

DEVELOPMENT OF A CONSUMER ENGAGEMENT STRATEGY FOR THE COMMISSION

Background Paper

July 2008

This document is part of a priority program initiated by the Australian Commission on Safety and Quality in Health Care in its 2007-2008 work plan. The content of the document has not been endorsed by Commission members, Health Ministers or State and Territory Health Departments.

CONSUMER ENGAGEMENT STRATEGY: BACKGROUND

The Australian Commission on Safety and Quality in Health Care's aspiration is to promote a more person-centred health system as an important driver for improved safety and quality. Patient centeredness is a term designed to encourage new perspectives and new forms of integration and collaboration for patients, carers, consumers, communities, clinical and managerial staff.

Here, a "person-centred" or "patient-centred" health system would emphasise attention to patients' and consumers' psychosocial as well as physical needs, that treatment choice takes personal preferences into account, and that self-care is supported as well as treatment. Central to this is the development of a sense of partnership in care, and facilitation of patient involvement in decision making about treatment.

In working towards a people-centred health system, the Commission values:

- Engagement with consumers, patients and carers
- The right of people to be heard and involved in their care and the health system

The Commission is developing a new Consumer Engagement Strategy as an important way of expressing these values.

The Commission is consulting stakeholders about the Strategy and this paper provides some background for the consultations and highlights issues that will be explored during the consultations.

THE STRATEGY DEVELOPMENT PROCESS

Purpose

The Commission is working to promote patient centred care in all of its programs and projects, and specifically in the Australian Charter of Healthcare Rights, Open Disclosure, and Clinical Handover. The Commission's Consumer Engagement Strategy will set out how the Commission will work with patients, consumers, carers, health care advocates and the general public to best achieve its aim of leading and coordinating improvements in safety and quality in health care.

The Consumer Engagement Strategy should demonstrate best practice in the way in which patients, consumers, carers, health care advocates and the general public are engaged in the Commission's work.

How the strategy will be developed

The development of the Strategy will draw on a literature review and the perspectives of consumers and patients to examine existing and innovative models of consumer engagement. The literature review will include publications by consumer organisations, academics and other organisations that have undertaken work in this area including those with their own consumer engagement strategies.

The main activities to be undertaken as part of the Strategy development include:

- ongoing liaison with an Advisory Group established to provide expert consumer input to the development of the Strategy
- consultation with key stakeholders, including consumer organisations
- a public invitation to make submissions about the development of the Strategy
- a review of relevant literature to identify possible models of consumer engagement
- preparation of documentation for the Strategy.

Anticipated outputs

It is expected that the Strategy produced as part of this work will address:

- the Commission's goals for consumer engagement
- the most effective ways in which patients, consumers, carers, health advocates and the general public can be involved in the various activities that the Commission undertakes
- how the Strategy can be implemented and the resources that would be needed to implement it effectively.

The Commission's Approach

The following statements reflect the Commission's approach to developing the Strategy:

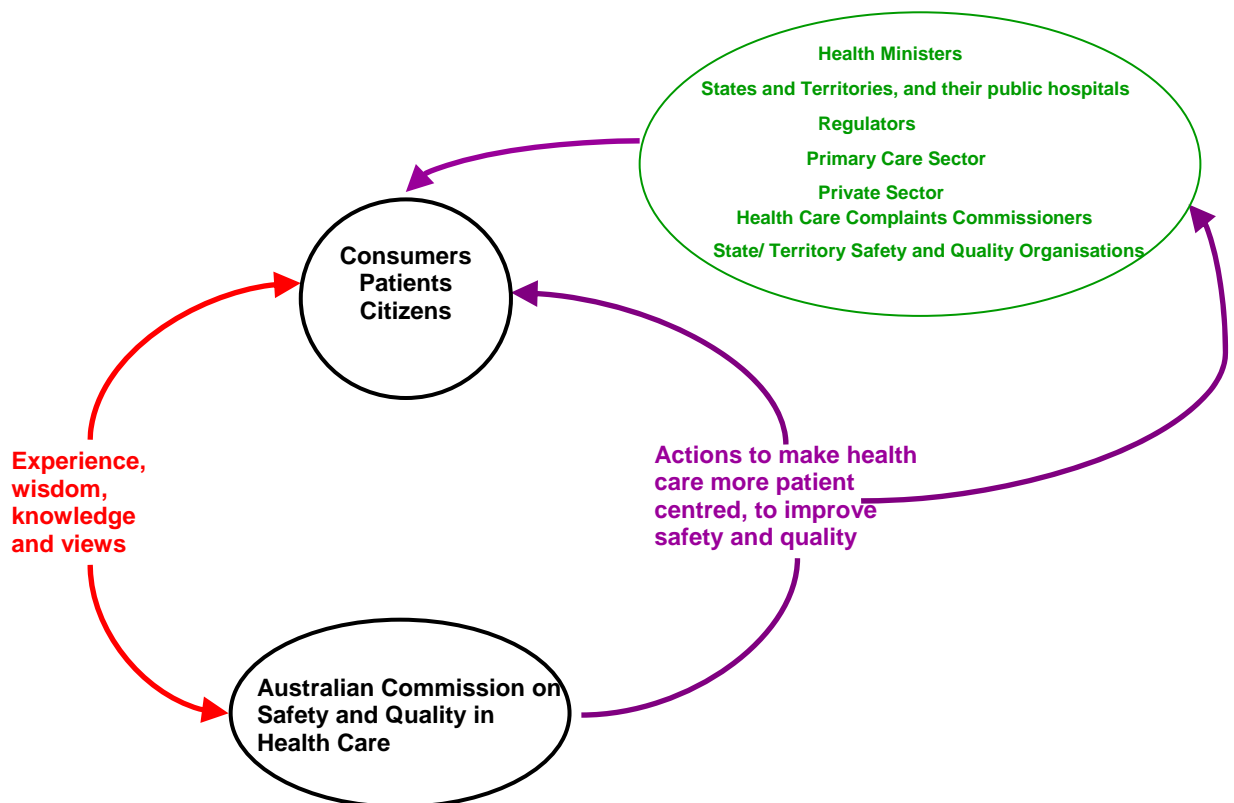
- The Commission:
 - is committed to showing leadership in promoting people-centred health care,
 - is committed to involving consumers and patients in its work.
 - sees the experiences, knowledge, wisdom and perceptions of patients and consumers as essential to its work to improve safety and quality.
 - 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.
- Note 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.

Issue : 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?

The diagram below is a model of the contribution of patients and consumers to the Commission's work. The goal of the Strategy is to find effective ways to enable and support the communications depicted by the red arrows.

Figure 1: Model of the contribution of consumers and patients to the Commission's work to improve safety and quality



APPROACHES TO CONSUMER INVOLVEMENT

Who should be involved?

Research suggests that people become involved in safety and quality in health care in various capacities:

- *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*

Individual Patients and Carers

The place of patients in healthcare is changing. Patients (and carers) are taking on more prominence as individuals are interested in sharing decision making about their (and family members) care with clinicians. Also, patients are increasingly being involved in patient safety and practice improvement, including, for example, engaging patients in infection control initiatives and collaborating with consumers across the spectrum of care from prevention of errors to their investigation. Patients and service users have a role to play in service development as well as to support the provision of care. Patients are increasingly involved in service planning and evaluation. For example, the New South Wales (NSW) Health Clinical Services Redesign Program (CSRP) has developed a method for capturing and analysing patient and carer experiences to improve the ‘patient journey’ through the NSW Health System. A patient journey refers to the process or progressive steps taken by a patient as they received health care. The project is based on research from the Picker Institute UK which found that patients and carers value:

- Access to Care
- Respect for Patient values, preferences, and expressed needs
- Coordination and integration of care
- Information and education
- Transition and continuity
- Physical comfort
- Emotional support and alleviation of fear and anxiety, and
- Involvement of family and friends.

Consumers who have a specific interest in health

Many people who have previously been patients and/or had family members who have been patients, or people who have specific knowledge concerning the health system, medicine, or system related issues more generally, are increasingly becoming involved in safety and quality in health care. For example, people with an interest in health and knowledge of error prevention in other high risk system based industries choose to become involved in safety and quality initiatives. Such people contribute to service redesign and setting the strategic direction and governance of safety and quality. For example, the NSW Clinical Excellence Commission has appointed a consumer with knowledge of safety and quality and systems issues in aviation, to its governing board.

Consumer group involvement in health care

In Australia, much of the literature and many of the current structures in place to facilitate consumer involvement in health, have evolved from the contribution made by organised consumer groups.

Organised consumer group involvement in health care is not new in Australia. The health consumer movement has a long history and has made, and continues to make, a significant contribution to the theoretical and practical issues surrounding consumer involvement in health.

The Consumers' Health Forum of Australia (CHF) was formed in May 1987, with the aim of providing a national health consumer voice. As an independent non-government organisation, CHF influences the Australian health system by representing and involving consumers in health policy and program development. CHF membership organisations reach over a million Australian health consumers across a wide range of health interests and health system experiences. For example, the CHF has a Consumer Representatives Program which aims to nominate, resource and coordinate consumer representatives for national health-related committees. The program provides consumer representatives to over 230 Department of Health and Ageing, portfolio and related committees and working groups with a health remit. See www.chf.org.au

The Health Issues Centre was also formed around this time (1985) as an independent, not-for-profit organisation to promote equity and consumer perspectives in the Australian health system. They continue today. Their mission is to improve the health outcomes for Australians, especially those who are disadvantaged. The focus of Health Issues Centre's work is mainly in Victoria, but they do take a national approach where appropriate. The Health Issues Centre works with a wide range of consumers, health providers, researchers, governments and other health organisations to achieve their mission through:

- policy analysis and advocacy from consumer and equity perspectives;
- consumer-focused research;
- promoting and supporting consumer participation; and
- disseminating information.

The centre has produced literature on consumer participation in health care generally, as well as some specific literature on consumer participation in safety and quality, such as *Making Space for the Consumer in Safety & Quality (A Guide for Consumer Advisory Committees in Victorian Public Health Services)* 2006. See www.healthissuescentre.org.au .

In 1996, the *Taskforce on Quality in Australian Healthcare* report recommended that Australian healthcare processes and systems be redesigned to have a stronger consumer focus. This led to the establishment of the Consumer Focus Collaboration, which in turn established the National Resource Centre for Consumer Participation in Health (NRCPH). The NRCPH performed the following functions:

- A clearinghouse for information on consumer feedback and participation methodologies; and
- A Centre of Excellence where people could seek advice and assistance to develop, implement and evaluate consumer participation methods and models; and Centre for Research and Special Projects on consumer participation topics;

A selected list of NRCPH publications and projects is at Attachment 1.

In October 2004 the NRCPH closed. Since then, the participateinhealth web site has been managed and maintained by Health Issues Centre. Health Issues Centre maintains this section of its web site with funding from the Victorian Department of Human Services. It provides information and practice examples about consumer participation. The web site also includes resources to help consumers, carers and community members participate in the health system and to assist health services to include consumers and the community in their decision making processes. See the Participate in Health section at <http://www.healthissuescentre.org.au/participate/> .

The publications section of the Participate in Health website has also been preserved by the [National Library of Australia](http://pandora.nla.gov.au/pan/30432/20050306-0000/www.participateinhealth.org.au/clearinghouse/index.html) at <http://pandora.nla.gov.au/pan/30432/20050306-0000/www.participateinhealth.org.au/clearinghouse/index.html>

Members of the Public or Citizens

Whilst investment in consumer involvement has been evolving in the United Kingdom and Canada for a number of years, the importance of this investment has only been recognized in Australia relatively recently. Despite low investment in consumer engagement in Australia, models of best practice have been emerging over many years, including those which involve support, collaborations and representation amongst consumer networks. Engagement at the “member of the public”, or “citizen” level refers to involving consumers, not just the public as represented by associations, health professionals, lobbyists and interest groups, in policy formulation, priority setting and program delivery. This level of engagement 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.

Issue: Which specific groups or individuals should be involved in the Commission’s work and why?

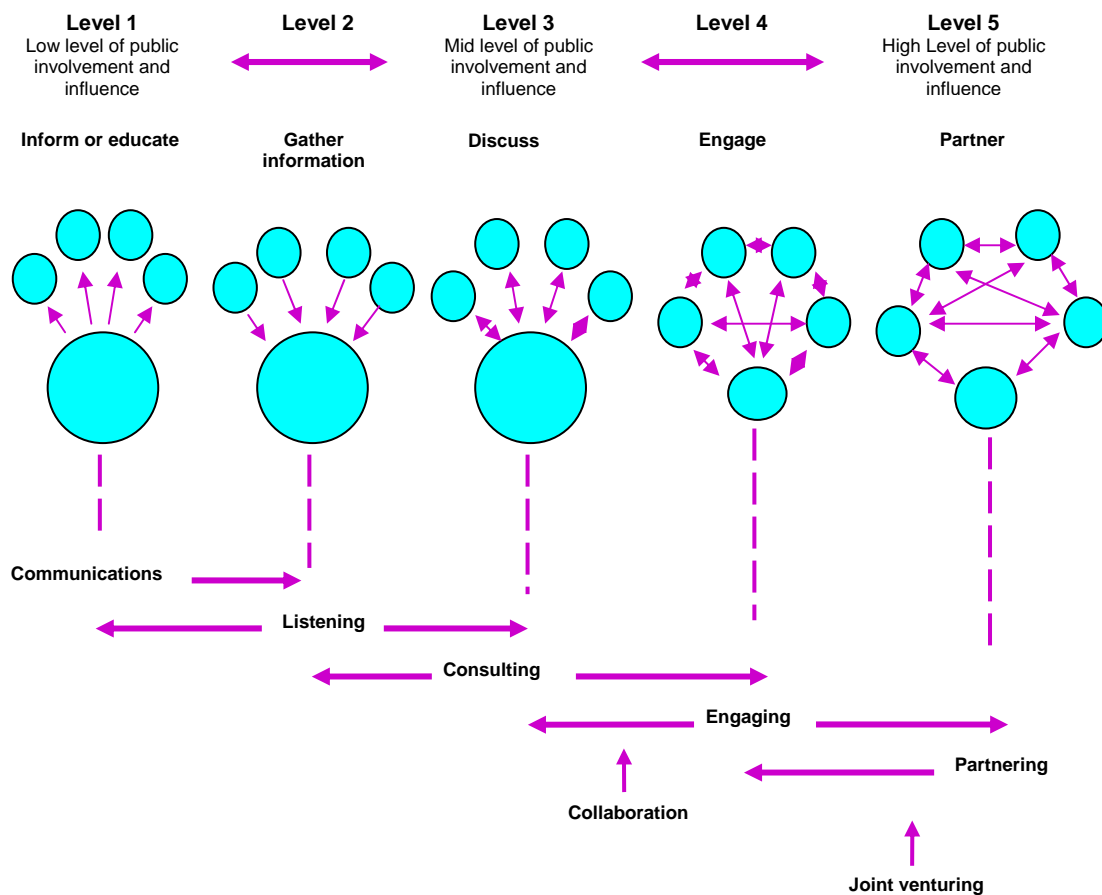
How should people become involved?

Research demonstrates that people become involved in safety and quality in health care in the following areas:

- *Individual care* – where patients are involved in their own individual care;
- *Program, institutional or departmental involvement*– where patients, carers, consumers, community members and citizens are involved in decision making about health care service or institutional re-design and safety and quality improvement. This involvement is at the program, institutional or organisational level rather than the individual level; and
- *Setting the strategic direction/governance* - where patients, carers, consumers, community members and citizens are involved in setting the strategic direction and the governance of safety and quality issues across the health system.

Techniques for Involvement

Regardless of the area of involvement, there are various techniques utilised for involving people. The techniques sit along a continuum of levels ranging from information sharing and educating through to partnering, as demonstrated by the following diagram:



Adapted from Health Canada

Level 1 techniques – information or education

The objective of *Level 1* activities is to convey facts. For example, Level 1 activities are used to communicate factual information about a policy, program or process. Generally a decision has already been made and the public needs to know the outcome, although there is no opportunity for influence. Examples of Level 1 activities include advertising, mail-outs, information kits and web postings. The Commission uses level 1 techniques when it provides updates about its work on its website or in print.

Level 2 techniques– listening and gathering information

The purpose of *Level 2* activities is to listen and gather information and views. Policy decisions are still being shaped and there may not be a firm commitment to do anything with the views collected. Level 2 techniques include bilateral meetings with stakeholders to identify, define or clarify issues and exchange information, community or public meetings, questionnaires and surveys. The Commission used level 2 techniques when, following the evaluation of the open disclosure pilot, it held meetings with rural consumers to discuss their views on open disclosure.

Level 3 techniques – discussing and consulting

Level 3 techniques involve a two way information exchange. Generally, individual groups have an interest in the issue, are likely to be affected by the

outcome and there is an opportunity for them to influence the final outcome. Discussion among and with stakeholders is encouraged and their input may shape future directions. Techniques include computer assisted participation, written submissions, an issues conference, workshops, and convening an advisory committee, board or council to advise or comment on recommendations for action. For example, the Commission used level 3 techniques when it held workshops to gather information about consumers' views on accreditation reforms.

Level 4 techniques - engaging

Level 4 techniques are used when there is a need for discussions about complex, value-laden issues. There is the capacity for citizens to shape policy and program decisions that affect them and the opportunity for shared agenda setting. There are open time frames for deliberation on issues and the options generated together are respected. Examples of level 4 activities include some working groups and workshops, dialogue (a structured, usually moderated, process to discuss and deliberate on issues allowing participants with differing values and priorities to build a common understanding of the problems and opportunities), public forums and round tables.

Level 5 techniques - partnering

Level 5 activities are aimed at partnering with consumers. There is a need for consumers and consumer groups to manage the process. There is an agreement at the outset to implement solutions generated by consumers and groups and to develop policies and programs in partnership. Examples of level 5 activities might include health planning, implementation, research, and evaluation undertaken in partnership with consumers.

Research on consumer involvement

Research in the area of consumer involvement in safety and quality indicates that:

- Organisations that employ a variety of techniques of consumer involvement obtain better information about their organisation from those people who use it;
- Different techniques of consumer involvement work for different groups of consumers;
- Some techniques work better for different areas of involvement in organisations;
- The purpose of consumer involvement in particular activities will often determine what technique is needed; and

- Using a variety of techniques to explore a particular problem or issue is likely to provide information that can more readily be acted on by staff. ¹

Techniques used in Development of this Strategy

The development of the Commission's Consumer Engagement Strategy will use level 1 to level 3 techniques:

- Level 1 involves providing information about the strategy on the Commission's website;
- Level 2 involves bilateral meetings with stakeholders to identify, define or clarify issues and exchange information in relation to consumer engagement approaches;
- Level 3 involves seeking written submissions about the Strategy and constituting an Advisory Group for the project which is made up of consumer representatives.

¹ (*Enabling the Consumer Role in Clinical Governance – A Guide for Health Services*, (2003), The Victorian Quality Council, The Victorian Government Department of Human Services, Melbourne, Victoria).

CONSUMER INVOLVEMENT IN THE COMMISSION'S ACTIVITIES

The Commission currently involves consumers in its work, both in relation to improving the safety of their own care and improving the policies, systems and practices that make health care safer for everyone. For example, there is currently a consumer representative on the Commission's governing body. Consumer representatives have also been involved in Commission's programs and projects, for example the National Open Disclosure Project and the Patient Charter Project. The Commission has established a partnership with the Consumers Health Forum to collaborate on consumer engagement.

The Commission wishes to explore how its consumer involvement practices can be built into a more evidence based, strategic framework.

Case study

The following case study describes some of the Commission techniques in developing the Australian Charter of Healthcare Rights. As the Charter has not yet been implemented, it also describes some possible techniques that may be utilised in the future.

CASE-STUDY THE COMMISSION'S AUSTRALIAN CHARTER OF HEALTHCARE RIGHTS
LEVEL 1 Involvement in individual care
An example of a patient being given a copy of the Australian Charter for Health Care Rights when admitted to hospital is an example of Level one involvement in Individual Care. The Charter is akin to a fact sheet: It is a compilation of key information on an issue for the public. The aim in providing the Charter to individual patients is to inform and heighten awareness about what they can expect as an individual, by providing a broad overview of Patient Rights.
LEVEL 2 Involvement in institutional assessment of Charter
An example of a patient being asked to complete a structured questionnaire or survey on their opinion of how effective or informative the Australian Charter of Healthcare Rights was for their stay in a particular hospital is an example of a level 2 involvement at the institutional level. The questionnaire or survey is used by the Institution as a means of gathering information to measure attitudes and obtain opinions in order to inform service delivery at the institutional level.
LEVEL 3 Involvement in program development
An example of a person participating in a workshop hosted by the Commission to participate in developing the Patient Charter is an example of a level 3 activity at the Program level. The Commission held workshops at various centres around the country at which participants from diverse groups and backgrounds who shared a common interest in the Charter but brought different perspectives on how it should be addressed, were involved in group discussions. People with differing values, priorities, group affiliations and individual experiences all contributed to identify potential issues and expectations in relation to the Charter.

LEVEL 3 Involvement in the Reference Group for the Charter : Setting Strategic Direction

The Commission appointed a reference group to shape the development of its Australian Charter for Health Care Rights by advising on the strategic direction for the program. The reference group consisted of various members, including consumer representatives from the Commission's governing body and consumer and patient groups.

LEVEL 4 Involvement of Health Consumer Partnerships

The Commission partnered with CHF, eg CHF identified health rights as a priority for the consumer network and held a workshop and meeting with its members to discuss and take their input to the Commission. CHF advised the Commission on ways to consult with health consumers.

Possible components of a Consumer Engagement Strategy

The following are examples of consumer engagement that could be incorporated into the Commission's Strategy:

- Appointment of a consumer engagement expert to the Commission staff
- Establishment of a consumer/citizen advisory committee to provide advice
- Continuing to include consumer representatives on specific-purpose working groups established by the Commission
- Establishment of a panel of consumer experts that can be drawn on by the Commission
- Partnerships with consumer organisations
- Public consultation processes that enable consumer and citizen participation

These are only examples of possible components of a Strategy and there are other possibilities which could be considered.

More information about the Commission's work, its work program and activities is available at www.safetyandquality.gov.au .

Issue: 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?

Supporting consumer involvement

There are a range of ways to support consumer involvement and there may also be barriers to effective consumer engagement, for example, the availability of expenses, appropriate orientation etc. Other issues which the Strategy could address to promote effective consumer involvement include:

- How information will be shared with and communicated to consumer representatives
- Providing feedback to consumer participants on the outcomes of their involvement
- Wherever possible, allowing sufficient time for meaningful consultation
- Monitoring and reviewing the effectiveness of consumer involvement

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 FUTURE OF THE STRATEGY

The Commission will consider the draft Strategy and a report on its development in October 2008. Depending on the Commission's views, it is expected that information about the Strategy and its development will be available on the Commission's website soon after the Commission's meeting.

The Commission is developing the first version of the Strategy in the knowledge that it will be regularly reviewed to ensure that it reflects good practice in consumer involvement and stakeholder feedback. The Commission will welcome feedback on the Strategy at anytime. The Strategy and details of how to provide feedback on it will be published on the Commission's website.

Attachment 1 Selected NRCPH documents and projects

The NRCPH produced a series of documents and carried out a series of projects on consumer participation in health, including:

- *Consumer and Provider Partnerships in Health Project (2001-2002)*
- *Consumer and Provider Partnerships: What makes them Work 2003*
- *Consumer feedback in Australian Public hospitals 2001*
- *Consumer Participation Needs Assessment 1999*
- *Consumer Participation in Australian Primary Care : A Literature Review 2002*
- *Consumer participation in Primary Health Care Project (2002-2003)*
- *Education and training for consumer participation in health care: resource guide*
- *Feedback, participation and consumer diversity – A literature review 2000*
- *Feedback, participation and consumer diversity – An annotated bibliography 2000*
- *Feedback, Participation and Diversity Project 2000*
- *Hospital Audit Toolkit for consumer participation 1999.*
- *Improving health services through consumer participation – A resource guide for organizations*
- *Organisational Self-assessment and Planning Tool for consumer and community participation 2003*
- *Review of existing models of reporting to consumers on health service quality – Summary report and guidelines*
- *Stocktake of models and approaches to facilitating consumer access to health information – A report*

Attachment 2

References

Department of Human Services, Doing it With Us Not For Us: Participation in your health service system 2006–09, Department of Human Services, Melbourne, viewed 9 July 2008, <http://www.health.vic.gov.au/consumer/downloads/do_it_with_us.pdf>

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