

Health Consumers Queensland
Information paper

...your voice in health

Consumer and
community
engagement and
patient involvement
and participation
in health service
planning, delivery
and evaluation

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1. Introduction

This information paper is the first in a two-part series of papers, focusing on consumer and community engagement and patient involvement and participation in health service planning, delivery and evaluation. It is based on an extensive review of the literature and current practices within Australia and other international contexts. It is not intended as an authoritative document but merely as a guide for those intending to engage with their consumers, patients and community at a variety of levels for various reasons and outcomes.

This paper may be used to inform and assist community organisations and government agencies, who want to undertake consumer or community engagement or patient involvement in the planning and decision making processes of their organisation or agency. In addition, the paper is a tool for staff of organisations and agencies to assist them to improve their knowledge, skills and competencies in consumer and community engagement in the health sector. Engagement is about the journey, not the destination, if an organisation or agency wants to maintain good relationships, credibility and integrity with those with whom they engage, beyond the engagement activity and the initial outcomes.

The second paper focuses on informing and assisting consumers, communities and patients about the engagement process and how they can provide quality input into health services planning, delivery and evaluation processes. It must be acknowledged that the consumer or patient is central to the Queensland health system and that all interventions should be aimed at ensuring consumer or patient-centred care and support, in an environment where quality, safety and effectiveness of service delivery is paramount.

Health Consumers Queensland (HCQ)

supports: consumer, community and patient involvement in all aspects and stages of the persons' health care journey. Two of HCQ's terms of reference directly relate to consumer engagement, representation, capacity building and participation by consumers and the broader community in health matters.

Term of reference 2 Health Consumers Queensland's term of reference 2 states:

“Develop a plan and framework that promotes and informs individual, broader community and systemic health consumer engagement and representation in Queensland, in line with contemporary and innovative service delivery and sector best practice.”

Term of reference 3 Health Consumers Queensland's term of reference 3 states:

“Work collaboratively with Health Community Councils to develop strategies to increase consumer capacity and participation in councils and provide advice around consumer engagement initiatives and activities in local communities.”

2. Background

The People's Charter for Health

builds on the 1978 Declaration of Alma-Ata, s IV, which stated that people have a right and duty to participate individually and collectively in the planning and implementation of their health care.¹ The Charter fosters the “perspectives of people whose voices have rarely been heard [and] encourages people to develop their own solutions and to hold accountable local authorities, national governments, international organisations and corporations.”² Participation of people and organisations is essential to the formulation, implementation and evaluation of all health and social policies and programs. Consumer engagement in Australian health policy is poorly understood, and inconsistently practiced.³

For some time now, Australian health consumers have been asking for greater involvement in their individual care planning and in the planning and evaluation of health programs, services and policies that influence their lives and the lives of their families, friends and community. Consumers argue that they can make a difference and be a part of the change process for the common good. In simple terms, health consumer/patient and community engagement and participation is an interactive process between a health department, service or practitioner and health consumer/s for information giving, information seeking, information sharing and involvement in the decision-making processes that affect individuals and their communities of interest. Health consumers' individual and collective lived experiences provide useful information on the efficiency and effectiveness of their particular health systems.

Reports indicate that health system users in the future will be: more self-assertive and want inclusion in their health treatment

1 World Health Organisation. (1978). Declaration of Alma Ata: Report of the International Conference on Primary Health Care. Geneva: Author.

2 People's Health Movement. (2000). People's Charter for Health. Retrieved on 22 August 2008 from: <http://www.phmovement.org/files/phm-pch-english.pdf>

3 Gregory, J. (2008). Engaging consumers in discussion about Australian health policy: Key themes emerging from the AIHPS study: Discussion paper for the AIHPS national citizen engagement forum, 16 September 2008, Brisbane: AIHPS. p.2.

planning; better educated; older; more likely to have multiple health concerns; skilled at finding information; understand the technology to mediate health interactions; and have greater awareness when mistakes happen in the health system. Users will not be afraid to shop around for the health care and services to meet their needs and budgets.⁴

Participation in and engagement with

the health system is driven by either a social justice or scientific or managerial or market orientation. A social justice orientation includes involving consumers and community to ensure their rights are addressed, they achieve equity in service delivery and they are empowered to be full partners in their health care and service delivery. From a scientific orientation, consumers would be looking to comment on improved health outcomes and the effectiveness of clinical care. Using a managerial orientation, consumers would expect that as a result of their input, health safety and service quality was improved, adverse events were reduced and funds were used cost-effectively. A market orientation would include the outcomes of involving consumers to achieve market share and to have consumer needs met.

Whatever the orientation, encouraging consumer engagement and participation in health service planning, delivery and evaluation reduces political risk in a democratic society where resources are inadequate to meet identified demand and there is public call for professional and clinical accountability. "Involvement must be acknowledged, actively sought, accurately costed, fully funded and inclusive."⁵

As a means for government and organisations to demonstrate inclusion and transparency, consumer, carer and community participation:

*"encourages consideration and debate through processes that allow people to be involved in decision-making about their health care and that of the community. It necessitates the communication of your view, scrutiny of motive and an ability to listen and appreciate other's views and ideas. Through involvement decisions are made that may accommodate a range of perspectives."*⁶

4 Horey, D. and Hill, S. (November 2005). 3rd health policy roundtable: Engaging consumers in health policy at Parliament House, Canberra. Melbourne: La Trobe University School of Public Health.

5 Gregory, J. (2008). Engaging consumers in discussion about Australian health policy: Key themes emerging from the AIHPS study: Discussion paper for the AIHPS national citizen engagement forum, 16 September 2008, Brisbane: AIHPS. p.14.

6 Rural and Regional Health and Aged Care Services Division, Victorian Government Department of Human Services. (2005). Participation indicators: Participation in your health service system: Victorian consumers, carers and the community working together with their health service and the Department of Human Services. Melbourne: State of Victoria, Department of Human Services.

Underpinning all understandings

of consumer and community engagement and participation, the proposed facilitator should ask him/herself the following questions before any activities take place to ensure a mutually respectful, open, honest engagement process and circular flow of communication:

- » what is the purpose of this engagement exercise?
- » what will it deliver for health consumers and the wider health community?
- » who are the target community/consumers?
- » how will they be supported – reimbursement of expenses, remuneration for effort, catering, transport, venue access, assistance with special needs, child or carer supports, pre-session information, feedback post-engagement?
- » is there anything that participants would need to do in preparation for the engagement activity?
- » who are the related stakeholders?
- » what is the degree of interest in participation from this group's perspective?
- » what is the best time, location and other requirements for the target group?
- » what is the most appropriate engagement strategy for this particular group, to ensure the best possible participation?
- » are there any cultural, spiritual or significant considerations?
- » what outcomes are needed from this exercise?
- » how will the outcomes be reported back to the participants?
- » will there be opportunities for further feedback from the participants and others – to clarify the reported outcomes or to enhance the current data?
- » will a formal report be released after the conclusion of the engagement process?

3. Definitions

A common language *“Within health, there is no shared language about consumer engagement practice....a common language needs to emerge for discussing the work.”*⁷

To this end, HCQ is proposing the following definitions:

- 3.1 Community** refers to groups of people or organisations with a common interest. While some communities may connect through a local or regional interest in health, others may share a cultural background, religion or language. Some communities may be geographically dispersed but linked through an interest in a specific health issue by the internet, or some other means.⁸
- 3.2 Consumers** are members of the general public and their communities who use, or are potential users, of health services, including their family and carers. Consumers may participate as individuals, groups, organisations of consumers, consumer representatives or communities.⁹
- 3.3 Health consumers**, from a research perspective, are patients and potential patients, carers, organisations representing consumers' interests, members of the public who are targets of health promotion programs and groups asking for research because they believe that they have been exposed to potentially harmful circumstances, products or services.¹⁰
- 3.4 Carers** can be of any age, are unpaid, care for another person who needs ongoing support because of a long-term medical conditions, a mental illness, a disability, frailty or the need for palliative care. A carer may or may not be a family member and may or may not live with the person. However, volunteers under the auspices of an organisation are not recognised as a carer.¹¹
- 3.5 Consumer representative** is a member of a committee, steering group or similar, who voices the consumer perspective and takes part in the decision-making process on behalf of consumers. This person is normally nominated by an organisation of consumers and is accountable to them.¹²

7 Gregory, J. (2008). Engaging consumers in discussion about Australian health policy: Key themes emerging from the AIHPS study: Discussion paper for the AIHPS national citizen engagement forum, 16 September 2008, Brisbane: AIHPS. pp.3-4.

8 Queensland Health. (2002). Consumer and community participation toolkit: For Queensland Health staff. Brisbane: Author.

9 Queensland Health. (January 2003). Queensland Health position statement: Consumer and community participation: To promote community engagement in health. Brisbane: Author.

10 National Health and Medical Research Council. (December 2004). A model framework for consumer and community participation in health and medical research. Canberra: Author.

11 Queensland Government (February 2007). Queensland Government: Carer Recognition Policy. Brisbane: Author.

12 National Health and Medical Research Council. (December 2004). A model framework for consumer and community participation in health and medical research. Canberra: Author.

3.6 Consumer, carer and/or community engagement

- » Community engagement refers to arrangements for citizens and communities to participate in the processes used to make good policy and to deliver on programs and services.¹³
- » Consumer, carer and community engagement is the process by which the aspirations, concerns, needs and values of citizens and communities are incorporated in government, non-government and private sector decision-making, planning service delivery and evaluation.¹⁴
- » Community engagement is a powerful vehicle for bringing about environmental and behavioural changes that will improve the health of the community and its members through partnerships and coalitions that help mobilise resources, influence systems and change relationships among partners. It serves as a catalyst for changing policies, programs and practices.¹⁵

4. Eight consumer rights

Eight consumer rights as identified by Consumers' Health Forum of Australia¹⁶

Every health consumer has the right to:

- » satisfaction of basic needs
- » safety
- » be informed
- » choose
- » be heard
- » redress
- » consumer education
- » a healthy environment.

13 Queensland Health. (2002). Consumer and community participation toolkit: For Queensland Health staff. Brisbane: Author.

14 Health WA. (April 2007). WA Health consumer carer and community engagement framework: For health services, hospitals and WA Health following consultation across WA Health. Retrieved on 18 July 2008 from: http://www.health.wa.gov.au/hrit/cccef/docs/10278_WA_Health_Consumer.pdf

15 Fawcett et al., cited in Children, Youth and Women's Health Service. (2005). Community engagement framework: 2005-2010: Adelaide: Government of South Australia.

16 Consumers Health Forum of Australia. (2007). Charter of health consumer rights. Retrieved on 16 September 2008 from: http://www.chf.org.au/Docs/Downloads/FS_Charter%20of%20Health%20Consumer%20Rights.pdf.

5. Value of community engagement

Value of community engagement to governance, services and programs¹⁷

Community engagement

is a valuable tool in delivering quality governance, services and programs. A study from Vancouver indicated community engagement contributed to:

- » effective decision-making (means informing and engaging the public to ensure needs and priorities are identified and responsible decisions are made)
- » increased accountability (ensures an open and transparent process which is accepted by most consumers)
- » system sustainability (by building up the capacity of consumers in their communities to interact effectively in the system that affect their lives)
- » expertise and energy (emerge from individuals' and communities' own lived experiences for good solutions to their local issues)
- » improved outcomes for individuals and communities (as the consumer perspective helps to ensure policies are informed, relevant, appropriate and targeted and services are delivered effectively and efficiently to people's needs)
- » improved relationships (between health professionals, service providers and consumers)
- » political purpose (by reducing political risk and increasing public confidence in the policy process and legitimacy and credibility of decisions).

6. Principles of community engagement/participation¹⁸

Respectful engagement

and informed dialogue between organisations and consumers and their community of interest enables all participants to share ideas and viewpoints and to be involved in collaborative decision making. An emerging concept is one of partnering, where consumers and community groups who facilitate engagement strategies work in partnership with government agencies to improve outcomes locally. These partnerships are becoming increasingly more important in solving today's complex health and

¹⁷ Hariri, N. (October 2003). Framework for community engagement. Vancouver: Vancouver Coastal Health. pp.4-5.

¹⁸ Queensland Health. (2002). Consumer and community participation toolkit. Brisbane: Author.

social issues. In collaboration, they develop a common vision and community action plan, which aims to build on the strengths and resilience of the community and provide evidence-based practical service delivery responses and initiatives, determined by the local community in collaboration with the government agencies. The partnerships use and leverage resources, people, skills, expertise and networks to strengthen the capacity of the partners and to deliver effective services that contribute to an improved quality of life for individuals within their communities. To ensure the effectiveness of an individual organisation's engagement activities or partnerships initiatives, the following principles are important:

- » building relationships between all stakeholders based on trust, mutual respect and the sharing of power and knowledge is an essential foundation for engaging consumers and communities
- » working partnerships between all stakeholders in which the contribution of each is valued, provides a catalyst for organisational change towards ongoing engagement with communities
- » an integrated approach involves selecting methods and tools appropriate to the desired outcomes and ensuring that the process forms part of the organisation-wide cycle for organisational improvement
- » inclusiveness by ensuring engagement initiatives and health services reflect the diversity of consumers
- » removing the barriers to consumer involvement to facilitate practical implementation of community engagement strategies.

7. Trust in community engagement activities

To date, there has been little research into the effectiveness of consumer and community engagement within the health sector. Most evaluations done tend to be descriptive rather than focusing on how the engagement influenced the decisions.¹⁹ Too often consumers and communities have had negative experiences when participating in health-related forums, focus groups, surveys and other feedback mechanisms. It is important that any consumer or community engagement process heeds the need to gain and maintain the trust of its participants through:

- » open, continuous communication and flow of relevant information
- » honesty and fairness
- » willingness to share views and concerns

¹⁹ Gregory, J. (2008). Engaging consumers in discussion about Australian health policy: Key themes emerging from the AIHPS study: Discussion paper for the AIHPS national citizen engagement forum, 16 September 2008, Brisbane: AIHPS.

- » consistency of actions
- » their reliability to complete tasks and do appropriate follow-up.

8. Promoting mutual respect throughout community engagement activities

Consumer and community engagement

requires a positive mindset, organisational commitment, adequate resources and facilitators' knowledge of the particular health context and the required consumer or community engagement and interpersonal skills. In particular, it is important that the facilitator/s:

- » acknowledge each party as a unique human being
- » listen and understand others' experiences
- » accept others' views
- » respect participants' confidentiality
- » avoid stereotyping and judgemental behaviour
- » consider the timing of activities and accessibility to venues
- » act from others' perspectives when required.

9. Benefits to consumers of engagement/participation²⁰

It is important that any consumer or community engagement facilitator considers the likely benefits to any consumer or community representative who participates in their planned engagement strategy. Any activity cannot just benefit the facilitating organisation, but must have mutually beneficial experiences or outcomes. Benefits of engagement and/or participation include:

- » protecting the interests of consumers and families
- » putting consumers' lived experiences in the public domain
- » increasing understanding of health issues and health services
- » more readily identifiable individual and community needs
- » increased opportunities for a partnership approach to health status and care management
- » potentially better individual health outcomes and improvements in responsive care, quality and safety
- » increased capacity to contribute to health service and systems review.

²⁰ QIEP Consumer and Community Participation Program. (2008). Working together: Introduction to consumer participation. Brisbane: Queensland Health.

10. Barriers to engagement/participation²¹

It is also important for facilitators to know and acknowledge that many consumers or communities may want to participate in their planned activities but are unable to do so for a variety of reasons, including:

- » attitudinal barriers affecting staff and health consumers/patients
- » organisational barriers around time constraints and limited resources, funding and support to meet consumer expectations
- » lack of engagement activities included in planning processes
- » communication barriers linked to disability or cognitive, language, social or cultural diversity
- » consumers not interested or lacking the time to be involved
- » consumers' lack of knowledge and awareness of health and health services
- » consumers' lack of engagement skills and community networks
- » costs to consumer to be involved
- » consumers may feel uncomfortable about giving feedback or making decisions about their care and/or treatment
- » consumers' poor health and/or mobility issues
- » consumer issues are not followed-up or reported on to the consumer/patient/health-related community agency
- » distance to travel
- » geographic dislocation.

11. Methods of engagement/participation

There is no 'one best way' Consumer engagement involves selecting methods and tools appropriate to the identified target group and the desired outcomes. Some engagement methods may include, but are not limited to:

- » keeping key stakeholder groups informed of activities throughout the process of review
- » developing relationships with local, state and commonwealth government departments
- » seeking feedback from individual health consumers/patients and health-related communities/networks through a range of mechanisms
- » meeting with informal groups and networks
- » meeting with community leaders and elders

21 *ibid.*

- » watching the media for issues and ideas in the local, regional, state, national and international media
- » subscribing online to relevant Ministerial media statements
- » utilising secretariat staff and resources to follow up on issues and ideas
- » responses to discussion papers and case studies
- » joint projects with other government and non-government organisations
- » hosting a series of annual events in identified rural, regional, remote and urban communities for individual health consumers/patients and health-related groups
- » providing accurate, appropriate and accessible health information in a variety of formats to health consumers/patients, health related community groups and the general public
- » structured, facilitated consultations – a series of consultation meetings where individuals discuss key questions in small groups and then record their own personal responses on a worksheet. This provides detailed data that is both quantitative and qualitative. In addition, participants are required to nominate and prioritise key actions or criteria
- » where consumers are unable to attend face-to-face consultations, a copy of PowerPoint presentation slides and other worksheets can be forwarded to them with an invitation to complete and return the worksheets to the facilitator
- » partner with a peak non-government community organisation/s that can assist with access to their networks, organising a venue, advertising and registration of participants
- » facilitate a consumer and carer engagement working group to work alongside of key departmental business units to plan and assess annual consumer, carer and community engagement strategies and activities
- » develop a register of consumers, carers and health-related community organisations' who would like to be contacted to provide honest input and feedback when new and developmental projects are being designed and implemented
- » develop a consumer, carer and community organisations' reading group who can review and provide feedback on progressive drafts of documents, policy and proposals
- » initiate a number of voluntary consumer and carer engagement teams who may be called upon to provide feedback from a consumer/carers perspective on specific issues at hand or in training clinical health and governance staff about community engagement
- » ensure that more than two consumers are representative on any

group/committee where there are a number of clinicians/health professionals to avoid tokenism and to ensure a true consumer perspective is gained.

12. Methods of recruiting

Methods of recruiting consumer, carer and community organisations' representatives

The following is a list of methods to use, when recruiting consumer, carer and community organisations for planned engagement activities. The method may depend on timeframes and the human, financial and practical resources of the organisation. The list includes, but is not limited to:

- » developing a Consumer Register and including a registration form on the organisation's website
- » circulating the organisation's terms of reference
- » contacting local community service providers, service groups and organisations – inviting them to attend an information session; writing articles for their newsletter
- » working with known consumer organisations to identify their wider networks
- » contacting Indigenous elders and leaders of culturally and linguistically diverse communities and the community service providers associated with these groups
- » consulting people who have previously complained about a health-related matter
- » contacting people who have previously attended workshops, forums, focus groups
- » contacting the Health Quality and Complaints Commission, Health Consumers Queensland or one of the 36 Health Community Councils
- » advertising in local newspapers, radio and television
- » conducting a letterbox drop
- » hosting a shopping centre or public library display
- » putting an article in the Queensland Health publication, Health Matters
- » linking with regional and urban councils
- » developing flyers and handouts on consumer participation activities
- » placing an information bulletin and invitation on the intranet and internet sites
- » developing a consumer representatives checklist.

13. Who can be a consumer?

A consumer may be anyone who lives in Queensland and uses a public or private health service, including a member of a:

- » Queensland Health or private health service
- » service group like Rotary, Apex etc
- » church, religious organisation or values group
- » volunteer organisation like Volunteering Queensland
- » youth group
- » carer, aged or disability support group
- » education facility/institution
- » sport/recreational clubs
- » business
- » government department
- » non-government health consumer, advocacy, lobby or representative organisations.

14. Who can be a consumer representative?

There has been some debate around the title 'consumer representative'. HCQ acknowledges that there are various perspectives. Therefore, HCQ is offering some of these for the reader's consideration.

- » A consumer representative is a consumer, carer or community member who is nominated by and accountable to an organisation of consumers, carers or community members.²²
- » A consumer representative has experience of health services primarily as a consumer of the service. They commit to being well informed about the relevant health issues and represent a broad range of consumer views by ensuring they are accountable to others.²³
- » A consumer representative is a member of a government, professional body, industry or non-governmental organisation committee who voices consumer perspectives and takes part in the decision-making process on behalf of consumers. This person is nominated by, and is accountable to, an organisation of consumers.²⁴

22 Consumers Health Forum of Australia. (2007). Consumer representatives program: General information: What is a consumer representative? Retrieved on 16 September 2008 from: http://www.chf.org.au/consumer_reps_program/index.asp

23 Health Care Consumers ACT. (2008). Requesting a community representative: What is a community representative? Retrieved on 24 October 2008, from: http://www.hcca.org.au/cms/index.php?page=requesting_a_rep

24 Consumers Health Forum of Australia. (2008). Consumer representatives program: General information: What is the role of a consumer representative? Retrieved on 24 October 2008, from: http://www.chf.org.au/consumer_reps_program/

15. Factors that may influence the public and consumer perceptions and experiences in a health system

Micro level: individual treatment

- » effective, affordable, safe treatment
- » quality care
- » appropriate, non-judgemental treatment
- » relevant information to guide personal and substitute decision making
- » follow-up post-care
- » staff responsive to the individual, family, ethnic or disability perspective
- » accessible and navigable services
- » trust that practitioners will deliver competently and capably.

Mezzo level: interaction with health services and organisations

- » accessibility and availability of health professionals, services, treatment options and health equipment/technology when needed
- » competence of medical and allied health staff
- » efficient complaints handling and staff suggestions process.

Macro level: the greater system

- » governments' endorsement of peak health providers and institutions
- » public attitudes to health department, service providers, public and private health services
- » bureaucracy and the public service
- » media coverage
- » importance of health in the political agenda
- » quality management and accountability practices
- » sustainable funding levels
- » transparency in reporting and management of health issues
- » doctor's registration and regulation procedures.

16. Consumer representative protocol

It is important that a consumer organisation, that maintains a database of health consumers interested in being a voice at health-related consumer engagement and participation activities, develops a protocol to cover consumer representatives who are requested to provide input into government and non-government health-related activities.

Ad hoc arrangements are inadequate and do not serve the needs of any of the parties well. They especially devalue the consumer's participation and input and may deliver a negative experience with unintended consequences for the organisation's future community engagement activities and/or consumers' willingness to participate in future community engagement initiatives. A protocol will enable the organisation to:

- » better manage the onward referral of consumers
- » match consumers with the needs of the requesting organisation
- » protect consumers' confidentiality and dignity
- » ensure consumers are adequately recompensed for their out-of-pocket expenses, time and efforts
- » ensure consumers are respected for their valuable input
- » coordinate and monitor the work of consumers to ensure it is consistent with HCQ's mission and values
- » ensure consumers are provided with the relevant resources, orientation and training to fulfil their role

A protocol document worthy of mention is the Health Consumers Alliance of South Australia's Consumer and community representatives on committees and working parties. It can be accessed at: <http://hcasa.asn.au/images/documents/GI-Protocols280308CM.pdf>

17. Aboriginal and/or Torres Strait Islander perspective

Facilitating community engagement

When facilitating community engagement with Aboriginal and/or Torres Strait Islander people and communities, there are unique factors which must be taken into account. Key success factors include, but are not limited to:

- » establishing relationships and a shared vision – open, honest, sincere and accountable practices
- » government and community commitment – to the process and best possible outcomes

- » confidence in the process – transparency and understanding of how the process will contribute to required outcomes
- » clarity of roles and responsibilities of all stakeholders – clearly defined and communicated to the community
- » a clear purpose and objectives with tangible outcomes – feedback on how their views and opinions have been considered in government’s decision-making
- » respecting the diversity of the consumer and his/her community – protocols and processes will vary from community to community.²⁵

Be aware of:

- » access to required services and culturally appropriate information in a timely manner
- » culturally appropriate and sensitive service delivery and prevention strategies required
- » increasing prevalence of chronic disease/illness
- » issues of substance abuse, depression and suicide
- » shortage of skilled health professionals in rural and remote areas
- » preference for face-to-face discussions.

Respecting the cultures of Aboriginal and Torres Strait Islander people and communities – understanding:

- » long history of strong kinship
- » advanced systems of culture and lore enduring for thousands of years
- » strong family and kinship ties and connection – civic and economic participation
- » Elders and community members teach children the traditional methods of obtaining natural resources from the land, sea or waterways to survive
- » connection to country is fundamental to people’s lives
- » land and sea are central to cultural life and fundamental to spirituality, traditional law and history passed down through the generations
- » special relationships between people, their identity and country
- » concept of time – need flexible timetables
- » differences in language protocols between Aboriginal communities and Torres Strait Islander communities and English literacy levels

²⁵ Queensland Government Departments of Communities and Aboriginal and Torres Strait Islander Policy. (August 2005). Engaging Queenslanders: Introduction to working with Aboriginal and Torres Strait Islander communities. Brisbane: Authors.

- » appropriate sharing of information according to gender protocols

Planning an engagement activity:

- » engage early in the process to develop successful, ongoing partnerships
- » link with existing engagement strategies and initiatives where possible
- » manage risk of over-consultation
- » understand the community and its history – build a profile
- » identify key stakeholders – traditional owners, decision makers, elders, historical people and appropriate community members and organisations
- » identify what is and what is not negotiable
- » consider the community's resources
- » manage participants' and community expectations.

Visiting a remote community:

- » make contact through the appropriate channels and in the appropriate manner
- » prepare for the meeting and know the protocols
- » adhere to the laws of the community.²⁶

18. Perspective of people from a culturally and linguistically diverse background²⁷

The term culturally and linguistically diverse background (CALDB) refers to the wide range of cultural, ethnic, and specific language-of-origin groups that comprise the Australian population and Australian communities. It is important that medical, allied health and corporate health staff are culturally responsive to the diversity of cultural backgrounds, languages and abilities of persons with a CALDB.

Some strategies include:

- » promoting awareness and knowledge of various services provided by government and the health-related community and for-profit sector
- » having a culturally sensitive and diverse workforce, bilingual

26 Queensland Government Department of Communities and Office for Aboriginal and Torres Strait Islander Partnerships. (2005). *Engaging Queenslanders: An introduction to working with Aboriginal and Torres Strait Islander communities*. pp.19-33. Brisbane: Queensland Government.

27 DBM Consultants. (June 2005). *Queensland Health: Queensland community's perceptions of health services and preferred engagement strategies: Qualitative research summary*. p.45. Hawthorn, Victoria: Author.

- staff and across-staff cultural competence
- » establishing mechanisms for the recruitment, selection and ongoing support of CALDB consumers and carers to be involved in statutory, ministerial or advisory committees
 - » having 24-hour accessible and appropriate translation and interpreter services
 - » providing culturally relevant, accessible and acceptable health information in culturally and linguistically appropriate mediums
 - » using ethnic media to disseminate information
 - » having greater consultation with individual CALD communities around their specific cultural issues
 - » engage with the particular CALD community to identify community leader/s as the point of contact for each particular CALD community
 - » liaise with other organisations who have had successful community engagement activities with the particular CALD community – ensure they have not been over-consulted
 - » using face-to-face discussions in preference to more formal engagement mediums – use open-ended questions
 - » consider customs, religious practices, financial circumstances and social boundaries of the particular CALD community
 - » where possible, take the activity to the particular CALD community
 - » check back with the identified community leader/s to ensure that information collected accurately reflected the particular CALD community's views and that reports on the activities have the endorsement of the particular CALD community
 - » strengthening links with ethnic organisations to identify community leaders.

19. The disability perspective

The disability perspective on consumer and community engagement

People with various physical, sensory, intellectual, cognitive, psychiatric and other disabilities often experience challenges that other people do not. They may have acute health-related concerns and may experience financial disadvantage, social isolation, marginalisation and stigma. However, they still have the right to be treated equitably, but appropriately for their unique circumstances and needs.

Persons with a disability

must be provided with opportunities to be involved in all decisions that affect their lives through:

- » participation through stories – according to the social model of disability, listening to the life narratives and lived experiences of persons with a disability is critical to gaining some understanding of their unique life situation and the barriers they face in maintaining active citizenship
- » sharing of knowledge on current research, issues and trends
- » honesty about the twin concerns of risk and uncertainty
- » partnership in care planning – person with a disability and treating professionals as required, with family/carer inclusion at the person's request
- » informed choice – information provided in a variety of appropriate and suitably accessible options with comprehensive discussion about preferred options
- » the use of jargon and medical terminology should be reflective of the person's understanding and knowledge
- » communicating with the person in an appropriate manner (e.g. talking to the deaf person rather than the interpreter, explaining/describing graphics or overhead presentations to a vision-impaired person; not being too self-conscious of everyday words and sayings which might appear disrespectful to the person)
- » assistance and support to gain health literacy and disability accessible material
- » clarification of objectives of consultation/engagement activity
- » inclusion in groups and encouragement to participate – their 'voice' is important
- » understanding their role as a consumer in this particular engagement process – what am I to do/say?
- » accessible and appropriate venues, transport options and communication formats
- » where appropriate, take the activity to the particular disability community – many consultations intended for or to include persons with a disability are poorly attended due to the difficulty of travel, accessibility of travel and venue, costs of travel, unfamiliar surroundings and the need for personal support
- » the infrastructure, assistive devices, disability support staff, interpreters and other social and financial support to gain access and aid participation
- » the dot points in item 20 could also be applied to the wider disability population.

20. People with impaired decision making capacity

Consumer and community engagement for people with impaired decision making capacity²⁸

People with impaired decision making capacity comprise a significant portion of the client base of health service providers. They do not always have their health and dental needs adequately met. In their recent paper, the Office of the Public Advocate (Qld) highlighted the plight of this marginalised population.

“Physical health and dental care issues facing adults with impaired decision-making capacity have reached a critical point, both in Queensland and across Australia. Unless some action is taken, people will continue to suffer poor health unnecessarily and die earlier than other adults – things will get worse.”²⁹

Because they lack ‘voice’, they are also very vulnerable to abuse, exploitation and neglect by others. They should not be denied the opportunity to participate in consumer and community engagement strategies, if they so wish. They can be assisted to participate by:

- » ensuring any consumer/community engagement activity contains mechanisms to elicit the views and to ascertain the experiences of this group of vulnerable users of the health system
- » obtaining feedback from the person where possible and other relevant stakeholders
- » developing a culture which encourages and supports the relaying of information tailored to suit the needs of the target group
- » establishing rapport with the person, before any engagement commences
- » listening respectfully to the lived experiences of their encounters with the health system
- » providing appropriate support to participate (visual pamphlets, DVDs, good physical access to venues, trained and available staff, transport and assistive devices as required)
- » acknowledging carers and their existing supportive network as a valuable source of information, particularly the history of the person and their involvement in the health system (ensure no

²⁸ Office of the Public Advocate Queensland. (August 2008). Submission by the Office of the Public Advocate - Queensland to Australian Commission on Safety and Quality in Health Care development of a consumer engagement strategy. Brisbane: Author.

²⁹ Ibid.

- conflicts of interest and breaches of confidentiality occur)
- » ensuring engagement occurs through relevant interest groups, peak bodies, advocacy organisations and other health consumer bodies (but not too top-heavy)
 - » allowing sufficient response time for all participants, being mindful of physical and practical issues and resource constraints
 - » ensuring engagement is tied to mechanisms for systems improvement and that participants receive feedback throughout the process
 - » ensuring a multi-level and multi-faceted approach to engagement to accommodate a range of health, physical and cognitive needs.

21. Engagement/participation techniques

Below is a list of techniques and related structure with remarks informed by an extensive literature review.

Technique	Structure
Advisory or consultative committee	<ul style="list-style-type: none"> » up to 15 representative stakeholders » expertise-based around a particular area/topic » provides ongoing advice on community views or from a specialist perspective » public input into planning
Campaigns	<ul style="list-style-type: none"> » aim is to encourage support for a particular event, program or project » a public education tool
Consumer councils	<ul style="list-style-type: none"> » a government response to consumer concerns » participation in service planning, development and evaluation
Complaints handling	<ul style="list-style-type: none"> » information seeking » consultation
Consumer enquiries	<ul style="list-style-type: none"> » via phone, email or face-to-face meeting » replies to letters of complaint or requests for information
Discussion papers	<ul style="list-style-type: none"> » broadly outline proposal or options or requests for feedback on particular issues » encourages very broad discussion/responses
Expert panels	<ul style="list-style-type: none"> » an opportunity for consumer participation and balanced discussion on important issues » consumer has access to the 'expert'

Technique	Structure
Face-to-face interviews	» to gain a grassroots consumer perspective
Feature stories	» highlight the importance of the activity, project » increased public credibility or knowledge
Focus groups	» 6-10 people in a targeted audience » simple structure but directed to a particular issue or problem » message testing forum » 'ordinary' person's input into decision making process
Information hotline	» controls inwards information flow » promotes information consistency » image of accessibility – toll free number
Media release	» targets a specific audience or the wider community » informs, generates interest or seeks feedback » informs public of project milestones
Networking	» informal and formal relationships with individuals and organisations with common interests/goals » informal – through organisations and communities » formal – regular meetings, forums or newsletters and collaborative action » exchange of ideas and information » critical to service development and change
News conference	» opportunity to reach all media in one setting » message only needs to be conveyed once
Newspaper ads	» paid information that can reach a depth of consumers across a large geographic area – may satisfy legal notification requirements
Newspaper insert	» provides local community distribution and context of information can include a public questionnaire » advertising a community-based event for consumers
Phone survey	» random selection » invitation letter to participate sent prior to phone contact » contact with the broader community » to gain a consumer perspective
Policy – consumer engagement	» supports consumer participation, consultation and partnerships » provides an organisational context to support greater consumer and community engagement » requires clear review dates

Technique	Structure
Public inquiry	» information seeking and consultation
Public meeting or forum	» participants nominated by existing groups or organisations » means to present information and proposals to a broad cross-section of citizens » focus on specific issues » encourages a broad exchange of views
Public submission	» can be written or oral » expert individuals or recognised organisations who have community standing » grass-roots consumers who feel aggrieved by the system » background briefing paper to inform requests for a submission
Reports	» often credible sources of information particularly if produced by an independent third party
Research	» quantitative » qualitative » internal and/or external resources » Australian Bureau of Statistics (ABS) » academic institutions » public sector agencies
Round tables	» joint planning/decision making forums » usually between government departments and representative consumer groups
Samoan circle	» used with 10 to 500 people » good for controversial issues » central table surrounded by concentric circles of tables
Seminars and conferences	» focus on broad issues or public policy » allows for a range of people to present information and ideas
Submissions	» information seeking » oral and written presentation of views
Suggestion box	» self-completion » broad range of information sought
Surveys	» formal questionnaires either in paper-based format or electronically » ensure an appropriate and relevant sampling method » to collect specific information from a small sample of consumers » an indication of community views » wider coverage of all age groups, lifestyles and geographic locations

Technique	Structure
Websites	» potential world wide audience
Workshops	<ul style="list-style-type: none"> » a number of groups of 8-15 people » structured sessions with a professional facilitator » aim is to achieve recommendations for programs, plans, policies

22. A composite of participation types

A composite of participation types in a health care system from an individual, unit, or organisational perspective ^{30 31}

Participation type	Objective	Key instruments
Information giving and seeking as a precursor to participation	<ul style="list-style-type: none"> » consumers and community receive information and announcements » consumers and community provide information to staff » to support participation » to convey facts » to educate 	<ul style="list-style-type: none"> » face-to-face information provided e.g. clinical history » informal feedback from consumers and carers » brochures » seminars » responding to consumer complaints » surveys » observational trends » compliments notification » suggestion boxes » focus groups » public information campaigns » health consultation via pre-admission, hospital admission, discharge, outpatient clinic, community health and rehabilitation centres

30 Metropolitan Health and Aged Care Services Division. (2005). Bishop and Davis (2002); Shand and Arnberg (1996); Wensing (2002); Bauman et al. (2003) cited in Consultation paper: Participation in your health service system: Victorian consumers, carers, and the community working together with their health service and the Department of Human Services. Melbourne: Victorian Government Department of Human Services.

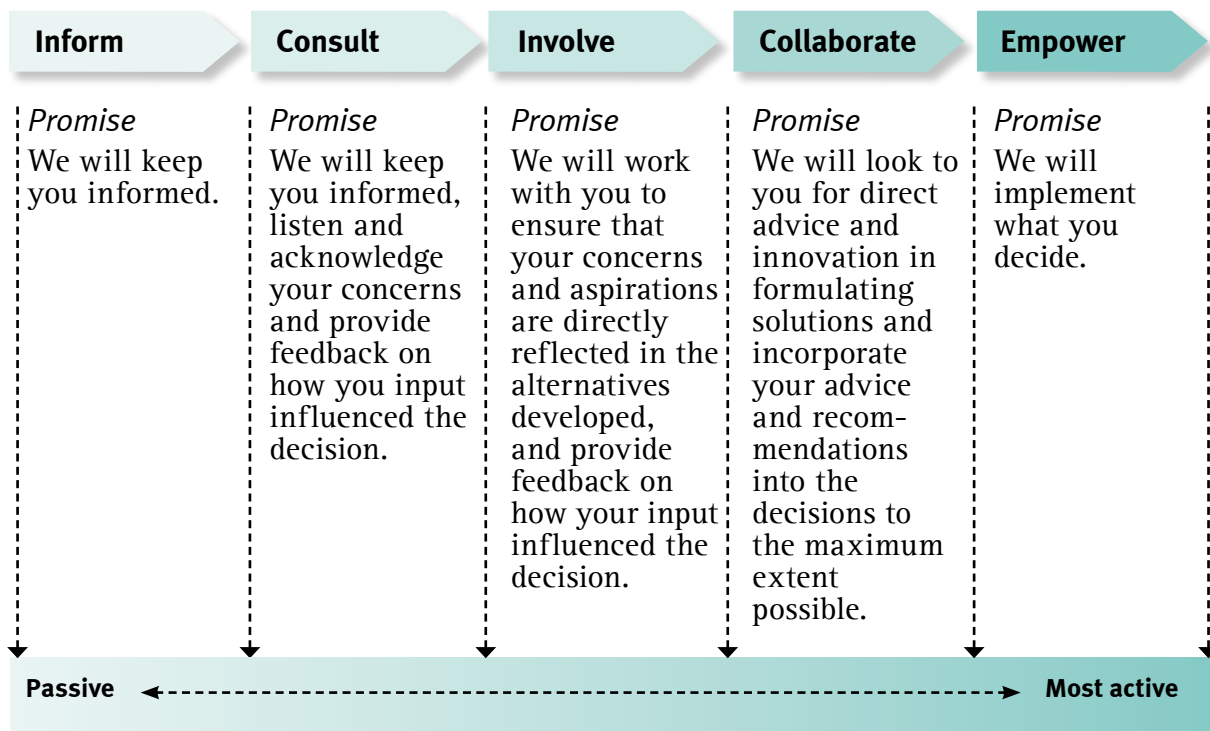
31 Consumer Focus Collaboration. (2000). Education and training for consumer participation in health care: Resource guide. Canberra: Commonwealth Department of Health and Aged Care.

Participation type	Objective	Key instruments
Consultation	<ul style="list-style-type: none"> » to gauge reaction to a proposal or care or treatment plan and invite feedback » consultation is only participation when information gathered can be incorporated into decision making or influence subsequent policy, care and treatment choices 	<ul style="list-style-type: none"> » personal preferences » key contacts » surveys » interest group meetings » focus groups » public meetings » discussion papers » public hearings » consumer/patient and carer/family meetings » health consultation
Partnership and Collaboration	<ul style="list-style-type: none"> » decisions are made jointly by consumers, carers, staff » to involve consumers, carers and representatives in aspects of government or health service organisational decision making » to involve consumers, carers and representatives in health care or treatment decision making 	<ul style="list-style-type: none"> » partnerships in care » joint planning sessions involving consumers and carers » advisory boards » community advisory committees » policy community forum » public inquiries » shared decision making » patient-centred care
Delegation	<ul style="list-style-type: none"> » to hand control to a board or community representatives within a specified framework » to ensure policy options are formulated at arms length from partisan politics 	<ul style="list-style-type: none"> » public enquiries » impact assessment studies » health service boards

Participation type	Objective	Key instruments
Control	<ul style="list-style-type: none"> » consumers and community make the decisions » to hand control of an issue to citizens » to hand control to the consumer of health care » community identifies issues, solutions and actions 	<ul style="list-style-type: none"> » referenda » community-elected board of management » self-management of care plan » advance care planning » program design and management

23. Consumer engagement perspectives³²

1. A continuum of participation



32 International Association for Public Participation. (2007). IAP2 public participation spectrum. Thornton, USA: Author.

2. The spectrum of participation



The model of participation

has been adapted from the World Health Organization and the International Association of Public Participation.³³ Each circle in the model depicts a type of engagement with varying levels of participation and control. The different types are not represented in a hierarchy, demonstrating people can be engaged in any of these ways, and that one type of engagement is not necessarily better than another. The model is not linear, because consumers do not progress through types of engagement in a linear manner.

Providers and consumers may choose to engage in different ways, depending on the issue and the circumstances. Sometimes the provision of information is sufficient, and sometimes consumers may want a partnership in, or indeed control over, an engagement process. The model thus describes a “horses for courses” approach to engagement, meeting the specific circumstances of the issue.

33 Vancouver Coastal Health. (2007). Community engagement framework. Retrieved on 28 November 2008 from: http://www.vch.ca/ce/docs/ce_framework.pdf

24. Some consumer engagement organisations

24.1 International Association for Public Participation

<http://www.iap2.org.au/>

The International Association for Public Participation (IAPP) is a non-profit organisation for members who seek to promote and improve public participation practices in relation to governments, institutions and individuals that affect the public interest while promoting the values and best practices associated with public involvement in decisions that affect their lives. IAPP was established in 1987 and currently offers a Certificate in Public Participation to individuals and staff of government departments.

IAPP core values for the practice of public participation include:

- » the belief that those who are affected by a decision have a right to be involved in the decision making process (involving and consulting)
- » the promise that the public's contribution will influence the decision (collaborating)
- » the promotion of sustainable decisions by recognising and communicating the needs and interests of all participants, including decision makers (informing and collaborating)
- » seeking out and facilitating involvement of those potentially affected by or interested in a decision (involving)
- » seeking input from participants in designing how they participate (consulting)
- » providing participants with the information they need to participate in a meaningful way (informing)
- » communicating to participants how their input affected the decision (informing).³⁴

24.2 Consumers Health Forum of Australia

<http://www.chf.org.au/>

The Consumers Health Forum of Australia Inc (CHF) is the national voice for health consumers. As an independent member-based non-government organisation, CHF helps shape Australia's health system by representing and involving consumers in health policy and program development. The Australian Government Department of Health and Ageing gives core funding for the CHF secretariat.

³⁴ International Association for Public Participation. (2008). IAP2 core values. Retrieved on 4 August 2008 from: <http://www.iap2.org/displaycommon.cfm?an=4>

Health consumers have a unique and important perspective on health as the users and beneficiaries of health care and, ultimately, those who pay for it. CHF takes consumers' views to government and policy makers, providing an important balance to the views of health care professionals, service providers and industry to achieve a health system that reflects the needs of all stakeholders. Member organisations reach millions of Australian health consumers across a wide range of health interests and health system experiences.

Health policy is developed through extensive consultation with members, ensuring a broad representative health consumer perspective. Current priorities include safety and quality in health care, safe and appropriate use of medicines and health care for people with chronic conditions.

CHF believes:

- » all consumers should receive affordable, safe, good quality health care at the time they need it
- » best outcomes are achieved when consumers are involved in decisions about and management of their own health care.
- » consumers should receive health care information when they need it and in a form they can understand, particularly about medicines.

CHF nominates and supports consumer representatives on government, industry and professional committees. In addition, it publishes a range of quality publications on various aspects of health care including the informative journal, *Health Voices*, available to members and subscribers. Two useful documents are:

- » Guidelines for consumer representatives
http://www.chf.org.au/docs/downloads/237_conrepguidelines_2004.pdf
- » Consumer Representatives Program: General information: Fact sheets
http://www.chf.org.au/docs/downloads/237a_guidelineinsertsx5.pdf

24.3 Health Consumers of Rural and Remote Australia Inc. (HCRRA)

<http://www.ruralhealth.org.au/hcrra/>

Health Consumers of Rural and Remote Australia Inc. is a not-for-profit organisation that works to improve rural health outcomes by involving consumers in the planning, implementation, management and evaluation of health services throughout non-metropolitan Australia. HCRRA members are given the opportunity to represent the views of people who live in rural and remote Australia, in

the planning and implementation of a broad range of health issues that directly affect them. HCCRA receives funding from the Department of Health and Ageing's Rural Health Support, Education and Training program. HCRRA aims to promote and support the inclusion of rural and remote consumer representatives on government and non-government committees; provide access to resources to inform consumers and develop their representative skills; lobby government on behalf of rural and remote consumers to encourage consumer participation; and to facilitate rural consumers' communication and involvement in health and community services in their areas. In addition, it is a focal point for the dissemination of information about rural health policies and programs to consumers and as a forum in which real experiences and common consumer issues for action can be discussed.

24.4 Health Issues Centre (HIC)

<http://www.healthissuescentre.org.au/aboutus/>

Health Issues Centre is an independent, not-for-profit organisation that began in 1985 to promote equity and consumer perspectives in the Australian health system. Its mission is to improve the health outcomes for Australians, especially those who are disadvantaged. The focus of HIC's work is mainly in Victoria but the organisation takes a national approach where appropriate. It works with a wide range of consumers, health providers, researchers, governments and other health organisations to achieve its mission of policy analysis and advocacy from consumer and equity perspectives, consumer-focused research, the promotion and support of consumer participation and the dissemination of information.

24.5 The Cochrane Consumer Network (CCNet)

<http://www.cochrane.org/consumers/about.htm>

The Cochrane Consumer Network is made up of fellow consumers who are committed to the philosophies of The Cochrane Collaboration and the importance of consumer participation in informed healthcare decision-making processes. The Network supports consumers by enabling communication, training and guidance in providing a consumer perspective to Cochrane reviews and other activities within The Cochrane Collaboration. It encourages consumers throughout the world to give their perspectives and have their say on priorities for health care and encourages the concept of evidence-based practice with a forward thinking approach to improvement of health care. The Network believes consumer participation aids the development

of high-quality and relevant systematic reviews, and that these reviews can actively inform evidence-based practice in health care with effective dissemination. It provides training materials and workshops to facilitate effective consumer participation and accessibility to Cochrane reviews by consumers, maintains a web site, publishes regular newsletters and provides an avenue for consumer representation, including from developing countries.

24.6 The Health Consumers' Council of WA (HCCWA)

<http://www.hconc.org.au/>

HCCWA was established in 1993 to be an independent patient group that brought the consumer perspective to health care. It is funded by the WA Health Department. Its role is to provide health information and referral, coordinate placement of consumer representatives on Statewide committees, conduct health issues groups, workshops and information sessions and provide individual advocacy for individuals with problems with the health system. HCCWA is able to comment publicly on all matters pertaining to health and contribute to the development of health policy, planning, research and service delivery. The emphasis is on consumer participation and representation at strategic levels in the health care system.

24.7 Health Care Advisory Council (HCAC) (NSW)

<http://www.health.nsw.gov.au/initiatives/hcac/index.asp>

The Health Care Advisory Council, consisting of Health Priority Taskforces and Area Health Advisory Councils, operates at different levels across NSW Health to ensure effective involvement for consumer and clinicians in planning, policy development and service delivery. It is the peak clinical and community advisory group in NSW, providing advice to the NSW Minister for Health and the Director-General, NSW Health. The Council publishes a quarterly newsletter as a communication loop with key audiences and especially highlights the achievements of Health Priority Taskforces

24.8 Area Health Advisory Councils (AHACs) (NSW)

<http://www.health.nsw.gov.au/policy/participate/ahac.html>

Each Area Health Advisory Council consists of between nine and 13 members appointed by the Minister, subject to review by Cabinet. Membership comprises persons having experience in the provision

of health services and/or representing the interests of consumers in health services and the local community. At least one member must have expertise, knowledge or experience in Aboriginal health.

24.9 Health Care Consumers' Association of the ACT Inc. (HCCA)

<http://health.act.gov.au/c/health?a=da&did=10069306&tpid=1082091590>

In the Australian Capital Territory, the Health Care Consumers Association provides a voice for consumers on local health issues. It was formed in 1978 by concerned health care consumers to provide a voice for consumers on local health issues, including consumer access to equitable, effective and appropriate health services. HCCA encourages consumers to be involved in all aspects and levels of health service planning and decision-making while supporting community members to undertake consumer representation following relevant training and support. Consumers work together to share their understanding, experiences and views, to identify shared priorities and goals and to represent these views to the ACT Government.

24.10 Community Advisory Committees (Victoria)

<http://www.health.vic.gov.au/consumer/downloads/cacg.pdf>

Community Advisory Committees are appointed in an advisory capacity to health service boards in Victoria, predominantly to advise on governance, policy and strategy in relation to community participation and its impact on health service outcomes. They have no executive authority but provide a central focus for all strategies and mechanisms for community participation and consumer involvement in the health service. Committees are enablers of community participation, rather than representing the sole response of the health service to its responsibility to engage the community. They have two roles – to assist the health service to appropriately integrate consumer and community views at all levels of its operations, planning and policy development. Secondly, Committees advocate to the boards on behalf of the community.

24.11 Health Consumer Alliance of South Australia Inc (HCA)

<http://www.hcasa.asn.au/>

The Health Consumers Alliance Inc of South Australia is the not-for-profit, peak body for health consumers in South Australia with a common goal to provide a strong, independent health consumer voice and the just and equitable distribution of health resources.

Its membership comprises individual and organisational members. HCA aims to create an opportunity for health consumers to lobby for consumer issues; develop alliances and partnerships with others interested in health consumer issues; play an active role in the development of policy affecting health consumers; and to promote a just and equitable distribution of health resources. In addition, HCA provides education and support for consumers and community groups in their efforts to achieve beneficial change in the health system and to promote greater public discussion about health priorities, services and relevant legislation.