AUSTRALIAN COMMISSION ON SAFETY AND QUALITY IN HEALTH CARE

DEVELOPMENT OF A CONSUMER ENGAGEMENT STATEMENT FOR THE COMMISSION

Consultation Report

November 2008

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Attachments

Glossary

Carers are families and friends providing unpaid care to consumers.

Citizen engagement is a process that:

- Involves citizens, not just the public as represented by associations, health professionals, lobbyists and interest groups, in policy formulation, priority-setting and program delivery
- Is a key component of “governance,” namely the process and traditions that determine how a society steers itself and how citizens are accorded a voice on issues of public concern, and how decisions are made on these issues
- Builds on, complements and generally moves beyond information distribution and consultation practices. It does not replace “traditional” consultation with stakeholder organizations, nor does it replace citizens’ role in the broader democratic process. Its purpose is to provide new opportunities to bring interested parties together as civic-minded individuals concerned about health issues. (Health Canada 2000).

Community means a group of people with something in common, such as people who live in the same neighbourhood, suburb or town or with a shared interest such as in the development of an accessible, effective and efficient health service that best meets their needs.

Community organisations are organisations that represent groups with particular shared interests within the community.

Consumers are users, or potential users of health services, including children, women and men, people living with a disability, people from diverse cultural and religious experiences, socioeconomic status and social circumstances, sexual orientations, health and illness conditions.

Deliberative techniques are techniques which provide participants with an opportunity to reflect, discuss, question and think. They involve participants considering facts and issues from multiple points of view, and discussion and other techniques which build participants’ knowledge and expand their understanding. They typically involve greater engagement.

Engagement is an informed dialogue between an organisation and consumers, carers and the community which encourages participants to share ideas or options and undertake collaborative decision making, sometimes as partners (Health Canada).

Health consumer organisations are organisations that represent health consumers generally, and/or particular groups of health consumers.

Respondent means an individual or organisation who participated in the consultation process through making a submission or attending a consultation meeting.

Involvement is the process of involving consumers, carers and community members in planning and decision making.

Participation occurs when consumers, carers and community members are meaningfully involved in decision making about health policy and planning, care and treatment, and the wellbeing of themselves and the community.

Patient-centred care involves providing care that is respectful of and responsive to individual patient preferences, needs and values and ensuring patient values guide all clinical decisions. It means a partnership between the consumer and the health provider and applies to all settings of care (Committee on Quality Health Care in America, 2001).

Representative is a consumer, carer or community member who is nominated by and accountable to an organisation of consumers, carers or community members.

Note: definitions of carers, consumers and participation are drawn from *Doing it with us not for us,* Department of Human Services, 2006).

Executive summary

Context

The Australian Commission on Safety and Quality in Health Care (the Commission) has been reviewing its strategic approach to consumer engagement. From July to September 2008, the Commission undertook a consultation process on the development of a Consumer Engagement Strategy.

Since this consultation, the Commission commenced development of a national safety and quality framework to provide strategic direction for improvement in the health care system. Its intent will be to ensure that the community can trust that the care they receive is safe and high quality. In 2009, the Commission will consult on the national safety and quality framework and will begin to deliver, and to support and encourage others to deliver, the elements of the framework.

The framework will shape all the Commission's current and future work, including its approach to consumer engagement. The Commission will use the valuable information gained through the consultation process to develop a high level statement of how consumers will be engaged in the Commission's work. The statement will guide how the Commission works with consumers to support and underpin the Commission's actions to implement the national safety and quality framework.

Summary of the consultation report

This report discusses the Commission's initial consultation on its future approach to consumer engagement. It:

- describes the background to this work
- sets out the consultation process
- refers to consumer engagement literature, including the general literature, a literature review commissioned for this project and literature raised in the consultation process
- discusses the feedback from the consultation process.

The consultation feedback is analysed according to key themes of:

- preliminary issues (such as language and process)
- principles for the Commission's consumer engagement
- who the Commission should engage
- engagement strategies
- barriers and support for engagement
- how communication could support engagement

The issues raised in the Background Paper and the literature are discussed in relation to the themes where relevant.

The feedback received from the consultation process will be invaluable to the Commission's future engagement activities and will be reflected at a high level in the statement, including:

- the encouragement of a partnership and patient-centred approach to engagement and care
- principles for consumer engagement
- an inclusive approach to engagement and involving harder to reach groups where appropriate
- the importance of multiple techniques, support for consumer engagement, feedback on engagement and evaluation.

The Commission notes the support for it taking a broader role in engagement across the health system and will consider this issue further in the evolution of its work on a national safety and quality framework.

In addition to informing its Consumer Engagement Statement, the feedback from the consultation process and the models and references recommended by respondents will be a valuable reference point for the Commission in its future engagement work.

The Commission will initially consider the draft framework and consumer engagement statement late in 2008. There will be consultation about the national safety and quality framework in 2009.

Once the final version of the statement is approved by the Commission, feedback will continue to be welcome, and the statement will be subject to regular review.

The Commission would like to thank all organisations and individuals who contributed to the consultation process, particularly those organisations who convened groups of consumers, carers, community representatives and consumer and community organisations to provide feedback.

1. Introduction

The Australian Commission on Safety and Health Care (the Commission) was formed in 2006 to lead and coordinate improvements in safety and quality. The Commission's role is to achieve safer, more effective and more responsive care for consumers. Accordingly, a key focus across all the Commission's work is on engagement with patients, consumers and their carers. The Commission has consumer input for each of its priority programs, as well as in its overall strategic planning and decision making. The Commission's membership includes consumer representation.

The Commission is now looking to build on its current engagement with consumers to look more broadly at the way patients and consumers are engaged in its work. To support a more active role in involving patients and consumers in safety and quality, the Commission is developing a national safety and quality framework, underpinned by a Consumer Engagement Statement. The Statement will set out how the Commission will work with consumers, carers and the community to best achieve its aim of leading and coordinating improvements in safety and quality in health care across the public and private sectors, from primary care and office based practice, to hospitals and other larger health services.

Process of developing the Statement

The Commission has worked with a Consumer Engagement Advisory Group to consider its future engagement with consumers, carers and the community. The work involves the following steps:

1. a review of relevant literature
2. development of a Background Paper for the consultation process
3. stakeholder consultation
4. development of a report on the consultation
5. presentation of the outcomes of the first phase of work to the Commission
6. presentation of a draft Consumer Engagement statement to the Commission
7. input on version one of the statement.

This document represents step 4 of the process. It reports on step 3 (the consultation process) and:

- describes the consultation process
- provides some context from the consumer engagement literature
- summarises the feedback received
- presents the Commission's response to this feedback.

Terminology

"Within health, there is no shared language about consumer engagement practice."
(Gregory & AIHPS 2008 p. 3)

As the Australian Institute of Health Policy Studies (AIHPS) has found, there is no consensus about the language and terminology that should be used to describe consumer engagement (Gregory 2008 p. 3). Terms such as 'consumer', 'community', 'citizen', 'participation', 'involvement' and 'engagement' are frequently used, but without clear or common definitions. "Terms such as 'consultation', 'involvement' and 'engagement' are often used interchangeably, although they mean different things to different people." (Health Canada 2001, Sicmes 2003)

This lack of consensus was demonstrated in responses to the consultation process, some of which expressed a preference for different terminology. In some cases, these preferences were directly opposed. For example, some responses preferred the use of the term 'consumer', others preferred the term 'community'. Some wanted the report to refer to 'person-centred' care whilst others preferred 'patient-centred care'. A number of responses asked for carers to be explicitly included.

As a result, the Commission has defined key terms used in this document in the glossary. This will also be the approach in the Statement, although the language may be further refined. The Commission has deliberately chosen language to reflect its intention to engage broadly, with consumers, carers, the community, consumer and community organisations, citizens and the general public. However, where the report refers to comments made during the consultation process, it generally reflects the language used in those comments.

In this report, the Commission refers to consumers, carers and the community. The Commission defines consumers broadly as users and potential users of health services. Although the definition is wide enough to include carers, the Commission has chosen to make a specific reference to carers to reflect their important role in the health system. Similarly, the term community conveys the Commission's desire to engage with the community, citizens and the public about safety and quality issues.

The Commission has chosen to use the term 'patient-centred care'. Patient-centred care involves providing care that is respectful of and responsive to individual patient preferences, needs and values and ensuring patient values guide all clinical decisions (Committee on Quality Health Care in America, 2001). It means a partnership between the consumer and the health provider. The Commission wants to reflect this partnership in its approach to consumer engagement. Although the term 'patient-centred' is sometimes interpreted as being specific to the acute setting, the Commission, in keeping with its role to improve safety and quality across the entire health sector, considers that 'patient-centred' encompasses all settings of care. Whilst some respondents expressed a preference for other terms such as 'people-centred', these terms are applied more broadly than health. The Commission considers that 'patient- centred' is the term that is used most often in the health context and the literature and is most easily understood. The Commission has defined 'patient-centred' broadly to include consumers and their carers and families.

2. Consumer engagement literature

This section presents a broad overview of consumer engagement literature that is relevant to the Commission's development of a Consumer Engagement Statement. The Commission has considered three broad categories of literature:

1. health consumer engagement literature generally
2. a literature review by the Monash Institute for Health Services Research focusing on patient engagement in safety and quality
3. specific literature referred to in the consultation process, as well as literature based on additional themes that were raised in the consultation process.

Literature on health consumer engagement

There is a significant body of literature about consumer engagement in health. The following overview of consumer engagement summarises key points drawn from the literature the Commission has considered as background to developing its Statement. It draws on background research for this project and *Conceptualising consumer engagement: A review of the literature* by Dr Judy Gregory for the Australian Institute of Health Policy Studies (Gregory & AIHPS 2008).

There are two strands to the Commission's interest in consumer engagement:

- engagement in its own work, which is generally at the governance, organisational, program and policy level
- encouraging and facilitating consumer engagement across the health system, at the individual, service, organisational and broad policy levels.

While the first strand will be the focus of the Commission's Consumer Engagement Statement, both strands are reflected in the discussion below.

Status of consumer engagement

Consumer engagement is recognised as a fundamental component of policy development and service delivery in the Australian health sector (Gregory 2007). However, there is little reporting on the extent or outcomes of consumer engagement.

Arguments for consumer engagement

There are a range of arguments for consumer engagement. Consumer engagement has been described as:

- an ethical and democratic right
- a way of adding legitimacy to decision making
- a way of improving health outcomes and policy outcomes
- a way of improving relationships with consumers
- a way of serving political or democratic processes (Gregory 2008, Ridley & Jones 2002).

Effectiveness and evaluation

The literature suggests that there is little evaluation of consumer engagement. According to Gregory (2008), most evaluations that are conducted tend to be descriptive rather than focusing on how the engagement influenced the decisions.

Engagement in health policy

The Australian Institute of Health Policy Studies (AIHPS) is conducting a major project considering consumer engagement in health policy specifically. This work is relevant to the Commission's Statement, because so much of the Commission's work relates to health policy.

The following themes have emerged from the AIHPS project (Gregory 2008):

- Consumer engagement in Australian health policy is poorly understood, inconsistently practised and under theorised.
- Consumer engagement is poorly defined.
- Consumer engagement is a mindset not a technique.
- Consumer engagement requires organisational commitment and a high level champion.
- Consumer engagement is an ongoing project not a fixed time event.
- Consumers need to be confident that their input will be valued and considered.
- Consumers usually need background information to contribute at the policy level.
- Different approaches to consumer engagement offer different opportunities for policy development.

Other aspects of the literature are discussed in relation to the themes from the consultation process in Chapter 4.

Literature review on patient engagement in patient safety initiatives

The Commission was particularly interested in literature focusing on consumer engagement in patient safety initiatives, in light of its role to lead and coordinate improvements in the safety and quality of health care.

Monash Institute for Health Services Research conducted a literature review for the Commission which considered the following questions:

1. What are the views of patients, consumers and the public regarding their involvement in patient safety initiatives?
2. What are the different methods and processes that could be used to effectively involve patients, consumers and the public in the planning, development and implementation of patient safety initiatives and programs?
   a. Have any of these methods or processes been evaluated?
   b. What are the critical success factors for these methods and processes?
   c. What are the limitations of these methods and processes?
3. What are the outcomes of involving patients, consumers and the public in the planning, development and implementation of patient safety initiatives and/or programs?

The review of both academic journals and grey literature identified a large number of articles and reports (9 028) referring to patient engagement in health care. However, very few were identified as directly relevant to the engagement of patients, consumers and the public in patient safety initiatives or programs. The literature review found very few primary research articles involving robust research methodologies. Further, it found that little work had been done to demonstrate the benefits of involving patients in the development, planning and implementation of patient safety initiatives or in work to improve individual patient safety. As a result, the literature review recommends further specific research to address the gaps in the literature. The literature review is available on the Commission’s website.

Literature raised during consultation

A number of submissions and consultation meetings suggested references that could inform the development of the Statement, as well as raising particular themes that required some additional literature to be considered. These publications have been referenced in this report and will be further considered in the development of the draft Statement. They are listed in the References.

3. Consultation process

The consultation process invited feedback on the Commission's proposed development of a Consumer Engagement Strategy. A Background Paper was developed to facilitate the consultation process. It contained information about the purpose of a Consumer Engagement Strategy, the Commission's approach to developing the Strategy, who the Commission should be seeking to involve, the types of involvement the Commission should be seeking and how the Commission could best support involvement.

The Background Paper:

- describes the consultation process
- raises the following questions:
    - What are your views about the Commission's approach to the development of the Strategy? Is there anything in the statements that should be changed, added or deleted?
    - Which specific groups or individuals should be involved in the Commission's work and why?
    - What aspects of the Commission's work are most important for consumer involvement?
    - In what ways should consumers be involved in the Commission's work?
    - Is there a preferred model(s) of involvement and/or a least preferred model? Why?
    - How could the Commission best support effective consumer involvement in its work?
    - Are there any barriers to effective consumer engagement by the Commission that would need to be overcome? How?
    - How could communication support the strategy and consumer involvement in the Commission's work?

The Commission sought feedback by:

- writing to key stakeholder organisations as defined by the Advisory Group, inviting feedback
- holding consultation meetings with 16 stakeholder organisations
- holding two consultation workshops with consumers and consumer organisations
- participating in a consumer workshop held by the Consumers' Health Forum as part of its partnership with the Commission
- publishing the Background Paper and an invitation to make submissions on its website
- inviting organisations and individuals who made submissions or participated in consultation meetings to comment on the draft consultation report.

Written submissions

The Background Paper was sent to 205 organisations and individuals with an invitation to provide a written submission. The distribution included:

- national health consumer organisations
- State and Territory consumer peak bodies, where they exist
- demographically based consumer organisations
- disease or condition based consumer organisations
- State and Territory governments
- State and Territory health complaints commissioners
- organisations who have developed consumer engagement strategies

The Background Paper was also available on the Commission's website, with information about the consultation process, and an invitation to make submissions. Some organisations also circulated the Background Paper within their own networks.

The Commission received 52 written submissions about the development of the Strategy. A list of organisations and individuals who made submissions is at Appendix 1. The submissions will be available on the Commission's website. There were requests for two submissions to be kept confidential, and the details of those submissions are not listed in the Appendix or the Commission's website, however the comments have been taken into account in this report. Table 1 groups the submissions according to the type of author:

Table 1

Category of author	Number of submissions
Individuals not representing an organisation	2
Health consumer organisation	6
Community or condition based organisation	7
Consumer Advisory Committees to health services	6
Government department	8*
Health service, hospital or community health facility	7
Professional or clinical peak body	16
Health Care Complaints Commissions	3
Total	55

*One Department made two submissions.

The Commission provided a further opportunity to comment on the draft consultation report and five submissions were received (see Appendix 1).

Consultation meetings

Meetings and teleconferences were held with 16 stakeholder organisations listed in Appendix 1, many of which were consumer organisations. In addition, the Commission held two consultation forums convened by the Health Consumers Network Queensland and the Health Consumers Council of Western Australia and attended the National Mental Health Consumer and Carer Forum. Further, as part of its partnership with the Commission, the Consumers Health Forum held a Consumer Engagement Workshop to inform its advocacy, develop best practice principles for consumer engagement and to feed into the Commission's work.

The Commission would like to thank all organisations and individuals who contributed to the consultation process, particularly those organisations who convened groups of consumers, carers, community representatives and consumer and community organisations to provide feedback.

4. Consultation feedback

4.1 Structure

The consultation feedback has been grouped according to the following broad themes raised in the submissions:

- preliminary issues, such as terminology
- principles for developing the Strategy
- who the Strategy should involve
- engagement strategies, including:
  - Areas and types of engagement
  - Specific strategies that the Commission could adopt
- barriers to engagement that the Commission needs to overcome
- how the Commission should support engagement
- how communication could support the Strategy
- other issues.

These themes cover the questions from the Background Paper, plus additional issues that emerged from the consultation process. The following sections of the report discuss each broad theme. Each section includes:

- an introduction to the theme
- a summary of feedback, by major themes and additional comments
- a summary of literature (where relevant).

Finally, the report explains how the Commission's Consumer Engagement Statement will respond to the feedback from the consultation process.

The term 'respondent' refers to an individual or organisation who expressed views in a written submission or at a consultation meeting.

4.2 Preliminary issues

This section discusses preliminary issues raised in the consultations, including:

- support for the Strategy
- the language to use in the Strategy
- the process of developing the Strategy.

Support for the Strategy

Summary of feedback

Respondents were overwhelmingly positive about the Commission's development of a Consumer Engagement Strategy. Twenty-eight respondents explicitly expressed support for the Strategy. One respondent emphasised the need for the Strategy to explain (using evidence) that to move towards a patient-centred approach is ultimately shifting the focus of healthcare away from services and onto people, and the need for evidence that this will actually result in safer and higher quality health practices. No respondents opposed the development of a Strategy.

Language

Summary of feedback

Twelve respondents commented on the language used in the Commission's background paper. Seven written responses and two consultation meetings suggested that the language could be more precise, clear and consistent and there could be greater use of definitions. There was an emphasis on the importance of all readers having the same understanding of terms. Two submissions observed that certain words are associated with particular philosophical approaches, and, accordingly, that the Commission should articulate the rationale behind its choice of language.

More specifically, most submissions referring to the use of language sought more clarity in relation to the terms used to describe who should/could be engaged and the terms used to describe why and how they should be engaged.

In relation to who, most respondents were comfortable with the term consumer, as long as it was clearly defined. One respondent opposed the use of the term consumer because it has economic associations rather than connections with community engagement and control. That respondent considers that if the term ‘consumer’ is used, at least it should always be used in conjunction with ‘community’.

In relation to how, one respondent considered that the term ‘engagement’ could mean interacting with consumers, carers and the community about their views, without involving them in the decision-making process. One respondent preferred the words ‘involvement’ and ‘participation’, which conveyed a sense of being part of decision-making. In relation to why, some respondents expressed a preference for the term ‘person-centred’ rather than ‘patient-centred’. Also, another respondent recommended that the Strategy refer to types of participation, rather than levels, to avoid any suggestion that some types of participation are more valued than others.

Views from the literature

As discussed in the introduction, there is no shared language about consumer engagement. A range of terminology is used by different organisations and in different documents. For example, WA Health uses engagement whilst the Department of Human Services Victoria uses participation and Queensland Health uses involvement.

Process of developing the Strategy

Summary of feedback

Nine respondents raised issues about the process of developing the Strategy, including:

- that the process of developing the Strategy should mirror the Strategy itself
- whether the consultation was sufficiently extensive
- the need to involve consumers in each stage of the Strategy’s development
- the importance of spending more time getting the practical options and implementation right – the principles of consumer engagement are universally agreed but can be difficult to translate into practice.

4.3 Principles for a Consumer Engagement Strategy

The Commission should make a commitment to putting what matters most to patients and the public at the centre of its work. Brisbane South Division of General Practice

Introduction

The Background Paper for the consultation process included a number of statements about the Commission's approach to developing the Strategy:

The Commission:

- is committed to showing leadership in promoting people-centred health care.,
- is committed to involving consumers and patients in its work.
- sees the experiences, knowledge, wisdom and perceptions of patients and consumers as essential to its work to improve safety and quality.
- believes that the perspectives of patients and consumers need to underpin the development of the Strategy.
- considers that the way in which patients, consumers, carers, health care advocates and the general public are engaged in safety and quality work should be determined by their preference, as well as by the nature of the activities being undertaken by the Commission.
- acknowledges that a number of different methods of engagement will be required.
- believes that system, policy and program drivers that promote the adoption of patient focused strategies need to be identified and encouraged.
- acknowledges the long history of consumer engagement in health that has been driven by consumers and consumer organisations.
- notes that many stakeholders such as Departments of Health, safety, quality and complaints bodies, area health services, and individual institutions, have existing consumer engagement strategies in place.
- recognises the need to draw knowledge from this history and experience, and support stakeholders' work in this area.

The Background Paper asked for comments about these statements.

Summary of feedback

Major themes

Twelve respondents supported the statements as expressed in the Background Paper. Other general comments included that there needs to be clarity about the role of the statements in the strategy, and that engagement needs principles to work.

Fourteen respondents raised other issues that could be incorporated into principles for the Strategy. These issues included:

- Partnering and inviting consumers, carers and community members to be part of the decision-making process across the Commission's work should be a core or overarching principle of the Strategy.
- Consumer representatives should be involved at all levels of decision making and governance.
- Consumer engagement processes should include health care stakeholders and consumers working together to reach best health care outcomes.
- A range of consumer representatives should be involved in policy, program and service decisions that affect the health of consumers.
- Consumers must have confidence and trust in consumer engagement processes.
- Involvement must first involve the identification of a range of expert consumer organisations.
- Involvement must be acknowledged, actively sought, accurately costed, fully funded and inclusive.

- Consumers have a right to participate in decisions relating to their own care and treatment and the design of health policy.
- The Strategy needs a statement of intent and the rationale and motivation behind involving consumers.
- The Strategy should acknowledge the central importance of primary care as a strategic component in the development of a safer, more effective and more responsive health care system.
- Recognition and promotion of the autonomy of the patient is a fundamental ethical principle and the Commission could look for opportunities to reinforce it.
- Principles and values that should underpin the Commission's work with consumers include:
    - Respect, collaboration, partnership, diversity, transparency, honesty
    - Authentic, meaningful involvement
    - Recognition of involvement
    - Sufficient time for meaningful engagement.

A partnership principle

*The development of a partnership relationship between the consumer and health professionals is in fact paramount in the delivery of quality health care…*Australian Dental Association

Twelve respondents commented on the partnership between consumers and health care providers. The majority supported the Strategy empowering partnerships between consumers and health care providers, and encouraging consumers to be partners in their own care. One respondent suggested that a patient-centred approach would be based on trust, empathy and respect.

Other views (expressed by individual respondents) are:
- the consumer should lead their own care
- where care is provided in office-based practice, the partnership should include members of the practice
- it is a significant challenge to change current paradigms and models of practice to achieve a partnership approach
- health care is already patient-centred
- partnership approaches could reduce safety, because it is the expert's role to make decisions about care.

Principles for specific aspects of the Strategy

One respondent suggested that seeking to identify the consumer, carer or community member whose experience and interests match the work area of the Commission should be a principle for any recruitment strategy for participation. Another suggested that a recruitment strategy might also consider options for development and broadening awareness.

Success factors

A number of respondents proposed factors that would contribute to the success of the Strategy based on their experience:
- clarity about the values and beliefs underpinning consumer engagement
- clarity about the purpose of each engagement activity
- clear processes that everyone involved is aware of and understands
- ensuring that there are realistic expectations
- recognising that the circumstances facing consumers, particularly their health status, can directly affect their capacity to participate
- sufficient time and resources for consumer participation to be effective and meaningful
- effective and sustainable consumer, carer and community participation requires leadership, resources, strong and effective partnership with consumers and consumer organisations and well-supported and skilled project staff.

4.4 Who the Strategy should involve

Introduction

The Background Paper asked for feedback about who the Commission should involve. It referred to four capacities in which people may become involved in safety and quality, based upon existing categories in the literature as well as current practices nationally and internationally:

- *individual patients, and carers* of patients who have received or are receiving care
- *consumers who have a specific interest in health*, but who may not be receiving care
- *organisations that represent groups of consumers* (that are often comprised of consumers and may operate as "gateways" to consumers)
- *members of the public, or citizens*

Summary of feedback

The issue of who the Strategy should involve received significant feedback. Forty two respondents commented on who the Strategy should involve. Respondents recommended that the Strategy should engage a range of groups. The feedback reflected different views about the purpose of engagement.

Major themes

A significant group of respondents saw it as important that the Commission engage directly with people who experience the health system differently from the average person, such as marginalised groups. For example, a number of respondents commented that there are safety and quality issues specific to people with mental illness.

Respondents who perceive engagement as a democratic right were concerned that members of the public or citizens should be engaged, some suggesting that participants should be randomly selected so that they were representative of the general public.

Respondents proposed the following groups should be engaged by the Strategy:

- all groups suggested in the Background Paper
- harder to reach groups, such as Aboriginal and Torres Strait Islander peoples, people with mental illness, people from culturally and linguistically diverse backgrounds, people with impaired decision-making capacity, people with lower literacy, homeless people, people with disabilities, and prisoners and people in custody.
- groups reflecting the diversity of the population, such as younger and older people, people of different sexual orientation, people from different areas across Australia, including geographically isolated people
- peak consumer and advocacy organisations
- disease specific organisations
- recent patients and carers, or "grass roots" consumers
- the general public, or citizens.

There was reasonable or strong support for including all these groups. There was a recognition of the importance of engaging with peak consumer organisations, but a majority considered that the Strategy must also engage more broadly. Some commented that there is a need to find a balance between experienced and grass roots consumers.

There was a recognition that the Strategy would need specific approaches to reach marginalised groups. One respondent recommended that because of the barriers to accessing health care and participating in health care decisions encountered by members of disadvantaged groups, a consumer engagement strategy should positively discriminate by deliberately including consumers that are also members of these groups.

Ideally the Strategy will provide a critical role for Indigenous consumers ….
Department of Health and Ageing

There were specific comments about the importance of engaging with Aboriginal and Torres Strait Islander peoples. The National Association of Aboriginal Community Controlled Health Organisations and its affiliates and other Indigenous primary health service providers were suggested as appropriate contacts. State officers of the Office of Aboriginal and Torres Strait Islander Health may be another link. One respondent commented that it is essential to incorporate a model of consultation and representation which includes Indigenous communities and families, as they provide a critical support structure to the patient/client/consumer.

Carers are seeking to be explicitly included in the Strategy in recognition of the important contribution they make to the health system.

Additional comments

Other groups that were proposed for inclusion, but by smaller numbers of respondents, included:

- consumers currently going through a complaints process
- consumers and carers who are involved in safety and quality initiatives
- people with chronic illness
- occasional users of health services
- consumers who have experienced adverse events who should be encouraged to participate in identifying issues, factors contributing to the adverse events, developing solutions and training and development of health care providers

Other comments were:

- The Strategy should be subject to an equity assessment process to ensure it is inclusive.
- The Commission needs to explain its rationale for engaging with different groups.

Views from the literature

Who gets engaged

The literature suggests that decisions about who should be involved in a consumer engagement strategy or process will depend on the issues to be considered (Gregory 2007). The literature demonstrates that targeted approaches may be required to engage harder to reach groups (for example, Keefe & Hogg 1999, Curtis et al 2004). Literature based in democratic theories of engagement supports the use of random selection and other techniques to involve the general public or citizens. Some commentators suggest that consulting only with established groups risks limiting the scope of engagement to groups and interests that already have a voice, and risks not reflecting the true spectrum of views (Gregory 2008).

4.5 Involvement strategies (how)

Introduction

The Background Paper asked how people should become involved in the Commission's work, through three questions:

1. What aspects of the Commission's work are most important for consumer involvement?
2. In what ways should consumers be involved in the Commission's work?
3. Is there a preferred model(s) of involvement and/or a least preferred model? Why?

Summary of feedback

Overview

Most respondents commented on this issue. There was a large volume of comments, which are grouped into two general strands:

- engagement in the Commission's own work, which is generally at the governance, organisational, program and policy levels
- the Commission's role in encouraging and facilitating consumer engagement across the health system, at the individual, service, organisational and policy levels.

Engagement in the Commission's work

General advice about how to engage consumers, carers and the community

*There is not one particular type of consumer engagement that will fit all consumers…*Health Issues Centre

Thirty respondents provided general advice about how the Commission should engage. The strongest message was that one size doesn't fit all. There is a multiplicity of engagement techniques and the Commission needs to select a technique that is appropriate to each issue and who the Commission is trying to engage about that issue.

It is not enough to put individual "consumer" advocates onto committees, boards and other structures...Central Australian Aboriginal Congress

Engagement techniques should be responsive to the needs of the consumers, carers and communities that the Commission is seeking to engage. The Commission should recognise the diversity of its audience, and consider issues such as literacy, culture, access and the other barriers discussed at section 4.6, particularly in relation to harder to reach and geographically isolated groups. A number of respondents recommended that the Commission should use deliberative techniques[1] where appropriate, to build the knowledge and understanding of those the Commission is consulting as well as obtaining their views.

Some respondents considered that the Commission should engage across the spectrum of types of involvement from informing to consumer, carer and community control. Others advocated for engagement towards the partnership end of the spectrum wherever possible, eg collaboration, partnership or control. One respondent emphasised that all types of engagement need to be equally valued.

There was a clear interest in the Commission building capacity in consumer engagement, including with consumer and community organisations, such as by:

- supporting consumers meeting together to facilitate learning and capacity building
- establishing a database of all consumer representative groups

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[1] Deliberative techniques involve participants considering facts and issues from multiple points of view, and discussion and other techniques which build participants' knowledge and expand their understanding.

- building the capacity of consumer representative bodies, including through specific funding of their projects, and/or using these bodies to convene discussion forums and feed information to the Commission
- establishing a consumer participation clearinghouse or resources collection, to build capacity and raise the profile of consumer research
- offering scholarships to unfunded health consumers to attend the Commission's annual or biannual conferences on safety and quality
- providing opportunities and supporting consumers to give papers at conferences.

Other strong messages were:

- The Commission should build on existing experience and use existing networks, for example consumer and community groups, including NACCHO and its affiliates and multicultural and ethno-specific organisations.
- Engagement should occur as early as possible to facilitate shared ownership and accountability of decisions and actions.
- Engagement has to be meaningful and valued or consumers will disengage. One respondent suggested that engagement should be tied to mechanisms for systems improvement.
- The Commission should create a conduit for information from consumers about priorities, safety and quality issues and ideas, eg a 1800 line for consumer feedback. The Australian Health Care Reform Alliance argued that the views of ordinary Australians should have a strong influence on the Commission's strategic planning and priority setting. The Alliance recommended that the Commission should explore the future of Australia's health care system and the key principles of a safe and high quality health system through a deliberative process engaging the Australian people.

Specific issues that the Strategy should cover

More specific issues raised about the Strategy included:

- The Strategy should explain how the Commission will provide feedback about the input received from engagement processes, how it has been taken into account and how the outcomes will be communicated to participants and the wider population.
- The Commission's approach to consumer engagement should be a model of good practice. The Commission should lead by example, and model the sort of engagement that should occur in the broader health system.
- The Strategy should promote accountability by explaining how the Commission will use the outcomes of engagement and by requiring reporting on the Strategy.
- The most effective way to ensure effective involvement is by developing a mechanism that incorporates primary care, as well as other sectors, to engage with people.

Areas of the Commission's work

There was a clear view that consumers, carers and the community should have a broad opportunity to engage with the Commission's work. Eleven respondents thought consumers should have the opportunity to be engaged in all aspects of the Commission's work, although they may opt not to be involved in particular aspects of work. Another clear message was that there should be an opportunity for input into the Commission's priorities and work program, not just existing projects.

Some respondents described the areas of the Commission's work where engagement should occur in general terms, such as policy development, project implementation, project evaluation, development of patient information and strategic planning. Others were more specific, and saw consumers as having a particular interest in individual Commission projects. Suggested specific aspects of the Commission's work where engagement should occur included:

- guidelines for involving consumers in safety and quality initiatives
- open disclosure
- adverse events
- primary care

- consumer and carer rights
- development of standards
- promotion of best practice in safety and quality
- monitoring role of safety and quality within Australian health care
- the Charter of Healthcare Rights
- patient focused interventions and impact on safety and quality
- accreditation eg the education and training of accreditation surveyors

Some respondents suggested areas which are beyond the Commission's span of responsibility, such as resource allocation conflicts and responsive care when things go wrong.

Specific approaches to engagement

A number of respondents advised the Commission to develop a comprehensive engagement strategy, whilst others focused on individual components of a strategy. Finally, a number of models of engagement were recommended.

A comprehensive engagement strategy

Some respondents advised the Commission to develop a comprehensive engagement strategy that would cover issues including:

- policy and legislation
- the need to build an evidence base for consumer engagement improving outcomes
- infrastructure support to non-government health advocacy, research, policy and support organisations
- a comprehensive recruitment strategy, incorporating peak health consumer advocacy groups, public advertising, diversity and network communication systems and incorporating a role for national health consumer and carer bodies
- consultation with specific consumer, carer and community members and groups to plan and develop the Commission's work
- public reporting on patient experience and the state of quality across the health care system, such as publication of quality indicators and data.

Support for individual components of an engagement strategy

Respondents supported the following components of an engagement strategy suggested in the Background Paper:

- consumer representation on the governance structures of the Commission (maintain or increase representation)
- a Consumer Advisory Group to the Commission, with representatives of consumers, carers, the community. Some suggested that the Group should include senior Commission management to ensure the Group had traction within the Commission and was embedded into its governance structures. Others suggested that the members of the Advisory Group would need to be supported by additional working groups to extend the coverage of engagement.
- a panel of consumer representatives that could be drawn on by the Commission
- partnerships with consumer organisations
- a dedicated role or unit within the Commission to support the Strategy and the Commission's engagement with consumers, carers and the community
- representation on project advisory committees.

Respondents suggested the following additional components:

- an independent Consultative Council to the Commission, which would be the source of consumer representatives and advice to the Commission. Representatives of the Council would sit on the Commission.
- Establishing a database of stories that could inform policy and act as a vital tool in driving quality improvement
- Involving consumers in the development of an annual report that details how the Commission has engaged with consumers, carers and the community

- Training, empowerment and support to consumers involved in the Commission's activities
- avenues for community engagement via the Commission's website
- hosting deliberative mechanisms, such as roundtables or a series of panels where consumers are provided with a safety and quality issue to examine and are then required to make recommendations
- hosting a biannual citizen's jury with consumers to examine issues of safety and quality within the Australian health care system
- the involvement of specific groups, for example one respondent argued that it should be included as a partner in the activities of the Commission, and that it must be a member of any Expert Panel and any Consumer Reference or Advisory Group
- information kits for Commission staff and consumers with resources such as template position descriptions, checklists for involving consumers on committees and reimbursement requirements.

Models of consumer engagement

Respondents were asked to comment on any good practice models of consumer engagement and any models which were not preferred. Overwhelmingly, respondents provided suggestions about good practice rather than poor examples. Some described their preferred model in general terms, whilst others pointed to specific examples of good practice.

Characteristics of good practice models included that they:

- are comprehensive
- use clearly defined terminology
- are based on principles or values that respect consumer, carer and community participation
- ensure coverage across jurisdictions
- use the full range of strategies and types of participation
- comprise legitimate processes which are linked to policy development and decision making processes
- specify clear goals of what the Commission wants to achieve before selecting a technique and recruiting consumers
- are clear about who should be engaged
- reflect well managed and resourced processes to enable the Commission to work effectively with consumers, carers and the community with time allowed for meaningful involvement and engagement
- ensure the effectiveness of programs is monitored and evaluated to continually improve systems
- involve recent patients, carers and consumers in specific projects for time-limited periods where their input is valued and will make a difference
- are inclusive
- specify a clearly defined scope and role for the strategy
- support engagement from the top of the organisation and build it from the ground up.

Specific examples of good practice recommended to the Commission were:

- *Making the Connections*, National Public Health Partnership
- Bayside Health Community Participation Model
- *Doing it with us not for us*, Department of Human Services Victoria
- *Position Statement on Consumer and Carer Participation*, Queensland Health,
- *Draft Consumer and Carer Participation Framework*, ACT Health
- *Consumer Guidelines*, Health Consumers' Alliance SA
- *Seat at the Table* program, the Breast Cancer Network of Australia
- Migrant Resource Centres
- *National Indigenous Consumer Strategy*, Department of Health and Ageing

Details of these documents are included in the References section. A number of other reference documents were recommended to the Commission and these also appear in the References section.

There were only a few examples of models of poor practice. These tended to be described in terms of generic qualities, rather than specific cases, such as:

- a standing committee of a few consumers who do not have real opportunity to change anything
- public opinion polls and symbolic consultation
- tokenistic approaches which do not take the views and needs of consumers into account.

The Commission's role in engagement across the health system

CHF encourages the Commission to take a strong leadership role on consumer engagement. Consumers Health Forum

A number of respondents made suggestions about the Commission's role in engagement across the health system, including issues such as:

- facilitating consumer engagement across the health system
- health literacy
- the need for the Commission to engage effectively with all its stakeholders, including consumers
- complaints management
- action that would support this wider role, such as reporting
- other issues that relate to a broader role for the Commission.

Facilitating engagement across the health system

There was also clear support for the Commission playing a capacity building role in relation to communication and engagement by health services across the health system:

- The Commission should encourage health services to involve consumers in their organisational decision making, and in particular in relation to safety and quality.
- In partnership with consumers, the Commission should develop guidelines for health services on how to involve consumers in quality and safety initiatives building on work in Victoria.
- The Strategy should include more meaningful approaches for consumers at the community level.
- The Commission should request annual reporting on how health services have involved consumers in safety and quality.
- The Commission should involve consumers in the development of written information for patients and guidelines to ensure health services involve consumers in the development of information.
- The Commission should develop indicators for consumer and carer engagement, involvement and participation in all health organisations. One respondent suggested that there should be measures of consumer participation with funding attached.
- The Commission should collect examples of practice in other health care settings in involving consumers in planning, delivery, treatment and evaluation.
- The Commission should leverage off existing consumer engagement occurring in the health system and make safety and quality a priority focus for consumer engagement in any setting.
- It would be useful for the Commission to encourage meaningful consumer, carer and community engagement in the private sector and a more direct consumer-health professional engagement at all levels and stages of health care. Providing a forum for discussions between consumers and health professionals.

The strategy needs to enhance the conversation between the health system and the community as well as between individual providers and consumers. Health Consumers Council WA

Health literacy and consumer capacity building

Low levels of health literacy were recognised by respondents as a barrier to engagement and to the improvement of safety and quality. A number of respondents argued that the Commission should take a lead role in building health literacy across the health system, for example by developing a national plan for improving health literacy and building health consumer capacity. One respondent noted the need for any work on health literacy to recognise its dependence on general literacy and numeracy, whilst another respondent recommended that this work should include patient empowerment or activation.

For example, respondents suggested that:

- The Commission should outline reform strategies to support and build the capacity of consumers and communities to be involved in their own health care and in the development, planning and implementation of health services, including the development of a national, comprehensive and coordinated capacity building program for health consumers.
- The Commission should use the Australian Charter of Health Care Rights as:
    - A framework for engaging the community to drive improvements in quality and safety
    - a framework for informing and educating the community about the organisation of health care in Australia
    - for consulting with marginalised and disadvantaged groups about their experiences of safety and quality.
    - to improve the community's health literacy about safety and quality in health care, with a specific focus on the needs of marginalised and disadvantaged groups
    - to explain to consumers how to be heard and involved in health care and the health system, including the right to communication when they speak a language other than English.

Engagement with other stakeholders

A number of respondents suggested that the Commission should have an engagement strategy which covered all its stakeholders, including health professionals.

Complaints

Some respondents saw potential to achieve safety and quality improvements through the Commission engaging with Health Care Complaints Commissioners and reform of complaints management. They suggested that the Commission could investigate more innovative ways of ensuring that complaints management leads to major gains in safety and quality and improvements in culture, including:

- engaging consumers from marginalised groups in improving complaints resolution processes and educating communities about the role of complaints in improving the safety and quality of care
- engaging with consumers to understand the values and priorities they are seeking from the complaints management system
- patient advocacy to support and empower patients to come forward

Other

Other views included that the Commission should have a role in relation to:

- promoting particular models of care, for example, one respondent recommended that the Commission adopt a policy that supports the planned development of community controlled comprehensive primary health care services throughout the Australian health system as a major mechanism to improve safety, quality and consumer and community engagement
- incorporating consumer engagement and a consumer focused approach into health practitioner curricula, to support an approach to patient-centred care
- setting national safety standards for health professionals
- researching and setting standards for consumer interactions with the culture of health care and how that culture affects the safety and quality of care.

Views from the literature

Types of engagement

Consumers, carers and the community can be engaged at the:

- individual level, in relation to individual care
- program or health service level
- organisational level, and/or
- policy level.

Consumer engagement is often presented as a spectrum of options from lesser engagement that offers little opportunity for input to greater engagement that can extend to partnership and joint decision making. Whilst ladder or hierarchical models are common, they have been criticised as making value judgements about different types of engagement (eg engagement at lower levels are of lesser value) or suggesting an aspirational level of joint decision making (Gregory 2008). Other commentators have argued that different methods of engagement are suited to different purposes.

The International Association for Public Participation has developed a Spectrum for Public Participation which is designed to assist with the selection of the level of participation that defines the public's role in any community engagement program (Inform, Consult, Involve, Collaborate, Empower) (IAP2 2007). It links techniques to levels of participation.

Health Canada has developed a 5 level continuum model (inform, gather information, discuss, engage, partner) which includes advice about when each level might work best (Health Canada 2000).

Some organisations refer to the types of engagement, rather than levels, to avoid any implication that some levels have more value than others. For example, *Doing it with us, not for us* (Department of Human Services Victoria 2006) refers to five types of participation: information, consultation, partnership, delegation and control.

The types of participation are discussed further in relation to the themes from the consultation process.

Engagement techniques

The literature extensively covers the wide range of possible engagement techniques. It is generally acknowledged that the technique should be appropriate to the purpose of engagement. For example, some techniques facilitate information gathering (eg surveys, focus groups), others facilitate discussion and collaboration (eg committee membership) while others facilitate informed input (eg deliberative techniques such as citizens’ juries).

There are a number of toolboxes and resources to guide selection of techniques, such as Health Canada (2000), the International Association of Public Participation (IAP2). State and Territory Health Department consumer engagement documents also discuss engagement techniques.

4.6 Barriers to involvement

Time, along with human and financial resources, are needed in order for consumer participation to be meaningful...Health Issues Centre

Introduction

The Background Paper asked whether there are any barriers to effective consumer engagement by the Commission that would need to be overcome, and how.

Summary of feedback

Respondents pointed to numerous potential barriers to effective engagement with consumers, carers and the community based on their experience with different models and programs. Many of these barriers are addressed in the section discussing how the Commission could support effective engagement which follows.

The feedback on barriers can be broadly grouped into the following categories:

- resources
- attitudes
- knowledge
- consumer, carer and community attributes
- organisational culture
- approach

Major themes

A lack of the human, financial and other resources to support engagement was the most significant barrier to effective engagement identified through the consultation process. Respondents highlighted that resource issues can be a barrier for the organisation seeking to engage with consumers, carers and the community or for the individuals and organisations that wish to engage. Inadequate support for consumers and carers participating on committees is a key barrier. It is critical to allow enough time for effective engagement.

Organisational culture and attitudes is another key area where respondents perceived that barriers operate to prevent effective engagement, such as:

- confusion about the rights of consumers to be engaged in safety and quality issues
- resistance or lack of understanding from the health care sector
- confusion about integrating consumer rights and insights into the design of health services
- political pressure and organisational values
- lack of understanding of the role, advantages and expert information that consumer organisations can provide to the Commission
- an expectation that one consumer advocacy organisation can speak for all consumers
- different power relationships
- resistance by health professionals and bureaucrats to consumers as reporters in health learning/feedback systems.

These barriers can be exacerbated by the organisation's practical approach to engagement, for example, through:

- inaccessible or technical language and acronyms
- lack of clarity around the terms used to describe approaches to consumer engagement
- use of communication media that not all consumers or carers can access
- lack of clarity about the goal of involving consumers, carers and the community.

Respondents commented that lack of knowledge can prevent consumers, carers and the community being aware of opportunities to engage, and can impede engagement itself. Knowledge barriers include:

- differing levels of expertise and knowledge on committees, which may be an impediment to consumers and carers participation
- lack of awareness of the Commission’s work
- lack of information about opportunities to engage
- low levels of health literacy
- unequal access to information, research material and data
- communication skills (health services and consumers/carers)
- lack of skills and confidence to participate.

Attitudinal barriers include unrealistic expectations of the engagement process, lack of empowerment and tokenism.

Respondents also identified consumer, carer and community attributes which may be barriers including:

- personal circumstances, such as health status
- cultural barriers
- competing demands
- geographic barriers
- literacy
- different educational levels
- gender
- ethnicity.

Some respondents commented that there may be difficulties in engaging consumers and carers, particularly those from specific groups.

Views from the literature

Barriers to engagement

The literature identifies many barriers to engagement, including:

- lack of resources, for organisations seeking to engage as well as those who engage or would like to engage
- culture and attitudes towards engagement
- literacy and knowledge of the issues

For example, see Nathan 2004, Chisholm et al 2007 and NHS 2007. The consultation process identified similar barriers to those discussed in the literature.

4.7 Supporting involvement

Introduction

The Background Paper recognised that there are a range of ways to support consumer involvement, and asked how the Commission could best support effective consumer involvement in its work.

Summary of feedback

Many of the responses to this issue addressed the barriers discussed in the previous section. Enablers or facilitators of engagement that respondents identified fell into 7 groups:

- leadership and culture
- role clarity/governance
- resources
- capacity building
- support
- communication

- recruitment and selection
- evaluation.

Several respondents suggested the development of a comprehensive organisational support process for consumer, carer and community participation that should incorporate guidelines for involvement including a recruitment strategy, sitting fee, expense policy and a quality and safety knowledge development strategy for participants. These guidelines should be incorporated into the terms of reference of the Commission's work areas.

Respondents proposed the following specific enablers.

Leadership and culture

The Strategy should develop a culture that promotes and supports consumer, carer and community engagement. The Commission's policies and procedures, including the Strategy, should demonstrate that the Commission values and is committed to consumer engagement. The Commission should carefully consider the internal culture and skills required for effective engagement. The Strategy should value consumer experience as input and evidence that is a valid basis for change.

Role clarity/governance

The Strategy should be clear about the goal of involvement, the roles of consumers, carers and community members who will be engaged and the expected deliverables. Other Commission documentation, such as project plans, should reflect the Strategy.

Resources

More respondents raised the need for proper resourcing of engagement than any other single enabler. The comments about resourcing fall into several groups:

- funding was seen as a critical enabler in several ways:
    - Sufficient funding should be allocated to consumer engagement within the Commission
    - The Strategy should provide for reimbursement of consumer, carer or community representatives for their time and expenses associated with engagement, including additional resources as required to enable harder to reach groups to participate
    - Resourcing networking and capacity building by consumer organisations.
- information - there should be open information sharing
- time –sufficient time to respond to requests for feedback should be allowed
- process/administrative
    - accessible language (also discussed in the following section on Communication)
    - accessible meeting and consultation processes, times and venues
    - good communication and feedback
    - provision for childcare or other caring responsibilities
    - good administrative support for any Advisory Group
    - meeting processes that encourage and value the contribution of consumers.

Capacity building

Respondents perceived a need for capacity building amongst consumers, carers and the community but also within the Commission. Specific suggestions included:

- training, upskilling and support for consumer, carer or community representatives, including leadership training
- training for committee chairs and other committee members to facilitate a supportive culture and valuing the consumer contribution
- skill development for senior Commission staff on consumer involvement
- skill development opportunities for consumers involved in the Commission's work based on topics identified by consumers

- an education process for consumers with impaired decision-making capacity which is tailored to their needs.

Support

There were many suggestions about how the Commission could support individual consumers, carers or community members that it might engage:

- a nominated mentor or support person on the Commission's staff and a "buddy" representative
- the availability of pre-meeting support and preparation
- support for a technical advisor to attend with an Aboriginal community representative to provide both a grassroots and technical perspective
- appropriate orientation
- appointing at least two consumer, carer or community representatives wherever possible
- being sensitive to the personal circumstances of representatives
- where appropriate, allowing representatives to have a backup representative and facilitating communication between the two, eg people with a mental illness, chronic condition or disability
- supporting each consumer, carer or community member on a Commission committee by a reference group to bring a broader consumer perspective and enable more meaningful contributions.

Communication

Skilled communication was seen as a key enabler and is discussed further in the next section.

Recruitment and selection

Suggestions relating to recruitment and selection of consumer representatives include:

- There should be guidelines for the selection of consumer representatives, including clarity about the role of committee appointments – whether members are participating as individual consumers, consumer advocates or consumer representatives.
- There should be position descriptions and terms of reference for consumer engagement.
- The guidelines for selection should facilitate engagement of a broad cross section of the public.
- A recruitment strategy might also consider options for development and broadening awareness, as well as asking for some type of translatable experience and interest in the work area.

Evaluation

Respondents considered that evaluation of the Strategy was critical to effective engagement. Some respondents suggested that the Commission should establish performance indicators for the Strategy (and consumer engagement in general) because what gets measured gets attention. One respondent advised that evaluation should consider the outcomes of engagement, as well as practice, process and management. The Commission's evaluation methods need to be developed in partnership with consumers and carers and shared with those involved in all aspects of the work.

Views from the literature

There are also many enablers of engagement noted in the literature, such as:

- organisational leadership and a champion
- training for organisations and consumers
- enough time and resourcing
- a clear framework for engagement
- good communication.

The literature reflects the issues raised in the consultation process. For example, facilitators of engagement are discussed in more detail in *Doing it with us not for us* (Department of Human Services Victoria 2006), the draft ACT Health *Consumer and Carer Participation Framework, Development of a Consumer Engagement Strategy – Background Paper on current research practice and experience* (McInerney 2008), and Gregory (2007).

4.8 Communication to support the Strategy

Effective communication is one of the key enablers of quality health care…
Department of Human Services, Victoria

Good communication must underpin consumer engagement… Consumers Health Forum

Introduction

The Background Paper asked how communication could support the Strategy and consumer involvement in the Commission's work.

Summary of feedback

Respondents provided substantial comments on this issue. Their suggestions about how communication could support the Strategy and consumer involvement in the Commission's work fall into three main groups:

- the need for a communication strategy
- suggested communication techniques
- recommended actions.

The need for a communication strategy

Some respondents suggested that the Commission needs to raise awareness about its work and safety and quality through a communication strategy. A communication strategy would support the Commission's work by informing the public about its activities, and how they can be involved and what differences and changes have been made as a result of engagement. The communication strategy should target specific audiences and be broader than the provision of information on the Commission's website to ensure wide community awareness. Other respondents considered that promoting the Strategy across jurisdictions and their communities will be a key factor in its success.

Suggested communication techniques

Respondents advised that the Commission's communication techniques should:

- be appropriate to the intended audience
- be broad and multi-modal
- use simple language and avoid managerial or technical jargon. If this language has to be used, practical examples of its use in settings familiar to consumers and carers should be provided
- use a range of consumers to road test documents to make sure they are genuinely accessible, appropriate and engaging to consumers, carers and the community
- enable consumers to play a role in the dissemination of knowledge through consumer organisations and individual advocacy
- avoid the sole use of electronic media as many consumers, carers and community members don't or can't access it so it can be exclusionary
- where electronic communication is appropriate, explore the use of timely and efficient communication methodologies, including listserves, secure website, internet surveys, electronic social networking, e-news, online journals, blogs and discussion forums. Providing skills and capital to consumers, carers and community representatives to use these technologies might need to be considered, especially when engaging special needs groups.

- at the completion of any community engagement activities, outcomes from the activity should be communicated to all participants.
- encourage partnering with health professionals, consumer organisations and government agencies on various aspects of the Strategy and highlight examples of best practice.

Recommended actions

Respondents recommended some specific actions that could improve the Commission's communication techniques, including:

- developing resources such as talking points to help start the conversation with consumers, carers and the community
- using the general media such as community newspapers as well as the Commission's website to inform and invite community engagement in specific activities
- publishing profiles of consumers/consumer organisations involved in the Commission's work and the contributions they have made
- engaging consumers as speakers at conferences, seminars and forums and including consumer segments in these activities
- using consumer and community organisation networks to promote material
- assisting in the development of feedback loops and tools for consumer, carer and community members working with the Commission to disseminate information
- presenting the Strategy and reporting on outcomes at safety and quality conferences
- addressing how information is shared with and communicated to consumer representatives in the Strategy.

Views from the literature

The literature confirms that good communication is a critical success factor in consumer engagement. For example, one of the objectives of *Doing it with us not for us* is to improve communication between all stakeholders (Department of Human Services 2006).

4.9 Other issues

Introduction

Respondents raised a number of other issues in their feedback about the Commission's development of a Consumer Engagement Strategy.

Summary of feedback

Each of the following issues were generally raised by one respondent and often go beyond the parameters of the development of the Strategy. Issues included:

- comments on the diagrams in the Background Paper
- comments on ways the Background Paper could have been improved, eg by the inclusion of local contacts
- a proposal that the Commission should consider a longitudinal study of people's experience in the health system
- a suggestion that the Commission should investigate the safety and quality of health care in prison
- arguments to support the need for reform of the current professional controlled primary medical care system
- privacy issues for carers in mental health
- medication interactions for people with mental illness.

5. Response and next steps

The Commission will draw on the feedback from the consultation process and the recommended models and references to develop a draft Consumer Engagement statement. This section explains how the comments from the consultation process will be taken into account in the draft statement and the relationship of the consumer engagement statement to the National Safety and Quality Framework.

Guidance for the statement

The Commission is currently developing a national safety and quality framework to provide strategic direction for improvement in the health care system. The intent of the framework will be to ensure that the community can trust that the care they receive is safe and high quality. The framework and its intent will shape the consumer engagement statement.

Language

As in this report, the statement will

- refer to consumer, carer and community wherever relevant
- use the word "engagement" in its broadest sense to refer to the involvement of consumers, carers and the community in policy, planning and decision-making. This term is intended to reflect the Commission's intention to be inclusive and proactive in its engagement.

Who the Statement will seek to engage

The Commission has a broad role to look at safety and quality issues across the health system. Accordingly, the Commission will seek the views of a diverse range of individuals and groups, with particular attention to groups that are harder to reach. Who the Commission seeks to engage will depend on the particular issue involved.

Peak consumer and advocacy organisations are often comprised of consumers and may operate as "gateways" to consumers. Their expertise and knowledge of consumer issues will be a valuable source of information for the Commission's work. More broadly, the general public or citizens may also have important insights into the safety and quality issues in the health system.

How the Commission will engage

The Commission agrees that its consumer engagement should involve multiple techniques, driven by the issue involved, and the consumers, carers and community that the Commission is seeking to engage.

The Commission will support consumers to participate in its work. It is committed to providing feedback on its engagement processes and to reporting on the statement and its implementation. The Statement will provide opportunities for consumer, carer and community involvement across the Commission's work.

The Commission will also draw on the characteristics of good practice and good practice models recommended to the Commission.

Overcoming barriers and supporting the statement

The Commission will ensure that it minimises the barriers to engagement identified through the consultation process. Its approach will incorporate key enablers of engagement.

Communication

The Commission recognises the importance of good communication in all its work, and particularly in consumer engagement. The Commission will provide relevant and accessible information about its work.

The Commission’s leadership role in engagement

The Commission notes the support for it taking a broader role in engagement across the health system. The Commission is committed to taking a leadership role through:

- modelling good practice in relation to consumer, carer and community engagement and
- helping to build the evidence base for effective engagement and its contribution to outcomes wherever possible.

The Commission is also considering the need to improve health literacy and the potential benefits for safety and quality. The national framework for safety and quality will contain more information on this issue.

Next steps

The Commission will initially consider the draft framework and consumer engagement statement late in 2008. There will be consultation about the national safety and quality framework in 2009. Once the final version of the consumer engagement statement is approved by the Commission, feedback will continue to be welcome, and the statement will be subject to cyclic review.

In addition to informing its Consumer Engagement Statement, the feedback from the consultation process and the models and references recommended by respondents will be a valuable reference point for the Commission in its future engagement work.

Appendix 1 - Submissions and consultation meetings

Submissions

ACT Health
Australian and New Zealand College of Anaesthetists
Australian Council on Healthcare Standards
Australian Dental Association
Australian General Practice Network
Australian Health Care Reform Alliance
Australian Healthcare & Hospitals Association
Australian Nursing and Midwifery Council
Australian Physiotherapy Association
Bayside Health Community Advisory Committee
Breast Cancer Network Australia
Brisbane South Division of General Practice
Cancer Voices NSW
Central Australian Aboriginal Congress
Central Northern Adelaide Health Service
Children, Youth and Women's Health Service, SA
Chiropractors' Association of Australia
Chronic Illness Alliance
Clinical Excellence Commission
Cochrane Consumers Network
Commonwealth Department of Health and Ageing
Consumers Health Forum of Australia
Greater Southern Area Health Service
Greater Western Area Health Service
Health Complaints Commissioner Tasmania
Health Consumers Network Queensland
Health Issues Centre
Heart Foundation
Heart Support Australia, ACT Branch
Hunter New England Area Health Service
Jennie Burrows
Melbourne Health Community Advisory Committee
Northern Health Community Advisory Committee
NSW Health
Office of the Public Advocate Queensland
Pharmaceutical Society of Australia
Private Mental Health Consumer Carer Network (Australia)
Public Interest Advisory Centre Ltd
Royal Australasian College of Surgeons
Royal College of Nursing Australia

Royal Women's Hospital
SA Health
SA Safety and Quality in Health Care Consumer and Community Advisory Committee
South Eastern Sydney Illawarra Area Health Service
Southern Adelaide Health Service
Southern Division of General Practice
Tasmanian Department of Health and Human Services
The Royal Australian and New Zealand College of Radiologists
The Royal Australian College of General Practitioners
Victorian Department of Human Services
Victorian Health Services Commissioner
WA Department of Health

Comments on draft consultation report

Australian Healthcare and Hospitals Association
Commonwealth Department of Health and Ageing
SA Safety and Quality in Health Care Consumer and Community Advisory Committee
Department of Human Services Victoria Participation Advisory Committee
WA Office of Safety and Quality in Healthcare

Consultation meetings and teleconferences

Carers Australia
CHOICE
Cochrane Consumers Network
Council on the Ageing
Federation of Ethnic Communities Councils of Australia
Health Consumers Alliance SA
Health Consumers Council ACT
Health Consumers Council WA
Health Consumers Network Queensland
Health Consumers of Rural and Remote Australia (teleconference)
Health Issues Centre
Health Quality and Complaints Commission Queensland (teleconference)
Mental Health Consumers Association
Mental Health Council of Australia
National Aboriginal Community Controlled Health Organisation (teleconference)
National Mental Health Consumer and Carer Forum
National Rural Health Alliance
Office of Health Review WA

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