterion of a good service. One person wrote '*does the consumer have a "map" of care laid out for them or does the consumer/family need to navigate the system themselves*'. Other aspects of accessibility seen as key indicators were how well integrated services were and how holistically people were treated. Consumer involvement in decision-making was also noted as important.

After accessibility in its various forms, the next most ranked criterion was how prevention-focused the system was (30%). This was summed up by two quotes: '*prevention should have a higher priority than cure*' and '*promotes health, not just treats illness*'. Strong health promotion and education and illness prevention strategies were seen as key parts of a good system.

Finally, the quality of care received was identified (26%). This included the level of skills and experience of the staff and the rigor of the initial and ongoing training they received.

Overview of how the health system has met needs

Participants were asked to identify the number of times they had a visit or an appointment with some form of health service (eg. hospital, GP, medical specialist, allied health practitioner, dentist, community health centre, drug and alcohol service) in the last year. Half (48%) indicated they used between 7 and 20 health services and 21% indicated they had accessed health services on more than 20 occasions throughout the past year. The national average is 11.7 services per Australian, per year (AIHW, 2006, p343); implying participants used slightly more services than the average.

Clearly there were mixed experiences from excellent to very poor. Nearly two-thirds (62%) indicated that the health care system had met their personal health needs and those of their family adequately (31%) and well (32%) in the last year. However, 14% felt their needs had not been well met and 7% indicated their health needs had been extremely poorly met, a total of 21% dissatisfied. Those with a chronic or complex condition or disability were more likely to have experienced poor services.

There was a tendency for people to express satisfaction with the services provided by their GP, although some concerns about the lack of time available to talk with him/her. However there was also a range of good practice examples given about the role of GPs. For some, there was a lack of attention by the system to prevention and for others a lack of integration of alternative therapies.

Treatment has been very good but prevention and rehab have been almost non existent. It's all about treating the symptoms presented as opposed to the cause.

I rely on government-funded services for dental and eye care. The waiting lists are so long that the treatment is dealing with issues that could have been prevented instead of preventing issues from arising.

I have a good GP, ([although] overworked and sometimes disorganised).

Access and equity

Over one fifth (22%) claimed that when they needed to access health services in a timely manner, they were not very available.

The three most common services consumers struggled to access were specialist services and general practitioners (especially in the country), and in particular strong concerns were raised repeatedly about the lack of access to dental services, including the lack of affordability of private dental services.

Difficulty accessing allied health services (including podiatry, occupational therapy and physiotherapy) and mental health services were also identified across the consultations. Other access issues mentioned related to physical therapy, complementary therapy, and aged care (which included HACC and dementia care) and for several rural consumers the 'hospital in the home' service.

For people in rural areas, barriers to accessing timely care included both the limited number of necessary services, as noted above, and also transport issues. Rural consumers reported often travelling hundreds of kilometers to access services.

(We need) good dental care within 120kms. At present we have to travel 500kms for urgent care. If we can wait six months, the nearest competent care is 300kms.

One sixth (14%) claimed they had received care that was culturally inappropriate. In metropolitan areas, long waiting lists for specialists and surgery were the key reasons for not accessing services. Concerns were expressed by some about the provision of information.

Chronic Care Coordination

Three quarters (77%) indicated that they had a chronic condition. Of these participants, 32% indicated their care was not very well coordinated and 27% found their care to be only adequate.

Affordability

For nearly half (45%) cost had prevented them from accessing essential health care in the past year. Essential health care was described as including dental and allied health. Further 38% claimed that they had paid for health care in the past 12 months and it had created a financial hardship/pressure for them and 31% reported the same had occurred when paying for medications.

Of services which consumers had foregone for cost reasons, dental services stood out starkly far in front of any other reasons. Over 25% of participants were not accessing dental services because they were too expensive. This finding is of course in line with a range of other indicators of grossly inadequate and highly inequitable dental services in Australia.

The other two significant sets of services where cost was a significant barrier were allied health (a diverse range but especially physiotherapy) and medical services of

one kind or another, mostly specialist and in-hospital services. Each affected about 8% to 9% of participants.

In addition, having a chronic condition, living in a rural area or having a family with multiple health needs also increased costs. For some the cost of the gap payment that is associated with private health insurance was a concern. Cost also impacted on consumers in different ways. Some had to reduce money for food and living expenses, others had reduced medication doses and some had gone without services or medication. Factors that reduced the impact of costs included access to the Pharmaceutical Benefits Scheme, particularly the safety net, and benefits received through entitlements under Veterans Affairs, disability support and family payments.

Paying for access to private oncologist has meant I have not had enough money for food and essential living expenses.

I now take one quarter to one half the dose that was recommended by the doctor to save money.

Participation in decision-making in health system

Nearly everyone (93%) wanted a very high or high level of involvement in decisions about their own health care.

People were asked to what degree the principles and priorities for the future health system should be informed by the views of citizens and consumers and 67% indicated very highly. This finding was supported by 28% who indicated it should be a high priority. Interestingly, the more people used services, the more important they valued their participation.

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Most important areas for improvement

Participants were asked 'What are the three most important actions that health services needs to take in order to provide better care for you and your family?' and then a similar question about three actions to provide better care for the broader community (or all Australians)?

The main actions specified by participants were very predominantly about increasing access to the system (on average 75% of participants mentioned this), whether geographically (especially in rural areas), via shorter waiting times or reduced cost. The next series of priorities was at a much lower level and included higher levels of training for professionals generally and incentives to work in rural Australia (34%), and a greater focus on prevention (25%).

The main differences between the actions nominated to improve care for participants and their families, and those to improve the system more broadly, were a greater priority for access, quality and a more holistic approach for self/family, but a slightly higher priority for the system in terms of prevention.

Typical comments included:

More information, easier access to relevant services. Information on how to use the health system for people with chronic conditions.

Medicines being affordable when needed. Dental should be made available on Medicare it is becoming too hard to maintain because of the cost being so extreme.

Keep cost to a minimum by utilising the taxpayer system to fund a Medicare system that supports every member of the community and prevents us (Australians) from following the American medical system.

Many services I need are not in the public system such as for my feet. They want me to pay \$900 for prosthetic shoes to help me walk.

One is concessions and provisions for isolated and remote patients; two is accommodation and three transport.

As I live in a small country town I would like more health professionals to be encouraged to work in rural areas. Providing incentives could be a way to achieve this result.

Availability of service, prompt attentive and no cancellation of appointment or treatments. More focus on care in the community and home care to prevent hospital admissions, which will mean that those who do have to go into hospital can do so without fear if cancellation.

Immediate/same day appointment at GP really important to keep an illness from getting worse.

Two-way street doctor-patient relationships: doctors listening to patients' concerns and thoughts, while being open regarding progress and honest about mistakes.

Electronic health records - client empowerment with health records 'owned by the client'.

Prevention / promotion is essential for a long term healthy Australia and less of a drain on future health care services. Educate me and my family in language we understand in a format we find useful, i.e. individualised. Re-visit the person.

Train more health professionals - supply needs to meet demand. We should not have to bring in doctors etc from overseas. Our universities need much more funding.

CONCLUSIONS AND DISCUSSION

This consultation exercise was undertaken on a very low budget and with limited human resources. It involved only 180 Australians, although they were drawn from remote, rural and metro areas, and across four states. It was not intended to be a representative exercise and it had some limitations in scope. Hence it needs to be considered with these cautions in mind. However, it still produced considerable consensus on a range of issues, and suggests some of the value that could emanate from a larger more structured exercise, aimed at influencing national health policy.

Firstly the pilot *Conversations with Australians* confirmed the findings of previous consultations regarding majority (although not unanimous) recognition of:

-  The importance of access and equity as crucial principles of Australian health care.
-  The significant access issues facing rural consumers.
-  Support for a stronger focus on prevention.

Cost of health care is clearly a crucial access issue: nearly half of those participating said cost had prevented them from accessing essential health care (including medication, dental and allied health) in the past year. Dental services stood out starkly as the service most missed out on, mainly for cost reasons but also because of lack of dental staff in some areas, especially rural areas.

The fact that these issues above repeatedly feature strongly in diverse consultation exercises across the country emphasises their importance.

Our consultation also found the following:

-  Mixed levels of satisfaction with the health system from very good to very poor. It is comforting to know that a significant number of Australians are receiving excellent care, but at the same time we are clearly failing to provide good care and experiences for too many Australians – up to a fifth among our 180 participants.
-  High support for consumer and citizen participation in health particularly as it relates to decision-making and priority setting (although for this question the audience by definition was somewhat biased).

Secondly it produced a rudimentary set of consumer-developed criteria against which the current system, proposed changes/reforms, and future systems can be judged.

The criteria that enjoyed the highest support among participants were as follows.

1. The health system/services should be:

-  Affordable - and not dependent on ability to pay
-  Accessible in geographic terms (especially for rural Australians) including access to specialists
-  Accessible in cultural and social ways (eg via language services, cultural sensitivity , accessibility to most disadvantaged) but also show respect more broadly for all users
-  Equitable – for all Australians

2. It should also ensure:

-  Continuity of care and assistance to navigate the system
-  Higher level of integration of services, and holistic approach
-  Consumer involvement in decision-making
-  A stronger focus on prevention than currently exists
-  Provision of quality care.

These offer the potential to be further developed through more comprehensive engagement, and to provide a useful consensus tool for policy developers and decision-makers to use in all health policy making and resource allocation decision making.

Fourth, a surprising aspect of the literature review was the limited number of reports that we were able to uncover about consultations with consumers and communities on bigger picture issues, such as resource allocation or underlying values and priorities in the system. Such consultations appear to be rare events and yet should be central to health system design, especially given that most policy processes are highly provider-dominated. It seems highly unlikely that such a fragmented and complex system as we have in Australia would have developed had such citizen input been more sought and more influential.

Yet it was not a difficult exercise, even with limited funding, to seek such citizen/consumer input. People were willing, enthusiastic even, to give up time to struggle with the issues and give input from both a personal but importantly also a citizen's perspective, thinking of the needs of their communities and broader society.

This limited consultation did provide some useful feedback about its limitations from participants. Crucially many said that although they were able to nominate and prioritise key criteria / actions, they would have benefitted from better quality information about how the system worked and was funded. This was not possible within the resources, but it is a valid point reinforced often in the literature, and in many of Health Issues Centre's consultations on diverse topics over the years. Further participants emphasised the need to find the right approaches to enable diverse people to have a say.

The findings in this report support the underlying assumptions of AHCRA's position that there should be a national consultation to underpin a new national health policy around which an Australian health care system could be designed. (The key elements of AHCRA's recommended approach are given in Appendix 1.) Further, the fact that the findings are consistent with other exercises shows that there are a set of underlying values and preferences within the community that need to be more strongly reflected in our health system. A national exercise to develop a more comprehensive set could also build support for the changes required to address them. As one participant in this consultation stated to us:

"Consumer mental health movement in SA has a motto 'Nothing about us without us'. Consumer participation must occur at all levels for reform to be effective"

APPENDIX 1 – AHCRA PROPOSAL ABOUT NATIONAL CONSULTATION

AHCRA recommended approach to a national consultation on the future of health care is that it should:

-  use a variety of complementary methods
-  involving representative samples of citizens broadly
-  also involve (smaller numbers of) high use health consumers
-  consult appropriately with those currently disadvantaged by, and under-using, the system.

The process should be:

-  future-focussed
-  information-rich
-  deliberative
-  transparent
-  iterative
-  well-resourced

Ideally it should be accompanied by a broader community awareness campaign to raise understanding of the key issues, and to motivate people to participate.

Hence as one example, it might consist of:

-  One or two citizens' juries with representative samples of citizens in each state or territory.
-  One or two deliberative councils with high use consumers.
-  Televoting (polling of a representative samples within each state/territory, with information sent to all participants well before phone polling).
-  Appropriate consultation with disadvantaged/under-using groups.

More information can be obtained from www.healthreform.org.au.