Australian Institute of Health Policy Studies

National Citizen Engagement Forum – 16 Sept 2008 Summary of the day

Introduction from the Minister – Hon. Stephen Robertson, Minister for Health (Qld)

- There is a disconnect between what people think about the health system (fed by media coverage) and people's own experiences of the system (which are generally positive). This presents real challenges for running health services.
- Qld Health has been on a journey of change. This has included an acknowledgement that the community needs to be involved more closely in discussions about health provision.
- Encouraging participation in health planning from local communities is important. Current initiatives include the advisory committees (Health Community Councils) and the new Health Consumers Queensland.

Session 1: How citizens can contribute to policy

Associate Professor Lyn Carson (United States Study Centre, Uni of Sydney)
Citizens as partners, co-learners, owners of government

- Engagement involving deliberative processes sits under the framework of deliberative democracy.
- Strengths of deliberative democracy: it can counter the influence of special interest groups (who need to be given a special role in engagement processes); it can provide a different take on a problem (a creative approach that the best and brightest may not see); it is appropriate for complex issues; it allows policy-makers to develop a clearer sense of the public interest.
- Citizens lack deliberative confidence.
- Three ideals are necessary for deliberative democratic processes: unaligned citizens (usually randomly selected), deliberative spaces (respectful, discussion-based, informed, moderated, with collective outcomes), influential outcomes (with recommendations to policy makers).
- Some examples include the UK National Health Service (Our NHS, Our Future) modelled along the lines of a 21st Century Town Meeting, consensus conferences in Denmark that feed into the parliamentary system, participatory budgets in South America where citizens decide how to allocate funds.

Professor Andrew Wilson (Queensland Health)

- At the practical level, engagement processes are very personal – about individual experiences and service availability. Decisions should be made through dialogue.
- The real politic of policy making (the five real processes): 1. A call on a Friday asking for a policy paper for a Monday Cabinet meeting. 2. A policy direction announced Monday lunch time, with policy-makers left to fill in the blanks. 3. A decision announced after months or years of discussion, which may have

involved formal processes, but they are often not open and invisible to the community. 4. An open process with White Papers and Green Papers available for discussion. 5. Situations that arise around opportunities for reform.
- Participation is an ethical and democratic right. It improves policy. It improves service quality and safety. It improves health outcomes. It makes services more responsive to the needs of consumers.
- Engagement can be used to develop principles and philosophy, develop options, test options, implement policy, interpret policy, and review policy.

Dr Bronwyn Fredericks (Monash University)
- People, regardless of whether consumers or citizens, need background information to inform their engagement and to make it meaningful. Further to this, background information may be needed to discuss the topic with other relevant people before the point of engagement.
- Engagement should not just be with individuals or groups who are perceived as 'the leader' or 'the leaders'. There are examples of where this happens in a range of environments.
- Be openly transparent about the engagement process and exactly what, where, when and why the engagement is happening.
- An organisation and its staff might need to look at how they filter their interpretations of the processes connected with engagement and the information gained through engagement. For example, 'Is our process and / or interpretation based on urban understandings? Is it culturally biased in favour of the dominant culture? Does it favour one gender over another? How do we incorporate people from multiple social positions?'
- Resources may need to be made available to enhance the level of engagement particularly if a lack of resources means minimal participation in engagement.
- Recognise that positive forms of engagement can result in longer term relationships that work towards continuous improvements.

Some examples from the table discussions
- Comments about random selection:
  - Who should be at the table? Randomisation may not involve specific voices.
  - Random selection is inappropriate for Indigenous communities and some marginalised groups. Specific engagement strategies are needed.
  - Engagement that doesn't involve typical stakeholders and experts is flawed.
  - Different issues require different selection processes.
- We need awareness of the variation of methods and the different meanings that people give to terms like randomness, consumer, resources.
- What do deliberative techniques produce? Are the outcomes the same?
- People often don't know when/if consultation has happened.
- How do we ensure that community debate takes place before policy-makers are expected to act on an issue?
- Need to articulate what the purpose of engagement is before embarking on it.
- Rushed requests for policy point to the need for ongoing collaboration and genuine engagement with an eye on the long term.
- How can participants achieve satisfaction through engagement?
- There's no need to aim for perfect engagement processes.

Session 2: How citizen engagement can 'value add' to policy development

Mr Tony McBride (Health Issues Centre)

- Citizens are increasingly going to take a seat at the government's dinner table. They can be stimulating guests if they're fed well. The current approach is patchy – more Maccas than nouvelle cuisine.
- Policy and practice are linked: look at the dessert menu before ordering your main course.
- Citizens will enliven and broaden the dinner conversation. Bringing different paradigms and assumptions to the table is important. We shouldn't expect consumers to be representative of *all* consumers.
- An open kitchen: transparency and openness build trust. You can invite friends to be involved in planning the menu and cooking. Citizens can be drivers, partners, and contributors to change and policy processes.
- Vary the menu according to the occasion. Vary the menu according to the purpose and context.
- Growing value: You get the best runner beans if you provide support and feed them. They will then feed you. As a tall person, I can also say this applies to consumers on health committees, etc. They often have lonely roles and need some or all of the following to be optimally effective: orientation, support, skill enhancement, decent information, networks and good committee chairing.

Mr Mitch Messer (AIHPS & Consumers' Health Forum)

- If we don't communicate with people, we can build inappropriate services.
- How do we give the information people need to make decisions for themselves?
- We need various ways to interact with communities. We need discussions before we start on the pathway, discussions along the way, and discussions when we implement decisions.
- Consumers have had a big influence on policy when they've had the opportunity. A good example is the National Medicines Policy.
- Consumer involvement has sometimes been tokenistic or less than welcome. Until recently, health policy making was the domain of professionals, with turf to protect. People can make rational decisions if you share information.
- We keep talking about a 'health system', and we don't have one. We have a number of systems and services.

Ms Jill Lang (Qld Council of Social Service)

Efforts need to be made to understand the challenges of engaging with:

- Small and 'hard to reach' population groups. Often these present as low incidence populations in large health surveys and can be missed. Such groups could be older homeless people; newly arrived refugees; mobile young people. Issues preventing their participation need to be acknowledged and addressed.
- Service resistant groups who do not access or under use mainstream health services and who tend not to respond to health promotion strategies. It is generally agreed that involving consumers in the whole spectrum of health-

related activities can improve the appropriateness, accessibility and take up of services; it can also contribute to building social capital and breaking down social exclusion in disadvantaged communities.

There is no 'one fits all' engagement strategy; multiple strategies need to be designed to engage across a diverse population and across the spectrum of the health care system.

Citizenship must be the firm basis for consumer engagement in healthcare, based in a human rights framework. This can be encompassed in organizational quality/accreditation regimes across all levels of healthcare but the starting point must always be the right of each citizen/human person to the spectrum of healthcare services.

Table discussions and deliberations
Table groups discussed common ground/seeds for change, then passed their idea to the next table. The next table was asked to build on it, strengthen it, take it further.

Seeds for change/common ground from 3 example tables
There's a growing sense of urgency for engagement. A plethora of reforms is underway, which will dramatically change the health system.

A human rights approach demands engagement. Information and education are vital to better outcomes and empowerment. Risks: engagement can be used as a political tool, it can be used to push a political agenda, it can legitimise inaction or a particular action.

Engagement needs to be comprehensive or inclusive – including all voices and stakeholders. Engagement with marginalised groups is not negotiable. All voices must be valued and are legitimate.

Second round seed for change/common ground from example 3 tables
Initial issue: Bring together all disparate community voices to influence decision making in policy based on open, transparent information. Joint opportunities for accountability between policy makers and citizens.
Contribution: Engagement needs to occur at a range of levels. Processes are needed which reflect and support diverse engagement and specific communities/groups. Need recognition of the broader concept of health, and how citizens can contribute to prevention and wellbeing. Recognition that consumers, families, and citizens need support to participate.

Initial issue: Multiple levels of engagement are critical and need to be across whole health continuum. It needs to be embedded across all levels of an organisation.
Contribution: A broadening of the concept of multiple levels of engagement. Needs to be holistic, across all levels of health. Need a culture of openness in an organisation. Need to identify champions and enabling leaders. Empower people to undertake engagement. Hold people to account for their engagement.

Initial issue: Engagement needs to be comprehensive and include all stakeholders and voices. All voices are valued and legitimate.
Contribution: Services and governments need to be strategic, comprehensive, inclusive. Engagement needs to be empowering for all people. Engagement is smart.

Session 3: How can an organisation create 'real' inclusive, deliberative, influential engagement?

Ms Fiona Armstrong (Australian Health Care Reform Alliance)

- Health is an obvious area for citizen engagement – we need health services that are responsive to people's needs. Consumers need to be empowered to participate. Health consumers are often vulnerable.
- Engagement can address complex issues (including resource allocation and questions that are divisive like abortion and euthanasia).
- There is no time like the present to begin a significant approach to citizen engagement. We need a national engagement process to meet the health needs of the community into the future.
- Engagement can build understanding with and in the community of the challenges faced in health care. It can create a sense of ownership. Improving health literacy is very important. The evidence suggests that Australians have low levels of health literacy.
- Engagement is valuable and necessary. It is different from consultation – perhaps there's convenient confusion about the difference.
- ACHRA has sought broad national consultation to ascertain the values and priorities of the community in relation to the health system. A range of methods is needed, involving broadly representative groups. Reporting back to participants would be important.
- What should not be done: invite people at the last minute, be unclear about purpose, don't provide information, don't leave much time for discussion, spend time talking about possible conclusions ahead of what might be said, don't listen to people equally, don't give feedback, don't make findings and summaries available in a timely way.

Ms Prue Power (Australian Healthcare and Hospitals Association)

- Define goals/outcomes for citizen engagement: AHHA believes we need to be clear about our goals/outcomes for a citizen engagement strategy.
- Health policies & resource allocation: AHHA believes that greater consumer involvement will result in more effective and responsive health policies. We promote the need to involve consumers in the planning, implementation and evaluation of health policies and programs. We also support increased citizen input into the allocation of health care resources to support the implementation of health policies and programs.
- Collect views of the whole community including marginalised groups.
- The public hospital and healthcare sector faces a number of specific challenges to increase citizen engagement which will need to be overcome in order to significantly increase community input into public hospital and health care policies and programs. These challenges include:
    - Politicisation of hospital policies
    - Impact on public hospitals of other health policies and practices.

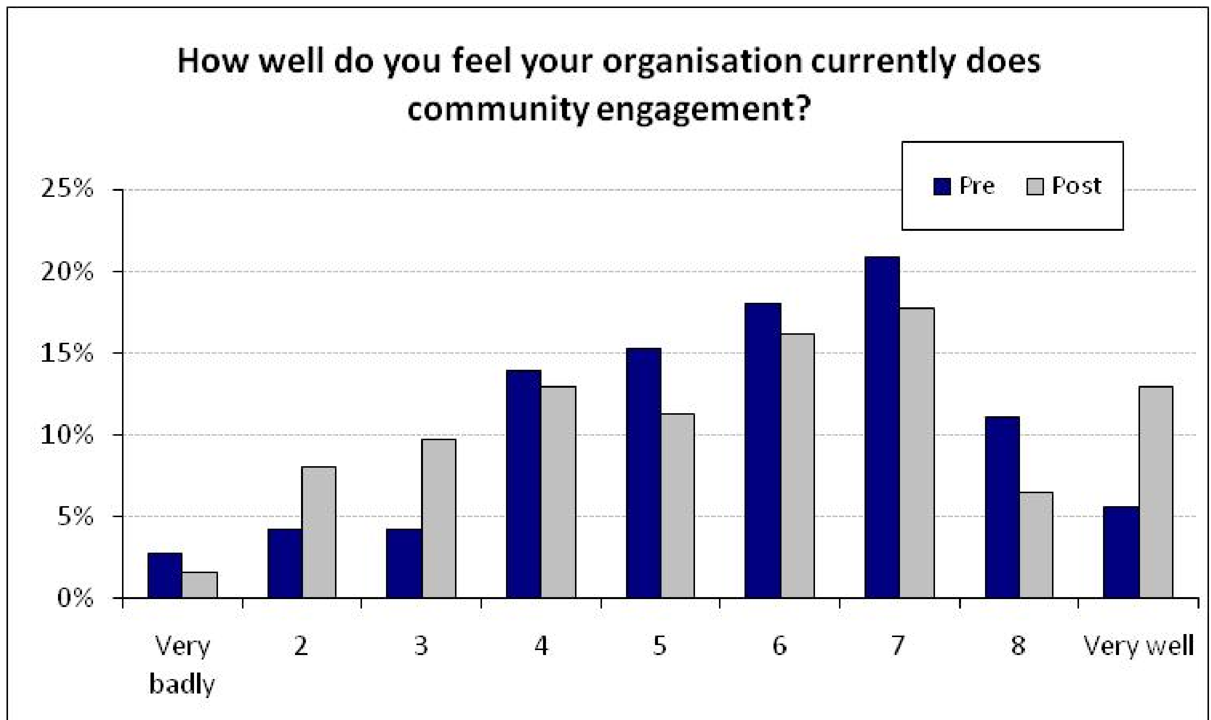
Ms Caron Molster (Department of Health, WA)
Reflections on practice of a deliberative process (community forums) about biobanks:

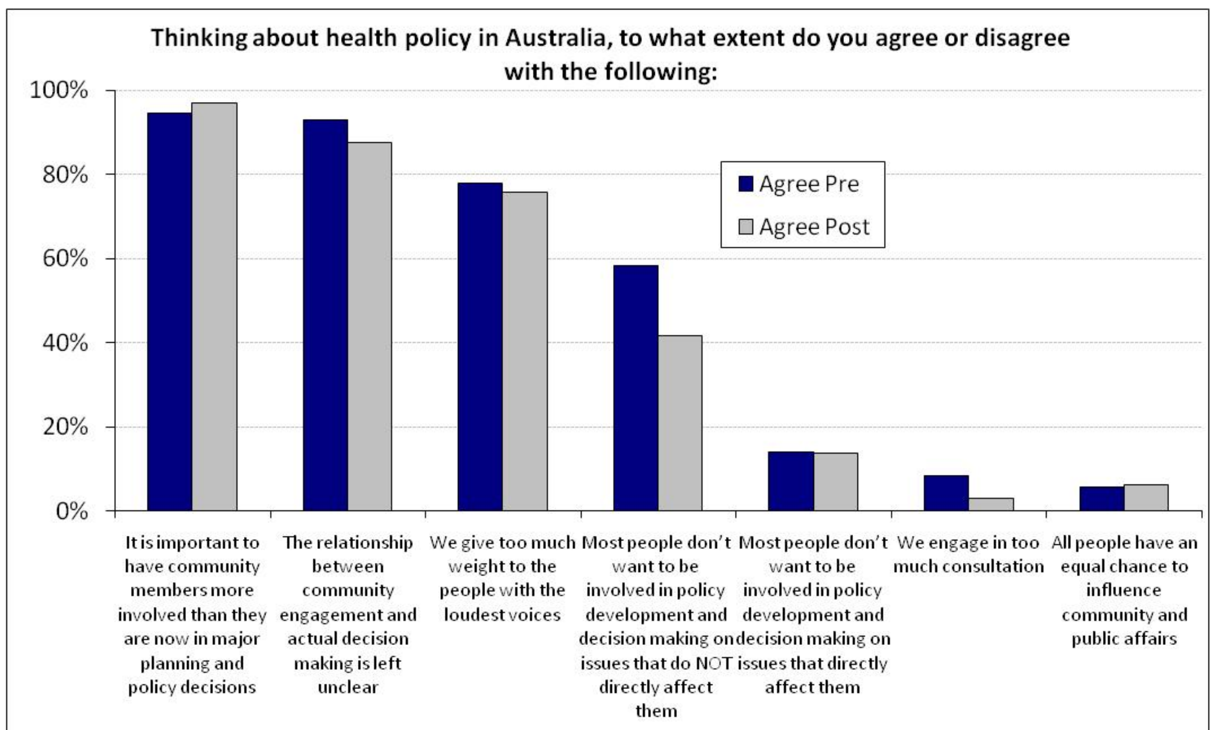
a) Four achievements that suggest the process will be influential in policy development: 1) the process has provided information unlikely to be gathered in another way; 2) improved the risk management processes; 3) increased the trust that decision-makers have in the public's ability to come to a reasoned decision; 4) satisfaction of the people involved in the process (organisers, decision-makers, participants).
b) The factors we think contributed to those achievements:
    - Demonstrate respect and trust of participants
    - Have support around the core – WA Health has an existing commitment to engagement
    - The project team became champions of the process
    - Time available to develop the project
    - Invested in partnerships with academics – provided theoretical grounding
    - Contribute to the evidence base – decision-makers get evidence that deliberative processes can contribute to policy making; evaluation is being made publicly available.

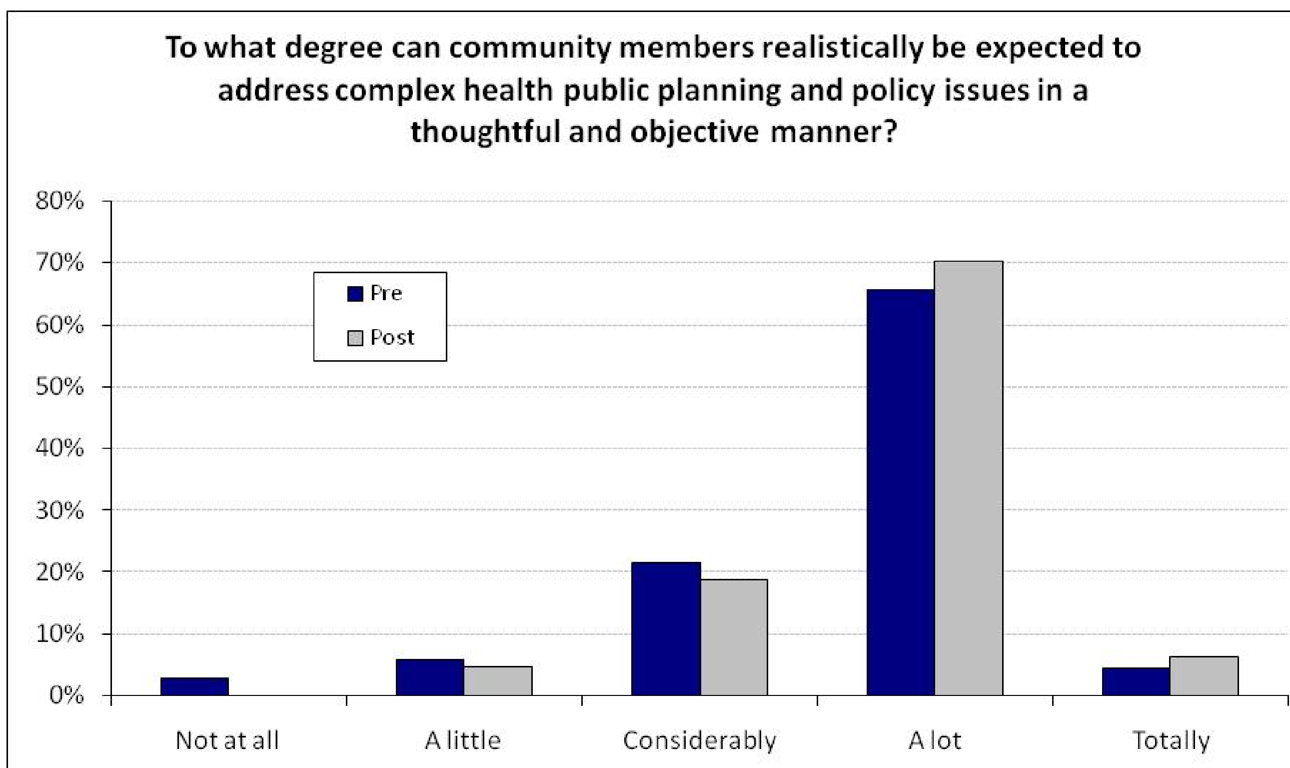
Discussion – creating a brief for the Minister to inspire him to support and encourage innovative, inclusive, deliberative, influential engagement – examples from 2 tables

Background: The current government had election promises around social inclusion. 2020 summit had consultation. Community cabinets. They're obviously thinking that consultation is a good idea.
Issues: Engagement can achieve better health outcomes. Supported by our recent survey. International activities to quote – they're off and running with a lot of engagement activities. A lot of health associations are addressing the issue and recommending strategies.
Recommendations: Multitude of reports suggest we need to get moving with this. Government has an opportunity to coordinate all the activities across the country. Let's get all the outcomes from activities and put them together. Sponsor a hotline or website to pull together the data and get the public to comment.

Australia has an opportunity to lead the way on the endorsement of a National Consumer Engagement Policy that will affect all Australians. It will undoubtedly improve health and support the ever-ailing health system. It will address the increasing costs of delivering health in a population that is becoming older, and sicker with chronic disease. We must engage with all citizens, especially those from our most disadvantaged communities. We need a national commitment to close the gap on the inequities of our Indigenous peoples and to bridge the divide of the huge differences of our ethnic communities. Taking control of our own health and becoming involved in the health core planning, implementation, and evaluation is the way of the future. Through citizen engagement, we can help to address the escalating evidence of chronic disease and the need to address prevention/wellness for our community, and to be more patient-centric.


How well do you feel your organisation currently does community engagement?
Pre
Post
25%
20%
15%
10%
5%
0%
Very badly
2
3
4
5
6
7
8
Very well


Thinking about health policy in Australia, to what extent do you agree or disagree with the following:
Agree Pre
Agree Post
100%
80%
60%
40%
20%
0%
It is important to have community members more involved than they are now in major planning and policy decisions
The relationship between community engagement and actual decision making is left unclear
We give too much weight to the people with the loudest voices
Most people don't want to be involved in policy development and decision making on issues that do NOT directly affect them
Most people don't want to be involved in policy development and decision making on issues that directly affect them
We engage in too much consultation
All people have an equal chance to influence community and public affairs



Barriers to effective community engagement in health planning and policy	Pre	Post	Difference
Lack of understanding about the value of community engagement amongst decision makers	65%	62%	-3%
Engagement being done too late in the process	57%	48%	-8%
Lack of accurate and complete information in the wider community	56%	64%	8%
Lack of evidence of community input being valued and implemented in final decisions	42%	41%	-1%
The resources in time, effort and cost involved	42%	56%	14%
Unbalanced media coverage of issues	31%	29%	-2%
Allowing enough time for sufficiently thorough deliberation	32%	41%	9%
Balancing the interests of stakeholders and the whole community	28%	23%	-5%
Choosing an inappropriate engagement technique for the issue	26%	27%	1%
Differing priorities of community members and experts / stakeholders	25%	14%	-11%
Scepticism about government agencies' motivations or agenda	18%	17%	-1%
Disinterest from people in being involved in the process	17%	20%	3%
Treated as a forum for protest rather than one for developing creative solutions	18%	20%	2%
Lack of understanding by community members about the complexities of policy decisions	15%	14%	-2%
The technical skills required (eg: design, facilitation, surveys, logistics, etc)	8%	15%	7%