



**3RD HEALTH POLICY ROUNDTABLE
ENGAGING CONSUMERS IN HEALTH POLICY**

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INTRODUCTION

Australia has long been an innovator in consumer participation in health with governments over 30 years responding to the desire of community members to be involved in policy making around health. The current complexities, stresses and changing demands in health policy make it a suitable time to examine whether the existing models, structures and processes of consumer participation in health are the ones that will continue to serve us well.

The focus of this paper is consumer participation in health policy. It is written to be provocative and raise questions for discussion. Consumer participation in health is a vibrant intellectual area that draws strength and relevance from its largely voluntary participants. However, this paper argues that much more attention and resources need to go into the development of a clearer conceptual and evidence-based framework for consumer participation, if future health policies are to be responsive to and reflective of community needs, and for good policy making to ensue.

USERS OF THE HEALTH SYSTEM IN THE NEAR FUTURE

A useful starting point is contemplation of what the profile of users of the health system might look like in the short-term future. This is the population whom health policy will address, and also from where consumer advocates will come. Australians will variously be:

- Better educated and older, and more likely to have multiple health conditions. They may also be more likely to articulate their different needs, eg consumer, carer, citizen;
- More skilled at finding information, although not necessarily skilled at evaluating it;
- More experienced in the use of technology to mediate health interactions, eg mobile phone for health information or for participation in clinical trials, and email for contacting their doctor, although face-to-face interactions will still be important to building trusting relationships;
- Wanting more say over critical decisions, eg choice of timing of death;
- More aware of mistakes that happen in the health system;
- Vulnerable to influence from marketing strategies that create demand, eg direct to consumer advertising;

- Forced to articulate information needs due to pressure on consultation time with health professionals;
- Shopping around for multiple providers to meet needs, eg from different professional groups and from different countries for services;
- Aware of successful campaigns that have influenced health policy, eg breast cancer screening;
- Conscious of their budget in health choices, eg Will they go into hospital as a public or private patient? Will they have an elective procedure in Australia or overseas?
- Still not sure how the health system actually works in Australia;
- More likely to be a consumer advocate – for themselves, for their parents, or for a group of like-minded people.

In thinking about the population more broadly, pockets of disadvantage will remain, but may shift depending on socio-economic circumstances and health service characteristics. There will be some populations with high levels of health and social needs that are likely to grow, such as people with dementia, indigenous people (half the indigenous population is now less than 20 years old), and people with mental health problems.

HEALTH POLICY MAKERS IN THE NEAR FUTURE

Health policy makers and their responsibilities may also change. We propose that they could be:

- Better educated, and more likely to have multiple responsibilities;
- Using evidence more in the development of policy options: more skilled at critical appraisal;
- More experienced in the use of technology and its future role in health care. They will use it regularly to mediate interactions, eg internet for meetings, although face-to-face interactions will still be important to building trusting relationships;
- Reacting to demands from people wanting more say over critical decisions, eg euthanasia;
- Working on the development of new systems to fix mistakes;
- Mediating demands from powerful vested interests;
- Increasingly required to develop or oversight the provision of independent health information services;
- Developing policies to minimize harms or ensure quality or constrain costs for new providers entering the market;
- Still tackling problems of shortages in the health workforce; monitoring health systems, drug usages, use of diagnostic and screening tests;
- Responding to disadvantage, lobbying, and pressure from treasury!

- And thinking about a consumer-oriented system in their spare time.

WHAT DO WE THINK OF WHEN WE TALK ABOUT CONSUMER PARTICIPATION?

In common parlance, consumer participation has multiple meanings:

- A social movement;
- A strategy to re-orient the health system;
- A form of democratic participation;
- A person on a committee;
- Some form of minimal feedback from patients.

This confusion in meaning and use of language bedevils any attempts to think structurally and politically about improving the health system through participative and responsive means.

Consumer participation is important for various reasons, not least because it is considered part of the democratic landscape of the past 30 years. There is emerging evidence from rigorous effectiveness studies that it can improve health outcomes, lead to more responsive care, facilitate people's involvement in treatment decisions, and improve quality and safety.¹

However, evidence of effects is slow to emerge, and is dependent on the studies that have been done and the task of summarizing diverse results. Familiarity with the debates and policy shifts can give us other important reasons for making consumer participation a clear policy objective *and* for making it more effective. In addition to better health outcomes, consumer participation:

- reduces political risk in a democratic society, particularly when there is never enough money and always too much demand;
- holds professionals and bureaucrats accountable in circumstances where consumers have little effective choice, eg, in emergencies, when they haven't got any money, when they are indigenous, when they live in the bush;
- drives clinical accountability (think professional indemnity and complaints);
- encourages review of workforce recruitment and training (what makes a good doctor or a good nurse?);
- makes for more responsive and equitable services.

There have been some notable successes in consumer participation, eg people involved in HIV/AIDS care and the women's movement in relation to breast cancer. An exciting new development is the formulation of a Victorian consumer participation policy related to publicly funded health services, including the development of performance indicators for consumer participation in acute and sub-acute services (Department of Human Services 2005b). In many ways, though, the features of the consumer participation landscape have changed

¹ See Department of Human Services 2005a for a definition of consumer participation, and <http://www.latrobe.edu.au/cochrane/reviews.html> for a list of relevant Cochrane reviews and protocols, eg the Cochrane protocol, to be published on *The Cochrane Library* in 2006, by Nilsen et al., (2004) "Interventions for promoting consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material".

relatively little over the past two decades. So, we will now describe some common practices in the area of consumer participation in Australian health policy development.

STRUCTURE AND FUNDING OF CONSUMER GROUPS

National and state/territory governments are major funders of consumer groups, including groups with a social focus, eg ageing, and groups with a single disease or health problem focus, eg mental health. Other sources of funding include charity work and associated fundraising, eg selling products unrelated to the organizational objectives, and membership/subscription fees.

In addition, Australia has for long been unique internationally for its support for a national peak consumer group, incorporating many 'voices' and linking them to department imperatives and policy making. The Consumers' Health Forum (CHF) was established from a review of community participation in the Commonwealth Department of Health presented to the then Minister for Health, Dr Neal Blewett in December 1985 (Baldry 1992). Structurally, it has changed little since it was formally established in the 1986 Commonwealth Budget. It consists of a coalition of community and consumer groups that relies on the experiences of its membership for its understanding of the health consumer perspective.

If we assume that the myriad of small and large consumer groups operating at local and national levels could be called a sector, then it is one that could be described as follows: under-funded, duplicative, insufficient access to continuing professional training for its staff and committee members, an uneasy mix of voluntary and paid staffing arrangements, no career structure, multi-functional (and usually over-committed to different functions) eg services for members, advocacy on behalf of members, responding to policy makers, researching issues for members, lobbying, fund raising. Increasingly, consumer advocacy functions are also being established within health services, or as component parts of health foundations. One possible implication of this is that there is better access to participative structures for a broader population.

The proliferation of small groups creates many dilemmas for policy makers, as it does for consumers! For instance, there are a myriad of small overlapping groups, with tiny staffing and infrastructure. They may be responsive to their membership but can they link to government policy making demands? The similarity to solo, small business general practice comes to mind as an analogous structural policy problem.

Much of the work that is done is by necessity responsive and not proactive. There is little time for strategic planning, and few opportunities for sector-wide conferences. Much of the research that is done focuses on processes or is concerned with issue-raising and so linked to the advocacy function rather than evaluation. Some partnerships with academic institutions exist but are not a common feature.

Our experience is that a surprising number of consumer groups are wary of the evidence-based health care movement, as their commitment is to forms of research that are more interpretive of experience. Fear that choices might be reduced make some fiercely critical of effectiveness research. This leads to a lack of insight into how different forms of research can strengthen our understanding of what models improve health. On the other hand, there is little funding support for researching effective models of consumer participation (at individual level up to policy level), virtually no training for consumers to become adept at evidence-based concepts and practices, no academic fellowships, no work placement schemes allowing cross-employment for government or consumer personnel, and

no long term research program. The absence of Australian health literacy baseline data highlights this: as does the lack of public debate on national health information provision standards for health care patients and carers.

A challenge for consumer groups who rely wholly or substantially on government funding is the capacity to be critical and to be an independent voice. For example, funding conditions may restrict organizations to service delivery rather than advocacy functions. It could be argued that independence could be strengthened if they were linked into other networks, enabling the generation of irrefutable research findings.

One additional difficulty with the current arrangements is the failure to establish structures that flexibly link to the policy making structures addressing problems that run across jurisdictions. Anecdotally, we hear that consumer groups struggle to join up across these divides. Some have addressed this by having state based groups with a national body, and also by linking to the CHF, but resources to develop understanding of cross jurisdictional issues need to be found within existing resources. Similarly, the capacity of consumer groups to contribute to the formation of legislation, regulation, new administrative protocols, national policy parameters and services requires knowledge, skills, infrastructure and networks that are beyond many groups.

PARTICIPATIVE PROCESSES: CONSULTATION AND REPRESENTATION

Consultative processes

Overall, the main focus of consumer participation in Australia has emphasized democratic participative models. There is a strong oral culture underpinning the values of consumer participation, with shared support for the expression of people's voices, and the value of 'being there' when decisions are made.

The first finds expression in consultation. Public and community consultation is established practice in health policy development for Australian governments. There are statutory obligations for public consultation for organizations such as the National Health and Medical Research Council (NHMRC) and the Australian Health Ethics Committee, with consumers acknowledged as stakeholders in policy development. Over time a range of 'toolkits' have been developed for government, health services and consumer groups, with the aim of improving the consultation process. Processes around consultation usually require some form of public meeting or written submission in response to an initial draft document, although 'ministerial advisory bodies' also function as a form of consultation mechanism. Consultative processes have been integrated successfully into many administrative procedures, and levels of government. Various problems have been identified, including inadequate response time frames, poor advertising of meetings and low attendances, expectations of joint ownership and control, feelings of poor preparation or knowledge of topic, and potential for domination by some individuals or groups (Thomson CJH undated).

Other forms of consultation and information gathering, such as targeted focus groups and local surveys, are also widely used but in a less systematic fashion (eg Australian Medical Workforce Advisory Committee (AMWAC)). A major issue is the failure to learn from the collective lessons that these consultations provide, largely because access to grey literature is limited and requires extensive resources. The opportunity to catalogue relevant reports offered by the National Resource Centre for Consumer Participation in Health was never fully realized and eventually undermined through funding uncertainty.

Recent developments in the United Kingdom include significant investment in public consultation to ascertain views about the future direction and reform of the National Health Service. Participants, who were paid to attend, discussed four topics: patient choice; investment; community service provision; and public involvement in decision-making (BBC 2005). What uncharted waters could we consult on in Australia: the future of Medicare, national health literacy benchmarks, research priorities, quality of health services in the public AND private sectors?

Representative participation models

This has been a major model for consumer participation in Australia. It emphasizes the value of individual experience, although this can present both a strength and weakness of this model. At a recent 'Researching Consumer Participation' symposium we held in Victoria, with over 100 participants from all parts of the health sector, it was concerning that there seemed to be a shared consensus that consumer participation meant only this: a consumer representative.

This model has been successful in achieving participation at a high level. A number of important national health policy related organizations include consumer membership on its committees, for example the Medical Services Advisory Committee, NHMRC, AMWAC, and the Safety and Quality Council. The CHF provides consumer representatives for over 200 committees from its membership and staff. Consumers are also included on state-based policy and service committees, as well as bodies responsible for accreditation and standards.

For some processes, the inclusion of consumers is long-standing, although it is usually limited to the involvement of one person. However, this approach is not universal or guaranteed. For instance, the recent review of the Safety and Quality Council makes no specific mention of a consumer member, rather the membership "should be chosen for their collective competence in corporate governance, health system reform or change management, safety and quality systems, and strategy development". The recommendations appear to relegate consumer participation to stakeholder consultation through a twice yearly reference group (Paterson 2005).

The weakness of the model is that it relies on the personal capacity of representatives to extrapolate from the personal to collective experience. Training in the use of evidence or understanding of how such evidence can be generated is uneven and absent in many areas. Consumer representatives have few 'powers' or a budget to commission needed work to support their role. Many health issues now require a high degree of health and scientific literacy, and familiarity with economic and policy analysis. Education for clinicians and for government personnel is available in many of these areas but few programs are available for consumer representatives.

Issues around the use of terminology remain. Are people who join consumer health organizations representative? And what obligation is there for them to provide a view that is consistent with the broader community? This is an important issue as there have been inappropriate influences on some consumer organizations through funding by industry groups with a vested interest in health policy, eg pharmaceutical organizations (Moynihan 2004, Moynihan 2003).

Another issue is how people maintain links to specific health-based organizations when there is no particular health need. For example, maternity organizations have been a strong source of consumer advocates in Australia and are seen as major influence on the formation of the Consumers' Health Forum, However as

their children age there may not be an appropriate health consumer organization which they can join.

A hidden tension in consumer groups is the value placed on lay knowledge and in lay people, compared with the skills and experience of staff in these organizations. This mirrors attempts to discredit informed or “expert consumers” who are seen to have skills and expertise not representative of “grassroots” consumers. The impact of this tension in the context of good policy making is not well understood.

Increasingly, health services are required to establish consumer/community liaison and advisory committees. In Victoria, this has provided a pool of consumers with growing skills and sophistication in terms of input to health service planning and review. Yet, as their responsibilities increase, it is likely that the consumer representatives will come from those people who are retired or do not have full-time employment responsibilities to meet the health service’s demands.

OTHER POLICY MAKING CHALLENGES

The failure to see consumer participation as implying much more than consultation and representation means that we are not exploring other structures or policy approaches to producing a consumer-oriented health system.

Lack of education about the health system and health research, coupled with the need for increased skills in communication and technology, place additional challenges on health consumers and their participation in policy development. Equally, a more participative health system, at individual up to policy levels, requires appropriate knowledge, skills and relationship building tasks of policy makers.

Few people have only one disease, especially as they age. Yet many clinical practice guidelines, and policy in national priority areas, run along disease lines. Despite progress in tackling chronic illness in a multi-dimensional way, policy discussion, information provision and research still has a tendency to focus on single diseases or conditions. Similarly, the issue of effective communication with consumers has to be re-discovered within each policy area. To give you a simple practical example: how do we get a recommendation related to the Level 1 evidence of beneficial effects of decision aids (from a systematic review of many trials by O’Connor et al, (2003)) integrated into all relevant clinical practice guidelines, without writing to each clinical practice guideline developer?

In conclusion, for more effective consumer participation, here are some things that we need:

1. Evidence base of consumer participation;
We need to develop a clearer conceptual and evidence-based framework for consumer participation at all levels and within different contexts. This involves building on the research that has already been done, by gathering, summarizing and disseminating it. We need to find out what consumer participation strategies and interventions work across the board, what work in different situations and contexts, what work for different groups of people, and how different techniques and methods can work.
2. Knowledge-building and iterative research;

We need to know more about what Australians want and need from their health services and we need to monitor these needs over time through the use of population-based surveys. We need iterative research programs that build from research that identifies problems, to research that tests solutions, to applied research that evaluates practical implementation. We also need better linkage and exchange programs, involving consumers, policy makers and researchers, to identify gaps and priorities in this area.

3. Knowledge translation processes for consumers;
We need to be able to access resources, training and skilled personnel to help consumers bridge their personal experiences with the processes of evidence-based policy.
4. Policy making on national standards around information provision and communication (consumer participation in health care treatment);
We need a systematic and evidence-based approach to the development of national standards for strategies for informing the population about health issues and for communication of health information between consumers and health professionals.
5. Structures and processes that make links across policy and service areas, and across jurisdictional policy responsibilities;
How can we better integrate key cross-cutting information into the existing structures for policy making?
6. Debate on consumer participation issues that crosses the public/private split;
For many Australians the experience of health care straddles public and private services, yet policy debate on consumer participation rarely encompasses this experience.

WHERE TO NEXT?

We can conclude that current models of consumer participation in health policy in Australia have proved to be acceptable to the governments and health services that have developed ways to incorporate them. The use of different models of consumer participation appears to have provided some flexibility and helped to address issues of inclusiveness by allowing specific populations to be targeted.

However the extent to which consumer participation has achieved robustness, flexibility and inclusiveness is difficult to ascertain, and there are some evident shortcomings in terms of modern policy requirements. There has been little rigorous evaluation of the impact of consumer participation on policy outcomes or the policy development process.

The UK Modernising Government White Paper (2001) identified changes that are required if policy making was to become responsive to twenty-first century challenges. The characteristics of 'modernised' policy are relevant to the inclusion of consumers. Policy relevant to modern times must be:

- Strategic – look ahead and contribute to long term goals;
- Outcome focused – aim to deliver desired changes in the real world;
- Joined up (if necessary) – work across organizational boundaries;
- Inclusive – be fair and take account of all interests;
- Flexible and innovative – tackle causes, not symptoms and not be afraid of experimentation;

- Robust – stand the test of time and work in practice (UK Cabinet Office 1999).

From this framework came a taxonomy of features for modern policy making, all of which are highly relevant to thinking through some challenges for consumer participation in health policy making in Australia. They can be grouped into three higher level categories:

Vision

- forward looking
- outward looking
- innovative, flexible and creative

Effectiveness

- evidence-based
- inclusive
- joined up

Continuous improvement

- review
- evaluation
- learns lessons (Bullock 2001)

We put forward this taxonomy both as a framework for discussion but also because it highlights some challenges for consumer participation policy making in this country – challenges for consumer advocates, for policy makers and for researchers. If we were to match current activities against these criteria, how would consumer participation rate (assuming we had a shared definition)?

Where to now?

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www.latrobe.edu.au/cochrane for a list of Cochrane systematic reviews and protocols on communicating with and involving consumers.