
Talking about consumer engagement:

Themes emerging from interviews about
consumer engagement in Australian
health policy

Australian Institute of Health Policy Studies Research Project

Consumer engagement in Australian health policy: Investigating current
approaches and developing new models for more effective consumer
participation

Working Paper 3

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Talking about consumer engagement: Themes emerging from interviews about consumer engagement in Australian health policy

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Preface

This paper is the third in a series of working papers to be produced as part of a research project examining consumer engagement in Australian health policy. The project is being conducted by the Australian Institute of Health Policy Studies (AIHPS). The project's title is *Consumer Engagement in Australian Health Policy: Investigating Current Approaches and Developing New Models for more Effective Consumer Participation*.

The first two working papers include a literature review (*Conceptualising Consumer Engagement: A Review of the Literature*) and a framework for analysis (*A Framework of Consumer Engagement In Australian Health Policy: Developing a Framework for the AIHPS Study*). Both papers are available at the AIHPS website (www.aihps.org). This paper provides a summary of the themes emerging from 19 qualitative interviews about consumer engagement in policy development.

The project is funded through AIHPS's core funding from state health, non-government, and academic partners, and through a competitive research grant received from Merck, Sharpe and Dohme. The research is being conducted by Professor Brian Oldenburg, Dr Judy Gregory, and Rebecca Watson, and is guided by a Steering Committee.

The objectives and design of the project are summarised in Appendix 3 of this paper. Put simply, the project aims to:

- Review the current practice of consumer engagement in Australian health policy development
- Explore the reasons behind current practice
- Consider some alternative ways of working.

The project involves an exploration of consumer engagement practice in both health policy development and in other fields, including examples from both Australia and overseas.

The Australian Institute of Health Policy Studies is an independent national institute devoted to studying the ways that health policy can improve the health of all Australians. It aims to improve the national capacity for health policy-relevant research and facilitate the community's role in influencing national health priorities. For further information about AIHPS, visit www.aihps.org.

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Summary

This paper discusses the themes emerging from a series of qualitative interviews exploring the use of consumer engagement in policy development. The interviews were part of a research project conducted by the Australian Institute of Health Policy Studies (AIHPS) to examine consumer engagement in Australian health policy.

Interview participants were selected because of the insight they could provide on the topic. Nineteen individuals with experience in consumer engagement were interviewed, including the CEOs of government departments, government policy workers, CEOs and policy workers from consumers' organisations, industry representatives, and private consultants.

The picture that emerges from the interviews is one of great interest in the potential of consumer engagement, and a commitment to developing its practice. There was also great diversity in the practice of engagement: participants described differing levels of confidence and experience in conducting engagement activities, different purposes underlying their engagement work, and different techniques. Diversity was evident both across organisations and within individual organisations. Participants described consumer engagement as a developing field of work which needs an increased focus on the sharing of ideas, approaches, and successes.

Participants recognised consumer engagement as providing an opportunity for consumers to contribute to policy development. Engagement can contribute to better and more balanced decision making, and some form of engagement is needed to provide a mandate for decisions. However, an engagement process does not necessarily imply a decision-making role for consumers.

The level of engagement offered to consumers varies, with many organisations using an information-gathering or research approach. Key techniques include having a consumer representative on a committee or conducting a research process (such as focus groups). Some participants discussed experiences with more deliberative techniques, such as citizens' juries, and were keen to see these techniques used more frequently.

Practical and contextual issues influence all aspects of consumer engagement. Of particular importance to participants was the need for an engagement champion within their organisation, and the need for good training and support for consumer representatives. Evaluation was described as an important but under-developed aspect of the work.

Introduction and overview

This project is designed to examine consumer engagement in Australian health policy. The project developed from a concern that, while there is increasing discussion about the need for consumer engagement in health policy, the success of current methods and approaches is questionable. The AIHPS committee that developed the original proposal for this research expressed concern that:

- ◆ There seems to be little evidence that current attempts to encourage consumer engagement are significantly influencing the development of Australian health policy
- ◆ Experiences in consumer engagement are not shared amongst health jurisdictions
- ◆ Findings to date are not openly discussed as part of the policy development process
- ◆ Health policy continues to be developed in response to political imperatives, with little overt attention being given to either the views and perspectives of consumers or to other available research evidence.

Through this project, AIHPS aims to contribute to the development of more effective strategies for engaging consumers in health policy development. This will be achieved by:

- ◆ Identifying and assessing the current approaches and methods for engaging consumers used by Australian government, non-government, and private health industry associations
- ◆ Comparing these approaches with those used in other sectors in Australia
- ◆ Identifying, assessing, and defining the distinctive characteristics of approaches being used in similar overseas systems
- ◆ Developing and refining new models for consumer engagement in Australian health policy development.

The project design developed by the Steering Committee involves four stages:

- ◆ A literature review exploring the practice of consumer engagement and reviewing both the theoretical and professional literature (*Conceptualising Consumer Engagement: A Review of the Literature* was published on the AIHPS website in August 2006)
- ◆ Qualitative interviews with individuals working in consumer engagement (discussed in this paper)
- ◆ Case studies of consumer engagement practice (to be developed in 2007)
- ◆ Workshops and analysis.

Framework guiding the interviews

Following the publication of the project's literature review in August 2006 (*Conceptualising Consumer Engagement: A Review of the Literature*), a framework was developed to describe consumer engagement in Australian health policy (*A Framework of Consumer Engagement in Australia Health Policy: Developing a Framework for the AIHPS Study*, published in September 2006).

The framework is designed to identify issues that can be used to review consumer engagement practice, plan consumer engagement programs, and identify the trade-offs that must be made when conducting consumer engagement. The framework summarises the key themes emerging from the literature review, and provides a structure for presenting the interview data and case studies to be explored through the research phase of the AIHPS study.

The eight interacting issues identified through the framework are:

- ◆ **Purpose** – why consumer engagement is conducted, and what purpose it is designed to fulfil. Underlying reasons can include ethics and democracy, improved policy outcomes, improved relationships with consumers, and serving political purposes. The purpose can be underpinned by different theoretical approaches to consumer engagement, and may also be guided by pragmatic issues such as a statutory requirement for engagement, or the desire to encourage acceptance for decisions.
- ◆ **Type** – the extent of engagement being offered to consumers. Engagement type is typically articulated as a continuum or ladder. The five-level description of engagement developed by Health Canada (2000) was adopted for this study (the five levels are: inform/educate, gather information, discuss, engage, and partner).
- ◆ **Initiator** – who initiates the engagement. Consumer engagement can be initiated by either organisations or consumers. Tied up with this issue are questions about whether the engagement is project-based or ongoing, conducted by policy makers or consultants, and conducted by senior policy makers or junior officers.
- ◆ **Who's engaged** – the consumers involved in the engagement. One key decision is whether to engage with consumers as individuals and/or with organised health consumers' groups. Related issues include whether specific groups of consumers are targeted for engagement, and whether the consumers want to be engaged.
- ◆ **Timing** – the stage of a project or policy development at which engagement is conducted.
- ◆ **Techniques** – the tools used to engage consumers in the issue.

- ◆ **Practical issues** – issues that influence the outcomes of engagement, such as the resources available; the information made available to consumers; consumer-related issues such as knowledge, skills, and confidence; and organisation-related issues, such as commitment to and experience with engagement.
- ◆ **Contextual issues** – the context within which engagement occurs, including existing political pressures, organisational issues, and previous experiences with policy development and engagement.

In addition to these eight interacting issues, the framework recognises evaluation as a separate but important element of consumer engagement. Evaluation is described separately because it does not influence the planning and development of consumer engagement. It has an important function in reviewing planning and implementation, providing a reporting and feedback mechanism, and facilitating the development of consumer engagement practice.

Research questions guiding the interviews

The interview phase of this research was designed to meet the first two project goals:

- ◆ Identify and assess the current approaches and methods for engaging consumers used by Australian government, non-government, and private health industry associations
- ◆ Compare these approaches with those used in other sectors in Australia.

With these goals in mind, the following research questions were used to guide the interview phase of the research:

- ◆ How important is consumer engagement in the development of policy?
- ◆ What is the underlying purpose of consumer engagement?
- ◆ What techniques are used to engage consumers?
- ◆ Is consumer engagement that is conducted for policy development different from engagement conducted for other projects?
- ◆ Does consumer engagement actually influence policy development?
- ◆ Is consumer engagement work evaluated?
- ◆ What are some critical issues for the success of consumer engagement?

Design of the interviews

A series of qualitative interviews were used to explore key themes relating to the conduct of consumer engagement in Australia.

Interview participants were selected because of the insight they could provide on the topic. Potential participants were suggested by members of the project's Steering Committee and by participants themselves. Although the goal of this project is to look at consumer engagement in both health policy and other sectors, most of the individuals approached for an interview either worked in the health sector or had some links to it. Given the extent of information available on the topic, and the diversity within the health field, it seemed appropriate to concentrate the research primarily on policy making in health. While there was no attempt to select a representative sample, participants were chosen to ensure that a range of views were canvassed. The project's Steering Committee played a key role in reviewing the people approached for interviews, and ensuring that different voices would be heard through the process.

The research procedure was subject to the research ethics guidelines of Queensland University of Technology. Individuals were invited to participate in the research through an initial telephone call which was followed up by formal letter of invitation (see Appendix 1). Following confirmation of the interview time, participants were sent the Interview Information Package (see Appendix 2).

The Steering Committee agreed to conduct approximately 20 interviews for this phase of the research. Formal invitations to participate were sent to 22 individuals, with 19 interviews being conducted. This high response rate (86%), shows both participants' interest in consumer engagement, and their desire to contribute to a national discussion about how consumer engagement contributes to policy development. The 19 participants are summarised in the table below. They include the CEOs of government departments, government agencies, and non-profit organisations; policy makers; managers with an organisational responsibility for consumer engagement; researchers; and independent consultants.

Organisation	Number interviewed
Health, government	6
Health, non-government	5
Non-health, government	2
Non-health, non-government	1
Health, industry	2
Health, consulting	1
Non-health, consulting	1

Table 1: Participants involved in the interviews

The interviews were conducted via telephone, and were audio recorded and transcribed. A summary of each interview was sent to participants for member checking. All interviews were conducted between October and December 2006. Participants were assured of confidentiality, and were given an opportunity to comment on this report before its release.

The interviews were deliberately informal. They were designed to uncover the issues about consumer engagement that participants felt were important, using the language and approach adopted by participants. The interviews allowed participants to set the direction of the discussion, and encouraged participants to use examples to illustrate their points. To achieve this informality, only a broad interview guide was used for the interviews. This guide was sent to participants prior to the interview, as part of the Interview Information Package (included in Appendix 2).

At the end of each interview, participants were asked to suggest potential case studies that could be followed up for the final stage of this study.

Relevant background of participants

Throughout this report, participants are described by number only. Names are not used and specific examples are not discussed to preserve participants' anonymity. The table below describes the relevant background of participants.

Participant number	Participant's relevant background
Participant 1	Health, government, senior policy worker
Participant 2	Non-health, government, section head
Participant 3	Health, non-government, policy worker/consultant
Participant 4	Health, consulting
Participant 5	Health, non-government, policy worker
Participant 6	Health, non-government, policy worker/consultant
Participant 7	Non-health, consulting
Participant 8	Non-health, non-government, policy worker
Participant 9	Health, industry
Participant 10	Health, government, CEO
Participant 11	Health, government, deputy CEO
Participant 12	Health, consulting
Participant 13	Non-health, government, deputy CEO
Participant 14	Health, non-government, policy worker/consultant
Participant 15	Health, industry
Participant 16	Non-health, government, deputy CEO
Participant 17	Health, government, policy worker
Participant 18	Health, government, CEO
Participant 19	Health, non-government, CEO

Table 2: Background of participants involved in the study

The interview with Participant 9 was not transcribed or used to inform this report, because early in the discussion the participant said that he did not have enough background in the area of consumer engagement to contribute to this project.

Definitional issues

A number of participants raised questions about the definition of consumer engagement, the choice of the term ‘consumer engagement’ for this study, and the terms that are typically used.

As Participant 3 noted, a variety of terms are being used by policy makers and practitioners to describe similar things. The terms ‘consumer’, ‘community’, ‘participation’, ‘involvement’, and ‘engagement’ are all in common use, but without clear definitions. Participant 3 commented that, because the words are in everyday use, people have an understanding of what *they* mean by them, but people can bring very subtle differences in their meaning that can potentially influence how they are interpreted. She noted that having a variety of terms to describe engagement activity might seem friendly and non-prescriptive, but it leads to questions about whether people are really talking about the same thing.

While some participants were quite comfortable with the term ‘engagement’ being used to encompass activities that involve consumers as participants in contributing to policy development and implementation, other participants found the term difficult (see pages 2–3 of *Conceptualising Consumer Engagement* for a discussion about the use of the term ‘consumer engagement’ in this study). Participants’ definitions of the terms varied widely. For example:

- ◆ Participant 12 described ‘engagement’ as collecting information from consumers and giving them a voice in the policy/project development process. In contrast, he saw ‘involvement’ as participating in decision-making about individual health care.
- ◆ Participant 3 preferred to use the term ‘participation’ instead of ‘involvement’ or ‘engagement’.

I use ‘participation’ because when I write it in plain language I talk about ‘taking part’ ... Rather than ‘getting involved’ ... I’m not quite sure what that means.... ‘Engagement’ in policy development, that means to me that you’re actively interested, but maybe not a player. (Participant 3)

- ◆ Participant 14 was uncomfortable with the term ‘engagement’.

For me it’s an obscure term, ‘engagement’. I’m not sure what it establishes. I would be looking at ‘involvement’ of consumers, carers, and communities. I guess that’s the word I’d be looking at – how you involve those members of the community at different levels of policy decision making. ... I’m confused about what [the term engagement] is meant to include. Consumer involvement or carer involvement is about informing people about the health care system or processes they could involve themselves in. It’s about complaints. ... Engagement, I’m thinking, is about your own decision making,

what you are engaging people to do. This seems to be jargonistic and unclear, and I wonder what that would mean to consumers. (Participant 14)

Participants also raised concerns about the use of ‘consumer’ versus ‘community’. Several participants saw ‘consumers’ as stakeholders who will be actively involved in an issue. Consumers will have background knowledge about the issue and may be members of a consumers’ organisation. In contrast, ‘community’ is a broader term used to describe the wider population (this distinction was made by Participants 2, 4, 6, 13, 16, 17, 18). Participant 4 argued that ‘consumer’ engagement tended to be subjective because consumers are involved in their own care or the care of people with like problems; in contrast, he saw ‘community’ engagement as a more objective means of participation because it canvasses broader views. For Participant 13, the terms allow for a distinction between the multiple interests that a person has in their engagement with a service system. He noted that, as a consumer of health services, he is interested in his own health and well-being, while as a community member he is interested in government expenditure and policy issues in relation to health. For this participant, it makes sense to simultaneously discuss both consumer and community engagement.

Language adopted for this study

The term ‘consumer engagement’ was adopted at the beginning of this study and will be used throughout, for consistency. Other terms will only be used in direct quotes from participants.

- ◆ A ‘consumer’ is defined as someone who makes either direct or indirect use of health services – that is, a current or potential user of the health system. This definition makes no assumptions about the consumer’s knowledge of an issue or their involvement in a consumers’ organisation.
- ◆ ‘Engagement’ is defined in a broad way to cover the range of activities used by governments, organisations, and individuals to generate consumer input in or discussion about policy.

Purpose

I began each interview by asking participants to comment on the importance of consumer engagement and the purpose that it fulfils. I was interested in exploring what participants felt consumer engagement could achieve, why it is conducted, and what motivates its practice in policy development.

Consumer engagement contributes to outcomes

All participants commented on the way that consumer engagement can contribute to outcomes. For many participants, improved outcomes – in policy making, in service delivery, in project development, and in health outcomes – provide the key rationale for conducting engagement (Participants 2, 3, 6, 11, 16, 17).

To me, that's the ultimate aim: you want the level of individual care ... improved. ... The purpose of [engagement] is to actually improve health policy and to have a more responsive health policy that reflects the values of the community. (Participant 3)

It improves outcomes in terms of better [outcomes at] population levels and individual levels. (Participant 17)

Participant 2 noted that consumer engagement not only improves outcomes, it also increases community satisfaction with the policy process. She cited quantitative evidence which shows a 20 to 40 per cent decrease in community complaints regarding the engagement process since her government adopted an engagement strategy as a specific part of its agenda.

Participants suggested that consumer engagement improves decision making and helps to develop meaningful and workable policies. This happens because consumer engagement involves people on the ground who are experienced in the issue; it gets them involved in developing policies and services (Participant 7). The engagement process provides a body of knowledge that makes the decision making process more informed (Participants 2, 4, 5).

It's about evaluating and monitoring what's happening within the health care system in a more inclusive way, so obviously it would improve your capacity to make decisions that are more relevant and that are more likely to work. (Participant 14)

If consumers are not engaged, then the likelihood of getting the problem definition right or developing a solution that's going to work is diminished. (Participant 11)

I think that the other really important part is that as the policy is developed, if you've consulted and engaged – not just kind of sent papers out but engaged with consumers and heard what their issues are and understood – then you can develop your policy and implement it in a way that's much more robust and much more likely to meet the needs of the community, but also gain their acceptance. (Participant 19)

Part of balanced decision making

Consumer engagement can be seen as an element of balanced decision making. It is one part of the decision-making process – along with an analysis of the economics, the environmental issues, the health issues, other related issues, and the engagement of other stakeholders. Balanced decisions should take account of all the relevant issues and perspectives (Participant 2). In this way, consumer engagement contributes to better and more robust policies.

From my point of view you make better policy decisions as a result. Policy decisions taken in a partial vacuum when that could have been overcome in terms of the range [of voices heard] is not as good policy making as policy positions when you have all of the perspectives represented. (Participant 16)

Consumer engagement can add transparency to government processes and improve accountability (Participant 17). It also helps to ensure that decision making and rationing are explicit (Participant 4).

Consumer involvement brings transparencies to health care processes and, as a result, improves accountability. Problems that are often not dealt with in the system or are dealt with inadequately ... it's easier to have them exposed in a consumer environment and dealt with in a more honest and transparent manner. (Participant 18)

Some participants noted that engagement can provide a mandate for policy decisions (Participants 3, 18). Without a clear engagement process, policies are less likely to be successful and less likely to be acceptable – either to the community or to government. In addition, policies developed without adequate consumer engagement are unlikely to be sustainable (Participant 3).

Most major initiatives now would ... fail without consumer involvement. They just wouldn't have the mandate. ... If you want to really seriously conduct serious change in our system, you need to involve the consumers. Otherwise it will fail from a lack of mandate. ... Ministers in particular, and the media, will be very sceptical about any proposal that doesn't have some evidence of consumer involvement in its

development. It may not have to necessarily be endorsed by consumers, but ... it's very hard to [make major change] without some consumer involvement now. (Participant 18)

One of the real values of consumer engagement is that it encourages consumers to accept the decisions made at the end of the engagement process. By participating in decision making, consumers feel some commitment to the outcome, even when that outcome does not mirror their original hopes (Participants 10, 19).

While recognising that consumer engagement contributes to outcomes, some participants noted that engagement is a process, not an end in itself. This means that policy makers need to focus more on the end result than on the processes used to engage with consumers and other stakeholders. It also means that policy makers need to be very clear about the goals of engagement – focusing on the goals helps to clarify planning issues such as who should be consulted and what techniques should be used (Participants 2, 3, 7, 13).

You can get caught up and think consumer participation is the goal, and lose sight that it's not the goal. The goal is health outcomes. ... We shouldn't get lost in the process of consumer participation. (Participant 3)

I like the public value frame: you need outcomes, you need trust, you need credibility, and you need accountability. ... Those four components are the centre to quality service delivery and good results. ... I see engagement not as an end to itself, but as a means to an end. And it's a means to making sure that good decisions are made by me and by the service provider about the best way to fix my health problems or to fix my concern about the health system. ... Everyone's got expertise to add to a solution, and engagement is essential to make sure that decision-making draws on that expertise. (Participant 13)

Participant 15 provided an industry perspective on the outcomes of consumer engagement when she commented that, for her organisation, the key value is one of mutual benefit. For Participant 15, consumer engagement involves building long-term relationships with consumers through consumers' organisations. She argued that the relationships can help her organisation to understand the needs of consumers, open lines of communication, and help to ensure that their products are used in the best way. However, she felt that it would be unlikely for the organisation's relationships with consumers' organisations to influence the organisation's approach to policy.

A democratic right

A common argument for consumer engagement found in the literature is that engagement is a democratic right. Participants in this study reflected this view, but also reinforced that, at a day-to-day level, consumer engagement has a very practical, outcomes driven focus. Participant 11 made this practical approach clear when he said that, while there may be an element of deliberative democracy in consumer engagement, he's not sure that he would be involved in it if that's what the major benefit was.

We think consumer engagement is very, very important. ... We look at engagement from a democratic perspective, but there's also the perspective that when you speak to the community you are taking another perspective on board that complements the expertise of health practitioners and makes for better informed decision making. (Participant 2)

Participatory democracy is where we started, but the reality you also have to take into account is the practical issues. ... You always come up with the same outcome, that community engagement really helped inform better decision making. (Participant 2)

We're living in a democratic society, so it's a democratic right to be able to have a say and contribute. (Participant 17)

It's not only an effectiveness responsibility, but also a moral responsibility to ensure that you have a consumer engagement process in the work that you do. (Participant 16)

Linked to the theme that consumer engagement is a democratic right, is the idea that consumers are demanding to be involved in both service delivery and policy discussions. Participant 3 suggested that people have become less trusting of the democratic process and no longer believe that government is doing the best by them, and for this reason are demanding engagement. This was supported by Participant 4, who suggested that people are cynical about government, and don't want decisions being made by government or health practitioners without an engagement process. The consumers demanding this engagement tend to be working through consumers' organisations.

Consumer engagement is politically vital

Consumer engagement was described by some participants as a political imperative. Politicians want to be seen to be consulting with the community and listening to the views of consumers. After all, consumer engagement is 'good for votes' (Participant 12). Participant 3 commented that much of the push for greater consumer engagement is coming from politicians, who want to be seen as being more consultative and allowing the

community to have a greater say in policy. Participant 4 described consumer engagement as being part of the ‘real politic’ – it is the practical reality of doing politics, and is a good thing to do; this participant suggested that politicians want to be perceived to be consulting widely with the community.

It’s politically vital. ... Every policy maker knows that. ... Consumers are going to be talking positively and stakeholders are going to be talking positively about whatever policy direction has been put into place, and if they’re not then the Minister knows about it, and everyone knows about it because this is the kind of media stuff that runs. And you don’t want your policy area on the front page of the newspaper. (Participant 1)

Consumer engagement uncovers issues that might not otherwise be heard

Consumer engagement processes can uncover issues that are directly relevant to consumers – issues that policy makers and practitioners may otherwise fail to notice. By listening to consumers’ voices, policy makers can consider a perspective that is not traditionally heard (Participants 3, 6, 11, 19).

An engagement process can help policy makers to understand what the problem really is, not just what it appears to be at first glance (Participant 11). For example, Participant 8 discussed the way that consumer representatives on a committee were able to describe the lived experience of the side-effect of treatment in a way that helped practitioners to realise that the consequences were real and important for consumers. Consumer engagement can persuade other stakeholders to address issues relevant to consumers instead of dismissing them or putting them aside for later consideration (Participant 19).

In addition, consumer engagement can help to define the issues that need to be addressed through the policy development process, and set the direction for communicating with consumers about an issue (Participant 10).

The [health] system as a whole is a remarkably fluid environment where if consumers are not engaged then the likelihood of getting the problem definition right or developing a solution that’s going to work is diminished. (Participant 11)

Consumer engagement provides a voice for consumers

A common theme from the interviews was that consumer engagement offers an opportunity for policy makers to listen directly to the voices of consumers. This is closely

linked to the point made above: that consumer engagement can uncover issues that might not otherwise be heard.

Consumers bring a perspective to issues that is different from the perspective of policy makers or practitioners, and allows for more inclusive and informed decision making (Participants 2, 3, 6, 7). Consumer engagement allows consumers to be part of the process – it gives them a voice and allows their issues to become part of the discussion. Participant 13 noted that everyone has expertise to add to the debate and the solution; engagement is an essential part of ensuring that decision makers draw on the expertise of consumers.

Consumers ask the questions that other people don't ask. ... [Consumers] think about it differently. You think about 'well what does this mean for me as the person in the bed', not the person looking at the person in the bed. Your questions are different. (Participant 3)

I think it contributes an alternative view that is a different way of thinking about the issue, and it's an alternative expertise. It's about providing evidence, offering the view that the bureaucrat or the policy maker or the health expert won't necessarily have access to because their pre-occupations are quite different to someone who receives care and treatment and how they experience well-being around a particular health issue. (Participant 14)

If you engage with consumers when you're developing policy, you actually get the real issues for people on the ground, as well as the issues that might relate to a health professional's workplace or a government's cost effectiveness. You actually get what it's like to try to work with the health system in a particular area. (Participant 19)

Including the voice of consumers in policy development helps to broaden out the policy process and make it more inclusive. Participant 16 argued that there is a public policy responsibility to ensure that policy makers hear the wide range of voices – otherwise decisions will be limited.

[Consumer engagement] brings a focus on the consumer into all our planning and discussions. Healthcare has traditionally been dominated by a provider focus, so the system is set up to assist providers in providing their services in the most convenient manner for them, rather than orientated towards the needs of the consumer. Providers argue that they can adequately represent the needs of the consumer, but we know that that's not necessarily the case. (Participant 18)

By incorporating multiple voices into the policy process, consumer engagement can generate an interesting debate, help to reduce the risks of making an ill-informed decision, and reduce the tendency for Groupthink (which might be created by a closed group

decision making process when everyone in the room thinks that they are making a logical decision) (Participant 11).

Participant 19 noted that consumer engagement can go beyond giving a voice to consumers in a policy-making context. It can also help to give consumers a voice in more public debates. Through the engagement process, consumers can become more sophisticated in their knowledge of policy issues.

By the time [the issue] starts hitting the press, there's at least a core group of consumers out there, who happen to be spokespersons for big consumer organisations, who feel they have been involved and have a little bit of ownership in this and are more prepared to speak. (Participant 19)

Consumers as stakeholders

Some participants described consumers as stakeholders in the policy development process. For these participants, the voice of consumers should be given similar attention to the voices of other stakeholders (Participants 1, 12).

The patient or the consumer is often an important stakeholder in whatever program, project, or initiative [our client is] trying to roll out, so it's very much from the perspective of using the consumer as an important stakeholder to collect information. (Participant 12)

But while consumers can be described as stakeholders, their voices may need special attention in order to be heard. Participant 16 noted that organisations need to specifically plan to hear the consumer voice. While industry and other stakeholder groups may be highly organised and articulate in their lobbying around policy, individual consumers and consumers' organisations may lack the resources needed to be part of the debate (Participant 16).

Can consumer engagement influence policy?

I asked participants to comment on whether consumer engagement can ultimately make a difference in policy making. Several participants argued that it does influence policy by encouraging better and more informed decision making. However, they agreed that its contribution is difficult to articulate (Participants 3, 12, 15, 17, 19). As Participant 1 noted, 'policy is such a nebulous thing. It has multiple strands running at the same time and interacting, so it's always hard to know where an idea comes from.'

But while engagement may have an *influence* on policy making, some participants noted that it is only one element of the policy process and that governments are unlikely to grant decision making power to the consumer voice. Governments ultimately make decisions, after being informed from a range of perspectives including consumers' (Participant 12).

At the end of the day, governments are responsible for implementing policy and making decisions about these things, and I guess we would never want there to be an elimination of the political process. .. I would see [engagement] as being a critical input to that process. ... Just because the community thinks a particular view, doesn't necessarily mean the government would take it on. (Participant 4)

Participant 4 went on to acknowledge the power of government decision makers and the authority of government ministers. He noted that decision makers must be convinced that a policy is a 'winner' politically before it will be adopted. He discussed an example from his own research, of a view that was widely held by consumers but was dismissed by government because it was seen as an election loser. A considered community view can be 'tramped' on by a government minister because the political implication is that they will lose government (Participant 4).

The commitment to consumer engagement

I asked participants to comment on their views about the commitment to consumer engagement – both within their own organisation and in the broader policy-making environment. The picture that emerged was one of varying commitment and varying expertise. For example, Participant 5 described his organisation as committed to engagement but very new to the field, while other participants described organisations with some history of experience in the area (Participants 2, 3, 6, 13, 14, 17). The two consultants interviewed both noted that the commitment to consumer engagement amongst their clients varies, but there does seem to be an increased willingness to accept its importance (Participants 7, 12).

Different agencies and different governments are operating at different levels and are not always consistent, even internally. ... You could have an area health board being very active in its engagement with citizens and consumers at an area level, but that not be reflected or represented at a political level or an executive level or state-wide basis. (Participant 13)

For many organisations, consumer engagement is a mandated part of their work. As noted in the literature review, the Commonwealth, State, and Territory governments require an engagement process as part of policy development, and this also applies to many

government agencies. Both Participants 3 and 6 suggested that a lot of engagement is only conducted because it is imposed on policy makers.

Really good bureaucrats understand the importance of community stuff. I don't think they're much rewarded for that at the moment. But the government is sensitive about ... being seen to consult. (Participant 16)

Several participants described organisations with an increasing commitment to consumer engagement. For example, Participants 2, 10, and 13 described engagement as an issue that characterises the work of their governments – it has changed the way the governments go about doing business. This change has come about within the last decade, and most notably in the last five years. Participant 17 discussed the way that engagement has grown in importance across her department, with a current focus being to ensure that there is a consistent process for conducting engagement.

I certainly think there's been a shift over time to a willingness and readiness to embrace higher levels of citizen intervention and influence. ... I think we've come out of the public management approach around efficiency and effectiveness and so on. I think engagement has become another one of the e's. You know, it's efficiency, effectiveness, and engagement. ... Now it's becoming more of the way in which governments do business. It is becoming more embedded as a way of doing policy. (Participant 13)

The currency of consumer engagement was noted by several participants (Participants 2, 7, 8, 12, 14, 15, 18, 19). While some participants described a maturing process that is now being embedded across their organisations and requiring less specialised input (Participants 2, 13), others described an emerging commitment. Participant 5 said that people within his organisation are now convinced of the merits of engagement, and it has become part of the planning cycle; he hopes to have a systematic engagement process in place within 18 months. Participant 6 described an increasing interest in consumer engagement over the past 12 months, with a wider range of organisations starting to plan for engagement as part of their work. She noted that there has been a shift in thinking, but questioned how it might translate into practice.

Consumer participation hasn't always been a priority, but increasingly it is. ... A change has occurred culturally, and clinicians are asking for it or demanding it. (Participant 14)

There's definitely been a shift in thinking that we want some sort of consumer involvement, and I think that the expectations of what the consumer will contribute ... have grown. (Participant 19)

Participant 18 noted that policy makers are getting better at planning for and conducting consumer engagement. He felt that engagement has become more systematic in recent

years, becoming a planned part of the policy process instead of happening in an ad hoc way. He also argued that consumers are becoming more articulate and better able to contribute in the policy environment. The end result is that ‘advocacy is becoming more sophisticated’ (Participant 18).

You know, 5 or 10 years ago we just didn’t know what to ask consumers, we didn’t know what supports they needed, we would often send them reams and reams of paper without any mechanism to assist them to understand, we would often schedule meetings at impossible times, we wouldn’t pay sitting fees or recompense expenses, it was very hard for consumers to deliver. So we’ve learnt a bit about that process. (Participant 18)

Participant 15 commented that consumer engagement is a relatively new area for industry. Very few industry organisations have staff with a dedicated responsibility for consumer engagement; it is still often combined with a responsibility for government relationships and other communication roles. She suggested that the move towards engagement within industry has been inspired by experiences overseas, particularly in the UK, USA, and Canada where work over the past 10-15 years has centred around the more empowered and informed consumer.

They [consumers] are becoming more knowledgeable and informed about a range of health issues and that’s being acknowledged by all stakeholders. ... Many of the [consumers’ organisations] are quite sophisticated and are becoming successful in advocating on a range of issues. ... Industry and consumer organisations are increasingly working together and through that engagement identifying mutually beneficial areas to work together. (Participant 15)

Participant 13 suggested that, over time, the focus on consumer engagement will completely change the way that governments work with communities. Instead of working with individual population groups and consulting through different government agencies, Participant 13 sees a future where government agencies will work together and simultaneously consult with entire communities on a range of issues. He described the way that his government is beginning to do this in its work with Indigenous communities in an approach that aims to explore the true complexities of the community’s issues (instead of only considering the issues relating to one portfolio area) and listen to the community’s views about their visions for the future.

Although the general picture emerging from participants’ discussions is one of increasing commitment to consumer engagement, some participants noted that the commitment to engagement will vary within organisations, and they still often find themselves having to sell its benefits. Participant 19 noted that there is some ongoing resistance to the idea of

engaging consumers, and she still finds herself having to explain why it is important. Participant 6 said that she is often surprised that she needs to sell the concept of engagement; she described great diversity in people's understanding of the value of engagement.

I've had interactions with some quite high level managers who have been quite resistant when I've enquired about whether they're considering consumer engagement in their process. I wonder whether it's maybe not understanding how you can involve consumers in an effective way, or also a sense of maybe wanting to have consumers involved – knowing it's a good thing, but being caught up in all the issues that are going on. (Participant 6)

Participant 1's comments about the commitment to consumer engagement were in direct contrast to those of other participants. He suggested that engagement has gone off the agenda in his organisation. He has seen little change in engagement practice over recent years, and suggests that the views of stakeholders, including consumers, have always been an important part of the policy process. However, he feels that the rhetoric about engagement has recently diminished.

Two participants were particularly critical of the current Commonwealth government's approach to consumer engagement.

- ◆ Participant 6 suggested that she has seen little leadership or direction from people in Commonwealth agencies for consumer engagement. She acknowledged that agencies receiving Commonwealth funding are required to conduct engagement work as part of their funding agreement, but questioned the extent of consumer engagement in policy development work. She also cited the de-funding of the National Resource Centre for Consumer Participation in Health and the Consumer Focus Collaboration as examples of the shift away from consumer engagement at the Commonwealth level.
- ◆ Participant 16 commented that: 'This government at federal level is particularly disinterested, I think, or is very select in what it wants to hear from community groups. ... I'm quite dismayed at their approach and the excessive access of business to very high places in this government, and it shows in the decision making. ... Your economy doesn't fall down, the world doesn't end, ... you just get ... decisions over the long-term slowly make a number of things worse than they should be when they could have been better.'

Type

In this section, I include themes raised by participants that relate to the extent of engagement being offered to consumers. The five-level ladder developed by Health Canada (2000) – inform/educate, gather information, discuss, engage, and partner – is used in this study to describe different types of engagement (see pages 12-16 of *Conceptualising Consumer Engagement* for a discussion of engagement types).

I chose not to question participants directly about the five-level framework, as I felt that it would impose a theoretical description on our discussion and may not make sense in the practical experience of participants' everyday work. Instead, I allowed participants to describe engagement in a way that made sense to them, and I use the framework here to interpret the relevant themes that emerged.

Three participants explicitly mentioned a ladder or matrix framework in their interview. These participants spoke about the processes involved in choosing a level of engagement for a particular project or policy.

- ◆ Participant 2 argued that policy makers need to consider the complexity and sensitivity of issues in their initial scoping work. Complexity and sensitivity need to be considered from both the technical perspective and the community perspective, and should be considered through consultation with relevant stakeholders and community members. 'Through that matrix you then decide on the level of involvement and the timing of involvement. In other words, it's not a question of – for example, you're building a hospital, should I have a citizens' jury – it's a question of what are the issues surrounding this?'
- ◆ Participant 7 suggested that decisions about the level of engagement require being clear about its purpose. She argued that the level of input being offered to consumers needs to be clear, so that consumers can understand what they are contributing, how their voices will be used, and whether they will get any feedback. 'If you're thinking to just get information, that's one thing, but if you're thinking to get some input into a decision, that's another thing.'
- ◆ Participant 13 noted that choices about the level of engagement offered to consumers are contextual. He described a matrix, with one dimension offering a continuum of intervention and levels of influence (the levels of engagement), and another dimension offering a continuum of methods.

There is a continuum across levels of influence and power sharing from information provision right through to co-production. ... For some people in some circumstances,

they don't want much engagement. They might just want information. They might not want to participate now, and that might be OK. ... But in other circumstances you want it down at the other end of the continuum: you want co-production. (Participant 13)

A key distinction evident in participants' comments was that some engagement is used to gather information from consumers (from which the organisation will develop policy) while other engagement processes are designed to get people involved in either developing policy or looking at policy options (Participants 6, 7, 10, 11, 12, 13). Gathering information fits clearly in the mid-level of Health Canada's ladder framework, while involving people in developing policy fits under either the 'discuss' or 'partner' levels. This distinction between two key types of engagement brings some implications about the way that engagement will be conducted, including whether consumers are involved in an ongoing way and whether the engagement creates a two-way conversation. Engagement that is designed to gather information is more likely to be a one-off exercise, and is more likely to be one-way (Participant 6). The different types offer different promises to consumers: an information-gathering approach includes no promise of ongoing involvement and may not include any promise to return to consumers to explain how their voice contributed to the final decision (Participants 6, 7).

Some participants noted that organisations need to be clear with consumers about what type of engagement is being offered. If the engagement sits at the level of gathering information, then consumers need to be made aware of this and not be led to believe that they may have some say in the final decision (Participants 2, 7).

I think governments are incredibly unclear and somewhat dishonest about that. ... They trip themselves up in the process so often. Government thinks they know what they want, say they don't, say there's a blank sheet of paper, and then get caught out when the community wants something different to what they want. ... If you're accepting change at the margin, then say so, but pay a lot of attention to what the margin is. And if people really hate what you are saying, then listen to that too. (Participant 10)

Participant 19 used examples from her own experience to describe different types of engagement. She has been on the receiving end of engagement which simply involves sending an email saying that a consultation paper is available online; she described this as 'zero level' engagement. The next level up might involve sending through a copy of the paper and asking for input (and her organisation is often forced to respond that they lack the resources needed to respond in the requested timeframe). Participant 19 said that she is particularly frustrated when her organisation is listed as being involved in the consultation process when either of these two approaches are used. She contrasted these approaches

with a more ongoing approach, such as a consumer representative being involved on a committee.

Consumer engagement as relationship building

Some participants described engagement as a process of relationship building. This approach seems to sit outside the five-level ladder approach, perhaps because the focus of engagement is on the relationship itself rather than on any policy or project outcomes. The relationship may open lines of communication without any promise of engagement in policy development or decision making. Building a relationship with consumers is an ongoing process, while specific engagement activities that fit into the ladder approach may be conducted for particular projects.

I think a lot of things come back to long-term relationships. That probably sounds a bit naïve. But I think in the ideal world that good consultation comes from a relationship that you've formed. ... If I'm working in a new arena, my approach is to initially go and meet as many people as possible, and ask them a series of questions, which later on mean that I can go back and say, I asked you these questions, now I've talked to lots of people and this is what I've come up with, can I test it out on you. (Participant 7)

We work with health consumer organisations ... very much from a long-term versus a short-term perspective. The short-term relationships tend to be when marketing or when product managers want to work with an organisation around a particular project, ... whereas we're really interested in developing a long-term relationship, really looking at the organisation's needs and issues as well as our own and working towards a true partnership. (Participant 15)

I think the benefits [of having a long-term approach] are really getting a better understanding of the organisation's needs and issues. ... You don't really get a very good handle on those issues unless you actually develop a longer-term relationship. (Participant 15)

Renewing the relationship, and sustaining the relationship with citizens and communities and consumers is not something that you actually get right and it sort of stops. Any relationship requires effort and sometimes it requires renewal, counselling, and support. (Participant 13)

I think participation is about long-term relationships. I think good policy development is about using those relationships in terms of engaging people in the development of policy. I don't think that the development of policy is a fast process. (Participant 17)

Initiator

The initiator of consumer engagement emerged from the literature as an important influence on the way that engagement is conducted. Engagement can be initiated by organisations or consumers and, when initiated by organisations, will tend to reflect the organisational categories, language, and definitions relevant to that organisation.

I did not specifically question participants about the initiator of consumer engagement, and the issue did not emerge from any of the interviews. Most participants focused solely on engagement conducted by their organisation. Some participants added to their discussion with examples of engagement practice that they knew about and, in some cases, example that their organisations had been on the receiving end of (Participants 3, 6, 7, 8, 14, 19). Participants 8 and 19 both work with consumers' organisations and, while the engagement activities they discussed were clearly initiated by consumers, we did not discuss the differences between engagement initiated by policy-making organisations or by consumers.

Three related issues were included in this part of the framework: whether the engagement is project-based or ongoing, whether it is conducted by people working within the policy-making organisation or by consultants, and whether it is conducted by senior policy makers or junior officers. These issues were discussed by some participants.

- ◆ Participant 10 identified two different types of engagement happening within his department – ongoing, long-term engagement which is conducted by regional coordinators with a special focus on engagement, and shorter-term project-based engagement that will be related to a specific project. The regional coordinators are well connected to their communities and well placed to know the major issues. The distinction between long-term and project-based engagement was also made by Participant 15.
- ◆ Participant 1 noted that a lot of the direct contact between his department and consumers happens at the most senior levels – including the Minister and CEO. These people often choose to put themselves in positions where they can hear what is going on and test policy assumption, and consumers tend to be keen to talk to senior people. He also commented that, in his department, consumer engagement is conducted by a very limited group of people, particularly in their work with Indigenous communities.

There are a handful of people whose job is to be the direct interface with our service ... they would spend a lot of time talking and visiting communities, but most of us don't and there's good reason for that. ... One of the complaints we get back from Indigenous communities is that they're just sick of this endless parade of bureaucrats

coming traipsing through the place saying ‘tell us how it’s working for you. (Participant 1)

- ◆ Two participants noted that engagement is increasingly being integrated into separate government departments, and that external experts were required less often (Participants 2, 13). The catalyst role of experts, who have developed tools and training, has allowed people within departments to take over the work themselves (Participant 2).
- ◆ Participant 8 suggested that there is some value in having engagement conducted by consultants who are impartial third parties. This can be particularly valuable for controversial issues as the consultant is more likely to be seen as impartial.

Who’s engaged

This part of the framework looks at which consumers get to be engaged, with a particular distinction between engaging with individuals and organised groups. In the interviews, I asked participants to clarify who they were engaging with and, in particular, whether they were engaging with the members of consumers’ organisations or unaligned individuals. For many participants, working through consumers’ organisations was the most common approach to engagement (Participants 1, 12, 15, 16, 18).

For some participants, the distinction between engaging with individuals and organised groups was the same as the distinction between ‘consumers’ and ‘the community’ (Participants 1, 4, 12, 18). For these participants, ‘consumers’ are stakeholders who are typically members of organised groups, while ‘the community’ is the wider population of individuals. Participant 4 argued that, while the consumer’s view is often included in policy making, the community’s view is rarely given any attention.

I don’t think policy makers give a continental about the community view per se. They are largely determined still by the consumer view, the political view, and their personal subjective view. I don’t see any process happening in Australia that actually provides the community view. (Participant 4)

There’s no expectation placed on us that we will directly consult with [individual] consumers. ... There’s an expectation that we’ll always consult with stakeholders. Stakeholders would be a broad group of people. ... What you’re trying to do is find ... effective responses to what the government wants to see happening ... and making sure that all your stakeholders are going to find what you’re doing is an appropriate course of action. (Participant 1)

Participant 15 made a distinction between ongoing engagement with consumers' organisations and project-based engagement with individuals that would generally be done through the marketing department. She would not normally consider the project-based engagement through marketing to be a major part of the organisation's long-term approach to relationship building.

Participant 17 argued that policy makers need to consult with both consumers' organisations and individual consumers.

I think people who have been involved with community organisations for a long time really have a fantastic experience and understanding from working with a whole range of different consumers and carers who might belong to their organisation and use the services of their organisation, so they've got a collective knowledge base to bring along in terms of development of the policy. [And] somebody who has just recently used or is continuing to use a service or a range of services has got that immediacy of experience. ... I suppose at a policy level what you're looking for is that those people with that immediacy or experience can also extend – extrapolate that to how their experiences might be able to benefit others. (Participant 17)

For Participant 19, the knowledge and experience that consumers' organisations can bring is a key part of their value in an engagement program. Consumers' organisations provide 'pointy end input from people who have thought about it a bit because they've used and tried it a bit'. This is a big advantage for issues that are complex or requiring attention to detail. However, Participant 19 noted that engaging through consumers' organisations can not replace the need to engage with the wider public about issues. In many cases, the representatives from consumers' organisations will know when a wider engagement process is needed, and will encourage policy makers to consult more widely.

Participant 18 said that, in his experience, consumer engagement most commonly happens with consumers' organisations, through a process of consumer representation on committees. He said that his department has moved to working through consumers' organisations because they tend to select better consumers. The consumers they recruit tend to have a greater mandate to speak on behalf of consumers because they are representing an organisation and have some infrastructure behind them. Participant 18 argued that the consumer advocacy his department receives has become more sophisticated and more productive since they started working through consumers' organisations. The issues brought up by consumer representatives now tend to be focused on systemic improvement and broad consumer issues rather than individual experiences.

Participant 18 suggested that his department may engage with different types of consumers at different stages of policy development and for different types of projects. For example,

a policy may be developed by a committee made up of a variety of stakeholders, including representatives from consumers' organisations, and then be released for broad public consultation when it is in draft form. He also suggested that policy work is most likely to involve engagement with representatives from consumers' organisations, while service delivery questions are more likely to involve engagement with individuals from the community.

I asked Participant 18 whether he was concerned that focusing so much of his department's engagement activities around peak consumers' organisations could lead to them having an unusual level of influence.

I think that's probably a fair criticism. On the other hand, the more organised and sophisticated the involvement, in my experience, the better the outcome. ... Although you could argue you are moving away from the grass roots, and the risk of capture is greater with organised peaks, I must say that my honest [opinion] is the advocacy is far more sophisticated and far more effective with the peaks. ... Usually what we do in a routine sense, is get representatives involved early, draft something up, and then at draft stage out it goes for broader consultation. So there's an opportunity in that process for the grass roots to come in at that stage. ... If a draft is really actively disliked, very few ministers will proceed. (Participant 18)

Participant 19 cautioned that consumers' organisations do not always have the time or resources required to engage with policy makers, particularly if they are not offered any specific funding to do so. She also noted that, while consumers' organisations want to be both informed and engaged, that is not their only task. Consumers' organisations have their own agendas to run and the needs of their members to consider. Participant 19 suggested that policy makers should talk with consumers' organisations about how and when they can be involved, instead of just sending out invitations to participate and expecting some response.

Participant 16 argued that engaging with consumers' groups is often more successful than seeking input from individuals because consumers' groups are more informed and more interested in giving a response.

Individuals have lives to lead, and they don't want to be sitting there commenting on government legislation. They want the problem solved. That's what governments are there for – to help them solve problems. ... That's not saying that I don't think some of that stuff can't work in terms of advertising broadly [about] stuff that you're doing, and I know that the Commonwealth Treasury did that with the laws that they're thinking of changing. ... People will engage with [issues] that they care about ... but a whole lot of stuff that governments do just seems very esoteric to most people and they don't want to have anything to do with it. (Participant 16)

In contrast to the comments made by most other participants, Participant 11 said that his department tends to consult primarily with individual end-user consumers through focus groups. He distinguished between individual consumers and groups who are representatives of consumers, and suggested that individuals are often more open in their comments.

What you will generally find with organised groups of consumers is that they've got an agenda and they are wanting to push a particular perspective, which may or may not be useful. ... The nature of the engagement [with organised groups] is more structured ... and rarely do things happen to surprise you. Whereas often in qualitative research, you will realise you just had the wrong orientation or you were putting the wrong interpretation on things ... and you get a reasonably robust view of what would work and why. (Participant 11)

Participant 2 regularly uses a range of community-based techniques to engage simultaneously with individuals and groups, and Participant 12 uses an information-gathering, research approach to engage with individuals.

Participant 3 noted that working through consumers' groups tends to be the most common form of engagement, and she expressed two concerns about the implications of this. One problem is that working through groups means that organisations are engaging with consumers who are already knowledgeable, active, and engaged in the issue. This can mean that the broader consumers' voice is ignored. In addition, Participant 3 was concerned about the responsibility that consumer representatives feel back to their group. She suggested that this responsibility can over-ride the consumer's responsibility to the broader group of health consumers – their responsibility to their group becomes almost akin to a responsibility to shareholders.

Participants argued that organisations need to think carefully about who to engage:

- ◆ Some health consumers may not feel comfortable about giving critical input because of their position as a recipient of care (Participant 3).
- ◆ Consumers' views are not homogeneous, and adequate engagement requires a diversity of approaches that go beyond small numbers of representatives from consumers' organisations (Participant 14).
- ◆ Some consumers face significant barriers to engagement, and Participant 6 argued that organisations are still very unclear about how to seek input from them. For example, Participant 6 noted that there is very little understanding about how to engage cancer patients in a participatory way.

- ◆ Organisations may need to engage with multiple groups of consumers, including those who have a real experience with the issue being discussed and consumers who can represent a broader community view (Participants 3, 5). Participant 4 described the way that consumers' views can shift when they move from being a community member with a general interest in an issue to having some direct experience of a disease.

Timing

I was interested in the timing of consumer engagement for most participants in this study, particularly whether engagement is conducted in an ongoing way or is linked to some project. When engagement is linked to a project, I wanted to learn whether it happens from the initial stages of project planning or near the end of the policy cycle.

The picture that emerged from participants was one of great variation in timing, influenced largely by the type of policy or project being considered, and the type of consumers being engaged. Participant 6 noted that decisions about timing should be made on a project basis.

I think agencies need to work out when is the most appropriate time to have consumers involved ... and it doesn't have to be all the time. (Participant 6)

Some participants described an ongoing process of consumer engagement designed to build and maintain relationships with the organisation's key audiences (Participants 6, 13, 15, 17). This approach to engagement is designed to keep communication channels open, develop trust, and provide information as needed (engagement as relationship building is discussed in more detail in the section discussing engagement type).

Participant 6 argued that, while engagement is typically seen as being project based, this may not be the most useful approach for many organisations. She discussed an example from her experience, where a health organisation undertook extensive development work with consumers during a two year project. At the end of the project, staff looked for opportunities to initiate a second project in the area. Participant 6 reflected that another project wasn't what was needed:

What needed to happen was participation needed to be built into all of the activities of the agencies that were participating, so instead of it being a stand alone project,

consumer participation was done by that group over there, it actually needed to be embedded into the work of all the units. (Participant 6)

A number of participants described an engagement process that varies throughout the policy cycle. In the early stages of policy development, engagement may consist of just one or two consumer representatives participating in a policy committee. As the policy develops, a wider engagement process may be needed to gather information or test ideas. Towards the end of the policy cycle, when a draft proposal is available, the process will be opened up for wider engagement with either consumers' organisations or individuals (Participants 11 and 18 very clearly described this process, and it was mentioned in part by Participants 1, 7, 10, 12).

Participant 11 argued that policy makers need to have concrete proposals in place before generating a general public discussion. While a range of engagement techniques (such as consumer representatives on committees or focus groups with individuals) can be conducted early in the process without generating a public debate, a broad public discussion requires solid evidence and concrete proposals so that the debate can be managed. Without concrete proposals, policy makers and ministers will find it difficult to respond to media attention and community questions or criticism.

One of the approaches we are grappling with now is when's the right time, and when have we got sufficient detail to have a constructive discussion. ... I think that with lots of these things, once you begin the process of talking more [widely] ... it's sensible to expect that it will ... broaden quite quickly. (Participant 11)

Some participants argued that engagement typically happens too late in a project, and this can create problems both for consumers and for the policy outcome (Participants 7, 14, 17, 19). Leaving engagement until late in a project can mean that it:

- ◆ Seems tokenistic and is less likely to be meaningful
- ◆ Happens only in a very limited way
- ◆ Leaves little opportunity for consumers to influence the decision or provide input
- ◆ Makes it difficult for consumers to provide meaningful input, because at a mature stage of policy development they require significant information to contribute well.

Participant 2 argued strongly that engagement needs to happen early in a project and continue throughout all stages. When engagement is left too late, projects can reach a crisis point, with outside professionals needing to be brought in to settle disputes. Participant 2 gave an example of a proposed hospital development where a lack of consumer engagement contributed to a community outcry. Through a community-focused capacity

building exercise, the development was not only accepted by the community, but actively welcomed.

We have examples of when it's done right. ... We've seen how getting people involved early means – instead of experts ... providing their expertise against *perceived* community needs, they actually do it against real community needs. And we've seen significant changes and significant savings through that being done. And that's apart from the community building that goes on. (Participant 2)

Consumers need feedback about their input

Several participants argued that the timing of engagement should allow for a process of returning to consumers with feedback about their input (Participants 2, 7, 11, 12, 13, 14). This iterative process allows consumers to feel confident that their input was listened to and valued. It also gives consumers an opportunity to hear about the final decision and understand how consumers' voices contributed.

Participant 7 argued that engagement processes rarely include a feedback loop that involves going back to consumers and saying 'this is what we asked you, this is what you told us, this is what we're going to do, and this is why'. She described an example from her own experience, of contributing to an engagement process about a local development, and being unhappy with the final decision; she was left with no idea of whether her written response had been received and understood, or how her comments fitted in with the comments of other residents in her area.

I think that many [people] would accept ... an outcome that's not necessarily the one that they started with ... if they could understand where the response has come from. (Participant 7)

It's not enough just consulting, just documenting what their views are. I guess it's ensuring that the position that they're putting forward, or the views that they're putting forward, drive some of the policy. It's essential that how the policy is developed is fed back so people have an understanding of it – that they made a joint decision, that they were part of the process, what the outcome has been. Often consumers who have been involved in things, not only do they struggle to participate because it has been set up in a way that excludes them – because of terminology, or because of meeting structure, or whatever – but also they are not clear about the outcome of their input. To me it is essential not only to diversify the involvement process, but to ensure that the consumer contribution is acknowledged and the outcome is communicated back. (Participant 14)

Techniques

Techniques are the concrete tools used to engage with consumers. I asked each participant to describe the techniques they typically use and comment on whether some techniques seem to be more successful than others.

Participants 2, 7, and 13 noted that a wide variety of techniques are available for consumer engagement, and the choice of techniques should depend on circumstances, the complexity and sensitivity of the issue, and the outcome being sought. There should be no ‘one size fits all’ approach to choosing techniques; instead, techniques should be chosen after the issue has been scoped and the policy makers have defined the consumers they hope to engage. Participant 3 suggested that policy makers typically choose from a fairly limited array of techniques, and they need to consider more alternatives and the potential benefits of multiple sources of information. She argued that policy makers and researchers are not yet sure of the best ways to conduct and implement consumer engagement.

Participant 14 noted that, while an array of techniques is available, her organisation rarely has an opportunity to move away from the traditional methods of consumer representatives, focus groups, or interviews. This is because much of their consumer engagement work is commissioned through other organisations who rarely want to take risks in trying more innovative techniques.

Consumer representatives

The technique discussed most widely by participants was the consumer representative – an individual consumer who represents the wider group of consumers in a committee process. All participants were familiar with this technique, and several described it as the most common way of achieving consumer engagement (Participants 3, 6, 17, 18, 19). Some of the participants work with organisations who regularly seek consumer representatives for their committees, while others work with organisations that recruit and support consumers for committee work.

In most cases, consumer representatives are recruited from a consumers’ organisation, which will provide training and ongoing support for the consumer. The representative is expected to provide a broad consumers’ input (rather than only their individual opinion), and will usually report back to their sponsoring consumers’ organisation as part of their work. In recent years, there has been an increasing focus on providing support and training

for consumer representatives to ensure that their input is valuable and to help ensure that the experience is a positive one for them (Participants 8, 18, 19).

Several participants discussed the benefits that consumer representatives can bring to committees, including a perspective that is different from that of other committee members (Participant 12), expertise that is relevant to the consumer experience of the issue (Participant 1), and an understanding of when additional techniques of engagement might be beneficial (Participant 19). Participant 19 also noted that consumer representative programs bring benefits to the sponsoring consumers' organisation – including the potential to be involved in national health policy and to become more informed about developing issues.

While participants were quick to recognise the benefits of a consumer representative program, there was a sense of frustration from some participants that this technique is relied on too heavily and that it is used alone when additional techniques might be needed (Participants 3, 6, 8, 14). There was also some suggestion that consumer representatives can be a tokenistic form of engagement – a way of fulfilling an obligation to engage in the easiest way possible (Participant 8).

Some participants raised concerns about the difficulties for consumer representatives in their work with committees. Participant 18 noted that being a consumer representative is hard work, particularly if there is only one consumer on a committee. It can be difficult for consumers to take a stand that is different from that of other committee members (Participant 3), and consumers can feel intimidated by the experience and expertise of others.

If you bring a consumer onto a panel where every second person's title is professor it can be extremely daunting, no matter how hard the professors try not to make it daunting. (Participant 5)

That can be quite stressful in terms of meeting with Chief Executive Officers of health services, people who make legal decisions about legislation, providers of health services, professors, etc. That can be quite daunting for consumers and carers speaking out in those forums. (Participant 17)

It is hard to advocate when you're in a room full of people who know the system really well. It's hard to advocate alone, particularly if you don't have as much expertise as the people around you. (Participant 18)

Participant 11 suggested that some committee processes – including discussions about rationing and 'what-if' scenarios – can create conflicts for consumer representatives and

can be difficult to communicate back to their sponsoring organisation. Other cautionary comments include that the individuals available to work as consumer representatives may not be representative of the people that the policy will apply to (Participants 3, 5), that consumer representatives are advocates for their sponsoring group rather than all consumers (Participant 4), and that having a consumer representative on a committee can cause frustration for other committee members by turning meetings into an education session for the non-expert (Participant 3).

As Participant 6 noted, there are limits to what one representative on a committee can achieve, and policy makers need to think carefully about when wider engagement might be needed. Participants 6 and 19 both pointed out that a good consumer representative will know when the committee needs to engage with consumers more widely, and should be able to bring this input to the committee.

Participant 19 was clear about the value of consumer representatives. They provide a consumer's voice on a committee, but should not be seen as a sole engagement technique.

I think if they're forming a committee, they should have a consumer representative on there. But let's be pragmatic about that. I think that if they're involving a range of stakeholders, then they need a consumer representative to provide that balance in voice. But I think they then need to recognise the limits to the role of a consumer representative. ... That person may well be able to assist them to identify the areas in which they have very little knowledge about what consumers or the community might be thinking, and where they need to do a more open engagement or consultation. (Participant 19)

Research approaches to engagement

A variety of techniques that I have clustered as research approaches to engagement were widely discussed by participants. These techniques fit under the information gathering approach to consumer engagement – they are used to listen to consumers' voices and uncover the issues that consumers feel are important. They can also be used to test policies, check assumptions, and validate decisions.

Focus group research is an engagement technique commonly used by Participants 11, 12, and 17. Participant 11 said that focus groups are increasingly being used by his organisation, and he described them as being more effective than any alternative. He suggested that focus groups can provide reliable information, rich and detailed perspectives, a quick turnaround, and can sometimes provide surprising results. Participant

17 suggested that focus groups are often less stressful for participants than other techniques, and can provide very strong results.

One of the reasons why focus groups work, I think, often better than [quantitative] research is that there can often be a level of interactivity. It's more a conversation than a question and answer. You're surprised sometimes by the answer. ... Often quantitative research doesn't necessarily convey the richness of perspective and the subtlety of differentiation within that. (Participant 11)

You realise through the process [of focus groups] that people like me, public servants or university educated, are atypical in the population. If we just designed and developed things based on our own judgements about what is appropriate then we are going to miss most of the population. (Participant 11).

Participant 12 also described a variation on focus groups, where the group setting is used to map out a process and identify the issues that patients or consumers may experience as they move through that process. For example, this technique may be used to identify the issues that consumers face in hospital emergency or when checking out of hospital. He suggested that this technique is particularly valuable at the beginning of projects, to define the critical customer requirements and direct policy development.

Quantitative techniques are also used to gather information from consumers. Participants 8 and 12 both use quantitative techniques to provide hard evidence and generate a snapshot of the broad consumer view. Participant 4 suggested that quantitative, randomised techniques are valuable because they are objective and will not be dominated by an unrepresentative view. Participant 12 argued that quantitative evidence is vital for providing benchmarkable data and monitoring change. However, he also recognised the value of qualitative data to identify issues and explore consumers' perspectives.

Participant 7 discussed the differing values of qualitative and quantitative techniques, and suggested that the two approaches are often used in opposition, with the quantitative approach working hard to prove the qualitative data wrong. Participant 7 described consumer engagement as primarily a qualitative approach, and suggested that few practitioners know how to fit quantitative data into their work. She also noted that, while quantitative data can provide some useful information, it can not help to generate solutions for issues, and can not pinpoint the value of early engagement with a community.

Research approaches to engagement overlap with market research and the development of marketing techniques. Participant 15 described the way that these techniques are separated from consumer engagement in her organisation, and are conducted by the marketing department. Participant 19 argued that organisations need to consider not only the

outcomes of research techniques, but also their planning process. She suggested that consumer input is needed in the planning of research techniques to help ensure that appropriate questions are asked and key points are not missed.

Reference groups and advisory groups

Reference groups or advisory groups were mentioned by a number of participants as a way of engaging with consumers (Participants 1, 2, 5, 10, 15, 16, 17). These groups are often made up of representatives from consumers' organisations, who are responsible for reporting back to their sponsoring group. What sets these groups apart from the consumer representative technique is that these groups are designed specifically to provide the consumer voice (rather than consumers becoming one voice on a broader committee).

Reference or advisory groups are responsible for informing the organisation's activities in some way. Participant 16 described the way that members of her organisation's Consumer Advisory Group are funded to participate and are encouraged to raise their own issues for discussion in addition to responding to the organisation's issues. Advisory Group members are also given an opportunity to discuss their concerns without members of the organisation being present.

A lot of the advisory committees that I've been on are totally driven by the institution – they want answers to the things they're talking about. Whereas we think we've got to share that leadership with our consumer groups. (Participant 16)

Participant 10 noted that reference or advisory groups are often established and then left disconnected from the policy process, so that they are unable to make any real contribution. In his organisation, he will 'gently encourage' relevant managers to connect with relevant advisory groups and pay attention to what they are saying.

Briefings

Some participants described briefings and information sessions as a way of engaging with consumers (Participants 15, 19). Briefings can be used to provide information to consumers (either to simply inform them, or to provide them with the background needed to become part of a debate), listen to consumers' perspectives, and build a relationship with consumers. Participant 15 described a process where member companies via the industry association will provide briefings to consumers' organisations to ensure that they are involved in discussions and informed around key issues. She noted that they are always

careful not to encourage consumers' organisations to form particular conclusions or support industry's position.

Public meetings

Public meetings were mentioned by some participants, and seem to be a valuable technique for engaging with individual community members. Participant 4 argued that public meetings can be useful if they are well-managed and well-facilitated. However, he suggested that the difficulty with public meetings is ensuring that they don't get hijacked by influential or erudite people who come from a particular perspective and dominate the discussion.

Participant 17 said that public meetings need to be part of a larger engagement process. Organisations need to build relationships with relevant consumers' organisations and involve them in discussions before they are invited to large meetings. Consumers' organisations are unlikely to respond if they simply receive an invitation to a public meeting without any context or previous involvement. This was echoed by Participant 19, who described a recent experience of being on the receiving end of a poorly conceived and poorly planned public meeting process.

Public meetings are part of the typical engagement process for consulting with a geographical community described by Participant 13. The public meeting might be linked to workshops with community groups, a meeting with the local Council, a community barbecue, and a negotiation about outcomes. Participant 18 described a similar process that may include meetings with the local Council and key organisations, seeking expressions of interest, and holding a community meeting.

Written submissions

Only two participants specifically mentioned written submissions as a technique that they regularly use.

- ◆ Participant 18 suggested that his organisation usually calls for written submissions in response to a draft policy. They release a general call for submissions, and use a targeted approach by sending the document to relevant organisations and asking for their specific comment. He noted that the targeted approach is more useful.
- ◆ Participant 16 argued that written submissions are valuable when consulting about specific, detailed issues. When submissions are received in written form, they can

become part of a transparent process that includes the public release of all submissions.

Participant 19 expressed frustration at organisations' over-reliance on written submissions. She suggested that consumers' organisations often lack the time and resources required to respond in a meaningful way and are regularly asked to meet inadequate timeframes.

Citizens juries

Three participants discussed citizens' juries as a technique they use to engage with consumers (Participants 2, 4, 17). Participant 4 was most vocal in his support for the technique, arguing that he believes it is the best model for engagement:

I think [the citizens' jury] is a very effective means of determining community opinion. ... One of the things you need is knowledge in order to elicit community views. When you do a telephone survey, for example, you get opinions based on where people are coming from at the time ... it's a result coming from an uninformed or limited information base. The objective of the citizens' jury is to ... give an independent group of people the opportunity to hear information. You have a much more informed body of people who balance things up. (Participant 4)

Participant 2 described both formal citizens' juries and charettes (an informal but similar approach) and suggested that they are useful in allowing participants to evaluate issues and consider a variety of perspectives. Through a citizens' jury, participants can be presented with a perspective from an expert witness that they may not otherwise get to hear.

Participant 3 noted that there is a push for citizens' juries as an engagement technique. While she does not have direct experience of conducting juries, she suggested that they sound conceptually simple and argued that they need to be conducted by people with relevant skills and following a careful planning process. Participant 17 also noted that the outcomes of citizens' juries are dependent on how they are run, who is involved, and the quality of the background material provided.

Informal techniques

Two participants noted that their organisations rely on informal, ad hoc approaches to engagement in addition to more formal techniques. They said that ad hoc approaches often provide very useful outcomes (Participants 1, 10). For example, Participant 1 suggested that the most constructive engagement can happen as a sideline to other meetings.

In that kind of environment, which is relatively unstructured, there's a lot that can go on which is a bit freer than what happens when we go to a community with a government hat on, and they have got to turn up with a community hat on, and we've got to go through the direct negotiations or discussions. ... I guess I'm saying that the points of engagement and influence are not necessarily just the ones that are purpose built. (Participant 1)

Practical issues

The practical issues raised by participants have been clustered into the four groups defined in the framework: the resources available, the information available, consumer-related issues, and organisation-related issues.

The resources available

The resource issue of most interest to participants was the need for training in consumer engagement. Several participants argued that consumers who are engaged in an ongoing way – through membership of a committee as a consumer representative or through membership of a consumers' advisory group – need to be well-trained and well-supported by their sponsoring organisation (Participants 3, 8, 17, 18, 19). Some participants also noted that training and induction is needed for a range of stakeholders, and that all committee members would benefit from being trained about how best to work with consumers (Participants 5, 13).

Three participants discussed the way that training and support for consumer representatives has improved in recent years (Participants 8, 18, 19). Participants 8 and 19 both described detailed procedures for recruiting and training consumer representatives and a requirement for reporting back to the sponsoring organisation. They suggested that these procedures have improved consumer representatives programs and help to ensure that the representatives are able to do their work well.

Participant 18 suggested that good training is one of the key requirements for a successful consumer representative. Well-trained representatives can be effective from the word 'go', because they understand the system and how it works, they understand how policies are developed, and they understand their role. Participant 18 described the need for a more formalised training program as 'the next frontier for consumer advocacy in health care',

and proposed that a certificate program with recognised competencies should be developed for consumer representatives.

Participant 2 raised a separate issue about resources; she argued that any resource constraints need to be communicated clearly to any consumers engaged. For example, if an engagement process is constrained by a specific budget, a timeline, or an initial government decision, those constraints should be explained to consumers at the beginning of their engagement. Participant 2 argued that consumers are most likely to accept constraints that are clearly communicated, and are unlikely to have unrealistic expectations of the process.

Participants 2 and 7 both argued that imposing strict time and budget constraints on engagement processes can be a mistake. Investing in consumer engagement in the early stages of project development can save money as the project progresses.

It's not about having enough time and money, it's about having the will. Saying it's extra money is an excuse. If you talk to the people first, then you might save money in the end. ... You could probably choose a lot of examples of big projects where they've had to go and backtrack because they haven't actually done the consultation in the first place. (Participant 7)

We know that when [engagement] doesn't happen the cost can be tremendous and I'm talking about tens of millions. (Participant 2)

The information available

Several participants argued that good information needs to be provided to consumers during an engagement process. This information falls into two categories:

- ◆ Informative material provided during an engagement process (such as the papers that consumer representatives need to read before a meeting, or informative materials distributed to consumers attending a public meeting)
- ◆ Follow-up information explaining the outcomes of an engagement process.

Some participants noted the importance of good information as a way of communicating with consumers about an issue (Participants 5, 10). As Participant 4 pointed out, consumers should be informed about an issue before they are asked for an opinion; it is very difficult to express an opinion or make a meaningful contribution without some level of information.

Information developed in consultation with consumers is more likely to be useful. Participant 19 noted that helping in the development of consumer information is a key contribution that can be made by consumer representatives on committees.

We feel that consumer representatives can contribute quite a lot to the design of both promotional campaigns and market surveys. ... If they're not asked to be involved, they're usually thumping the table as to why not. They get really cheesed off, as you can imagine, when the slick glossy brochure comes in for them to sign off on, and, you know, every photo in it is a gorgeous looking lady aged 25 that's supposed to be targeting lifestyle changes in 55 year olds. (Participant 19)

The need for follow-up information also emerged as an important issue (Participants 6, 7, 13). Policy makers need to go back to consumers, thank them for their input, explain the decision that has been made, and explain why (Participants 2, 13). Consumers' expectations of follow-up information are particularly important: if follow-up is not relevant, then consumers need to be made aware of this (Participant 7).

I think you've got to have some feedback loop. We've got your information, but this is what we came up with. ... It all just goes back to what the consumer was led to believe at the beginning. ... If a consumer ... has reason to believe that their information is going to be used in a fairly direct way, then they have the right to know what has happened in the end. (Participant 7)

Related to the need for follow-up information is the question of how policy makers manage the information they receive from consumers. Policy makers need to find some way of retaining the information they gather so that they don't ask the same questions multiple times, and so they can learn from previous experiences as they plan for engagement. Participant 11 also noted that information needs to be shared by policy makers across government divisions – both to help reduce engagement processes about similar questions and to share ideas for best practice. Both Participants 2 and 13 described examples of the ways that their governments have attempted to share this information.

You try not to go back to them and ask them the same question in two months' time. The one thing government hasn't cracked yet is actually how does it manage the knowledge it gets from citizens and consumers effectively, so we don't drive people mad by going back and asking them the same question time and time and time again. ... Governments generally try to do the right thing and consult, but that's not necessarily good engagement, especially if we've asked them before and not done anything about what they said last time. (Participant 13)

I like the idea of virtual local hubs. ... so the council or community centre [becomes] a repository of what people have said in the last lot of consultations, and the one before that. ... Once you consult and do something you change the context, so sometimes

you'll have to consult again because the context has changed. ... That's one idea, but we're a little way down from that. (Participant 13)

Consumer-related issues

Consultation fatigue was one of the consumer-related issues raised by participants in this study (Participants 7, 12, 13). Consumers can feel over-consulted, tired of being asked for their opinion, and cynical about whether their input will have any real influence on the final outcome. As Participant 7 noted, consumers are often cynical about engagement exercises, dismissing them as 'just another one of those exercises'. Strategies for overcoming consultation fatigue include having clear ground rules for the process, being clear about what level of influence consumers can have on the final decision, and having a good feedback loop for follow-up information (Participants 7, 13).

You don't get beyond [cynicism] unless you're able to translate what you say about views into action – be that just feeding back to people 'this is what we asked you, this is what you said, but this is what we're going to do, and this is why'. I think if you could do that as the minimum, then you'd be making some progress. (Participant 7)

I have yet to find a community that has been engaged with credibly that complains of consultation fatigue. I've never heard of it. In fact, usually you find a great sense of fulfilment that it has actually shaped the decision and it's a decision they feel very comfortable with because they have helped to shape it, and because the process has been open, transparent, and accountable. (Participant 2)

Other consumer-related issues discussed by participants include:

- ◆ Consumers may not be able to advocate as coherently as other stakeholder groups. For example, Participant 16 described a consultative group that included consumer representatives and other stakeholders:

There's absolutely no doubt that the business people are completely sure of their ground. They have legal advice, they have internal legal people. ... The community group has sometimes not even had time to read the material adequately, they often don't have a good economic background on which to comment, and they come at the issue in a completely different way. ... It's dismissed almost immediately by staff and the business people because they're just coming at the issue at a different perspective and from an often experiential perspective as opposed to a highly analysed position. (Participant 16)

- ◆ Engagement that is not conducted carefully can leave people feeling exploited or stupid (Participant 3).

- ◆ Long-term consumer representatives can become so familiar with what they think are the consumers' issues that they continually return to those answers instead of checking whether their assumptions are still up to date (Participant 12).
- ◆ Being a consumer representative can be a stressful experience – particularly when they are surrounded by CEOs, legal staff, legislators, and academics (Participants 5, 17, 18). Suggested solutions for this problem include training and having more than one consumer representative on each committee.

Organisation-related issues

Consumer engagement is most likely to be successful when organisations are strongly committed to an engagement process. In addition to being a mandated part of the organisation's work, engagement needs to be embedded across the organisation, valued by senior staff, and given both time and resources. Organisation-related issues raised by participants include:

- ◆ Consumer engagement needs an organisational champion who promotes its value (Participant 4, 6, 16, 17, 19). Without a champion, a commitment to engagement can easily dissipate, and policy makers can struggle to see its value. If the engagement champion leaves the organisation, the commitment to it can simply fizzle out (Participants 16 and 19 both described examples where this has happened).
- ◆ Large organisations can suffer from inconsistent approaches and patchy commitment to engagement (Participants 2, 13, 17). Participant 17 argued that large organisations need written processes for conducting engagement to help ensure that inconsistencies are minimised. Participant 13 suggested that the promotion of consumer engagement within government often needs to be targeted to middle managers; while senior bureaucrats get the message from ministers about the importance of engagement, middle managers who are likely to be responsible for its implementation need to be sold on the idea.
- ◆ Consumer engagement requires careful planning. Participants 2 and 6 both noted that organisations should plan for community engagement in the same way that they plan for anything else. Organisations need to consider how to make engagement a 'meaningful and important investment' (Participant 6), and make a deliberate effort to ensure that consumers' voices are heard (Participant 16).

For industry, an industry-wide approach to consumer engagement may be more beneficial than having organisations working alone. Participant 15 noted that:

[Until recently there] wasn't actually any industry approach to working with [consumers'] organisations. ... Now [industry-wide] collaborations are formed around a variety of different projects. ... And in terms of a policy perspective it's going to make more sense to work as an industry collaboration as opposed to individual companies. (Participant 15)

Contextual issues

The contextual issue raised most frequently by participants was the influence of the policy problem or issue being considered. Several participants noted that engagement processes – including the type of engagement and the technique used – are contingent on the particular issues being dealt with (Participants 1, 2, 12, 16, 17).

It's less about a global policy of engagement with consumers, and more about what's the health issue we're dealing with, what's the policy problem we've got to solve, and how are consumers organised or not organised in relation to that issue, and what are the implications of that for policy. (Participant 1)

Another important contextual issue is the population subgroup affected by the issue under discussion. Population subgroups need to be engaged in a way that is meaningful, and organisations need to be careful to ensure that the relevant population is part of the engagement process. It may not be appropriate to ask 'general' consumers to speak on behalf of a specific population subgroup (such as those experiencing a particular disease) (Participant 5). In addition, engaging with Indigenous communities can require a focus away from individual consumers to a broader perspective on communities or families (Participants 1, 10).

Participant 13 noted that focusing exclusively on population subgroups may not always be the best approach. He discussed his experiences of engaging with Indigenous communities who feel their issues are best addressed within the context of the broader geographical communities.

You've got mixed populations, and some of those communities ... are saying don't just come here and engage with [the Indigenous community]. Come here and engage with the whole of the community, because we can't fix our problems unless we do it as a whole community. (Participant 13)

Evaluation

I asked each participant to comment on whether they evaluate their consumer engagement processes and what evaluation techniques they currently use. While all participants agreed that evaluation is important, few participants were involved in direct evaluation of consumer engagement. Both Participant 2 and 13 described an ongoing, established process for evaluating consumer engagement used by their governments.

Evaluation is ongoing; we do it at every step. At present ... we've been looking at evaluating the planning of a consultation ... questions to say have you looked at the history, is there a history in the community that you need to take into account? ... The complexity of the issue. ... Are you providing the right type of information? Are you consulting in a timely way? ... All of these form part of the evaluation. (Participant 2)

Some participants suggested that consumer engagement is included as part of regular overall project evaluation (Participants 1, 11, 12, 18). While the impact of consumer engagement on the outcome is not specifically evaluated, the overall process and its outcomes are considered.

I'm pretty confident that if what we were doing wasn't going to be something that works for the consumer it would show up pretty clearly and pretty quickly in the kinds of daily [data] collections that we've got in place, even though none of these are directly asking consumers what they think of the service that they've received. ... Evaluation to us is always a part of the policy cycle ... every piece of evaluation is about adjustment to what we're doing and initiating new policy cycles. (Participant 1)

I think [evaluation] is part of the work we do, as opposed to a specific activity of evaluating consumer engagement. (Participant 12)

We evaluate our work, and our formal consultative committee has helped us [to] evaluate. ... We look at how effective we think our consumer consultative group is being, and we engage with those members in doing that. But we don't undertake really formal analysis of how having a consumer consultative group has influenced our decision making process. (Participant 16)

Most project-based initiatives have an evaluation component built in already, which will usually examine the effectiveness of the consumer involvement. ... But, no, as an organisation, I can't say that we've got an evaluation strategy well configured for our consumer involvement. I think we tend to move ahead as we learn, as an organisation, rather than formally evaluating as such. (Participant 18)

It is possible that the ability to evaluate consumer engagement requires some maturity in its practice (Participants 5, 6, 14, 19). Participant 5 suggested that evaluation will become

important to his organisation when they have more direct experience in engagement. Participant 6 said that her organisation is now ready to evaluate, and they have just reached the stage where they are thinking about evaluation indicators and possible methods.

I don't think we were ready to focus on evaluation two or three years ago – we were still convincing people that participation needed to happen. Now it's the right time to start reflecting. (Participant 6)

We're at the conceptualisation stage – we're just about to begin work on the business plan and look at how we develop evaluation. I know in the UK it's a new developing area, and it's becoming a priority for us. (Participant 14)

Evaluating the impact of consumer engagement can be difficult. It is an intangible area, and finding methods to articulate the impact of consumer engagement on an outcome can be difficult (Participants 3, 15, 19). Participant 17 suggested that organisations can say anecdotally that outcomes are better with engagement than they were before it was used, but finding hard evidence is more difficult. Her organisation is currently exploring methods for evaluation, including controlled before and after studies that will help to identify the contributions made by consumer engagement. She hopes that this evaluation will move beyond providing a record of engagement processes, to consider long-term impacts and outcomes.

References

Health Canada. (2000). *Health Canada policy toolkit for public involvement in decision making*. Ottawa, Canada.

Working papers from this project:

Gregory, J. (2006). *Conceptualising consumer engagement: A review of the literature*. Melbourne: Australian Institute of Health Policy Studies. Available: www.aihps.org.au

Gregory, J. (2006). *A framework of consumer engagement in Australian health policy: Developing a framework for the AIHPS study*. Melbourne: Australian Institute of Health Policy Studies. Available: www.aihps.org.au

Appendix 1: Letter of invitation

Dear xxxx

Interview about consumer engagement – Invitation to participate

We are writing to invite you to participate in an interview about consumer engagement for a research project being conducted by the Australian Institute of Health Policy Studies (AIHPS).

About AIHPS

AIHPS is an independent national institute devoted to studying the ways that health policy can improve the health of all Australians. It aims to improve the national capacity for health policy-relevant research and facilitate the community's role in influencing national health priorities. For further information about AIHPS, visit www.aihps.org.

About the research

This interview is part of a research project – entitled *Consumer engagement in Australian health policy: Investigating current approaches and developing new models for more effective participation* – being conducted by Professor Brian Oldenburg, Dr Judy Gregory, and Rebecca Watson on behalf of AIHPS. The project aims to:

- Identify and assess current methods for engaging consumers used within Australian health policy
- Compare those methods to the methods used in other sectors in Australia and overseas
- Develop new approaches for consumer engagement in Australian health policy.

Please see the attached information sheet for more details about the research project.

About the interview

The interview will explore your experiences with consumer engagement, with a particular focus on the value of consumer engagement as part of policy making. Through an informal, qualitative discussion with you, we hope to learn more about the practice of engagement, critical issues for success, decisions and trade-offs made when planning engagement, infrastructure requirements, and evaluations of practice.

The interview will be conducted by telephone, and will require approximately 30 minutes of your time. The interview will be recorded and transcribed, and we will send you a summary of our conversation for your review. Any comments that you make will be

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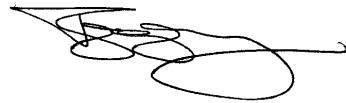
treated with the strictest confidence, and no identifying information about you will be published. Prior to the interview, we will send additional details about the research project and the interview format.

We hope that you are able to participate in this research. Dr Judy Gregory will contact your office in the next week to see whether you are available and, if possible, to arrange a time for the interview. If you have any questions about this project, please don't hesitate either Rebecca Watson (AIHPS Manager) via email at info@aihps.org, or Dr Judy Gregory (Principal Researcher) by phone on (07) 3356 7466 or 0431 909 684, or by email at judy.idc@bigpond.net.au.

Yours sincerely



Professor Brian Oldenburg
Chief Investigator
Australian Institute of Health Policy Studies
for and on behalf of the AIHPS Consumer Engagement Steering Committee



Dr Judy Gregory
Principal Researcher

Consumer engagement in Australian health policy: *Investigating current approaches and developing new models for more effective consumer participation*

AIHPS research project

This research is being conducted by Professor Brian Oldenburg, Dr Judy Gregory, and Rebecca Watson on behalf of the Australian Institute of Health Policy Studies (AIHPS). Funding for the research has been provided by Merck, Sharpe & Dohme's International Grant's Committee and AIHPS.

Project objectives

The project will explore strategies for more effectively engaging consumers in health policy development by:

- Identifying and assessing current approaches and methods for engaging consumers used by Australian government, non-government, and private health industry organisations, in terms of effective consumer participation
- Comparing these approaches with those used in other sectors in Australia such as urban development, environmental management, housing, and traffic planning
- Identifying, assessing, and defining the distinctive characteristics of approaches being used in similar overseas systems
- Developing and refining new models for consumer engagement in Australian health policy development.

Project design

- A literature review – to identify current approaches and methods for consumer engagement in health policy and in other fields (available at www.aihps.org)
- Informal interviews with key contacts – to consider the approaches to consumer engagement used in various sectors
- Case studies of engagement practice – to identify, assess, and define the distinctive characteristics of consumer engagement approaches
- A workshop program – to develop and refine new models for consumer engagement in Australian health policy development.

Project steering committee

Mr John Biviano (Victorian Health Promotion Foundation)
Ms Melanie Cantwell (Consumers Health Forum)
Ms Judith Griffin (Merck, Sharp & Dohme (Australia))
Dr Sophie Hill (La Trobe University)
Professor Vivian Lin (La Trobe University)
Professor Andrew Wilson (Queensland Health)

Project staff

Professor Brian Oldenburg (AIHPS/Monash University)
Dr Judy Gregory (Information Design Centre)
Mrs Rebecca Watson (AIHPS)

Appendix 2: Interview information package

Consumer engagement interview

Details of your interview

Date:

Time:

Method: The interview will be conducted by phone. You will be called by our teleconference company, Chorus Call, on xx xxxx xxxx (please contact Judy Gregory if you need to be called on a different number)

This interview is part of a research project being conducted by Professor Brian Oldenburg and Dr Judy Gregory for the Australian Institute of Health Policy Studies (AIHPS). AIHPS is based at the Queensland University of Technology. Funding for the research was provided by Merck, Sharpe & Dohme (Australia), and through AIHPS's operating funds.

Through this research, AIHPS hopes to learn more about the practice of consumer engagement in policy development – both in health and in other fields. AIHPS plans to explore current methods for engaging consumers, issues underlying consumer engagement practice, the evaluation of consumer engagement, and case studies of recent experiences. The research will culminate in a planning workshop, designed to consider both current and new approaches for consumer engagement, planned for early 2007.

Individuals who have direct experience in consumer engagement have been approached to be interviewed for this project. Your participation in the research is entirely voluntary, and you are free to withdraw from the study at any time without comment or penalty. Proceeding with this interview is deemed to be consent.

The interview will take approximately 30 minutes to complete. The interview will be recorded and transcribed. The recordings and transcriptions will be kept in a locked filing cabinet by the researcher for the duration of this project, and will be stored by AIHPS once the project is completed. The interview is intended to be anonymous and will be treated as strictly confidential. No identifying information about you will be published, and your name will not be recorded on the interview transcript.

AIHPS is an independent national institute devoted to studying the ways that health policy can improve the health of all Australians. It aims to improve the national capacity for health policy-relevant research and facilitate the community's role in influencing national health priorities. AIHPS receives funding from the health jurisdictions and participating universities, and is managed by a Board of Directors.

For further information about this research or AIHPS, please contact Rebecca Watson, AIHPS Manager, by email at info@aihps.org.

QUT is committed to researcher integrity and the ethical conduct of research projects. However, if you do have any concerns or complaints about the ethical conduct of the project you may contact the QUT Research Ethics Officer on (07) 3864 2340 or ethicscontact@qut.edu.au. The Researcher Ethics Officer is not connected with the research project and can facilitate a resolution to your concern in an impartial manner.

Thank you for taking the time to be involved in this research.

Principal Researcher for the AIHPS Consumer Engagement Project

Dr Judy Gregory

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Overview of interview discussion topics

- ◆ The importance of consumer engagement in your work
- ◆ The underlying purpose of consumer engagement (and whether the stated purpose is what gets implemented)
- ◆ Types of consumer engagement typically used
- ◆ Any differences in consumer engagement conducted for policy development compared with other projects
- ◆ Whether consumer engagement can influence policy development
- ◆ The evaluation of consumer engagement
- ◆ The process used to plan and implement consumer engagement
- ◆ Changes in the commitment to consumer engagement
- ◆ Proposed case studies for further research

Appendix 3: About the project

Project title

Consumer engagement in Australian health policy: Investigating current approaches and developing new models for more effective consumer participation

Project objectives

Develop strategies for more effectively engaging consumers in health policy development by:

- Identifying and assessing current approaches and methods for engaging consumers used by Australian government, non-government and private health industry organisations, in terms of effective consumer participation
- Comparing these approaches with those used in other sectors in Australia such as urban development, environmental management, housing, and traffic planning
- Identifying, assessing, and defining the distinctive characteristics of approaches being used in similar overseas systems
- Developing and refining new models for consumer engagement in Australian health policy development.

Project design

- Identify current approaches and methods for consumer engagement in health policy and in other fields – through a literature review and interviews
- Compare the approaches for consumer engagement used in various sectors – through a literature review and interviews
- Identify, assess, and define the distinctive characteristics of consumer engagement approaches – through case studies
- Develop and refine new models for consumer engagement in Australian health policy development – through analysis and workshops

Project steering committee

Ms Amanda Bresnan (Consumers Health Forum) (CHF was initially represented by Ms Melanie Cantwell)

Ms Judith Griffin (Merck, Sharp & Dohme (Australia))

Dr Sophie Hill (La Trobe University)

Professor Vivian Lin (La Trobe University)

Ms Sian Lloyd (Victorian Health Promotion Foundation) (VicHealth was initially represented by Mr John Biviano)

Professor Brian Oldenburg (Australian Institute of Health Policy Studies/Monash University)

Mrs Rebecca Watson (Australian Institute of Health Policy Studies)

Professor Andrew Wilson (Queensland Health)