



Health Consumers Queensland

...your voice in health

Consumer engagement framework

August 2010

Tomorrow's Queensland:
strong, green, smart, healthy and fair





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Message from the Deputy Premier

Toward Q2: Tomorrow's Queensland identifies the Queensland Government's aim to make Queenslanders Australia's healthiest people. Engagement with consumers and the general public provides government with important information to improve the quality and safety of healthcare in Queensland, both in the public and private sectors.

By listening to health consumers and their representatives, health practitioners and health agencies can acquire useful knowledge to enhance their health policies and procedures, and work towards better services and a better system.

As 'your voice in health', Health Consumers Queensland (HCQ) strengthens the consumer perspective in health matters. In their work with health consumers and health-related consumer and community organisations, HCQ listens to and provides me with invaluable advice about the state-wide issues that impact on consumers, their families and carers.

HCQ's Consumer Engagement Framework provides useful structures to guide meaningful and responsive communication and engagement between consumers and their representatives, health-related community organisations; and health practitioners and health agencies. The principles, model and eight step process detailed in the framework provide an effective means to assist consumers, health practitioners and agencies in their engagement around healthcare and health system reforms, towards quality, safe healthcare for consumers.

I congratulate Queensland patients, their families and carers, and HCQ's Chairperson, Ministerial Advisory Committee members and Secretariat on the development of this Framework and encourage health consumers and their representatives, and health practitioners and health agencies to use the Framework to ensure better health outcomes for all Queenslanders.

Paul Lucas MP
Deputy Premier
Minister for Health

August 2010

Message from the Chairperson

I am pleased to introduce Health Consumers Queensland's (HCQ) Consumer Engagement Framework for health in Queensland. The framework comprises eight principles, a model and an eight-step process that can be useful for health consumers, health practitioners and agencies.

HCQ developed the Framework to generate a 'commitment to conversation' between all health-related stakeholders. In the current era of health reform, it is intended that the framework assist health consumers and health practitioners to achieve better health outcomes and an improved health system.

I believe good health is about consumers' accessing health services that are responsive to and support their needs and decision-making around their healthcare, and are delivered in a manner that respects consumers' beliefs, values and culture. Increased consumer and community engagement promotes enhanced quality and safety in healthcare and treatment, and greater consumer satisfaction with health services, programs and systems.

The Consumer Engagement Framework complements contemporary community engagement frameworks used across government and the community. The eight principles provide the foundation for health consumers, individually and collectively, to be involved in and have a say about their healthcare and the health system, and for health practitioners and health agencies to engage consumers in a meaningful and respectful way. The principles reflect national and international human rights instruments, the 2008 *Australian Charter of Healthcare Rights* and the National Health and Hospitals Reform Commission Report – *A healthier future for all Australians: Final report June 2009*. The model and eight-step process build upon the principles and provide a practical guide for implementation.

I sincerely thank the dedicated group of people, including the Consumer Engagement Reference Group, members of HCQ's Committee and Secretariat, and contractors who have worked diligently since January 2009 to finalise this framework. I also acknowledge and thank the diverse health consumers, consumer and community organisations, health practitioners, statutory bodies and health agencies throughout Queensland who provided HCQ with their perspectives on effective health consumer engagement and this framework, towards better outcomes for Queenslanders.

Mark Tucker-Evans
Chairperson, Ministerial Consumer Advisory Committee
Health Consumers Queensland

August 2010

The vision for health consumer engagement in Queensland

“ supports the voices of Queensland consumers to achieve better health outcomes

Consumer engagement is an integral part of the development and delivery of quality health services and ensures a viable, responsive and effective health system. As Queensland and Australia move forward with their state and national health reforms, it is vital that health consumers are given meaningful opportunities to engage with health services and the health system.

Health Consumers Queensland (HCQ) supports the voices of Queensland consumers to achieve better health outcomes and is committed to the provision of consumer-centred, timely, safe, quality and responsive healthcare and treatment. Achieving this involves an environment where consumers have the access and support they require to actively engage. It also requires that the consumer perspective is listened to and valued in the development and delivery of health policies, programs and services.

Consumer engagement is more than participation, conveying the idea that a person or group of people are occupied, focused, and committed to an issue and ready to take ownership of the outcomes.¹ It is a dynamic process that can never be fully controlled.

The consumer engagement framework

“ a powerful tool for bringing about behavioural and environmental changes

Health Consumers Queensland has developed the consumer engagement framework to assist health consumers to better engage with their healthcare and the health system to achieve better health outcomes at an individual, service and broader agency level. The framework has also been developed to support and influence health practitioners and agencies to achieve meaningful and responsive consumer engagement.

Consumer and community engagement is a catalyst for change. It is the process by which the aspirations, values, needs and concerns of health consumers, citizens and communities are incorporated in government, non-government and private sector decision-making and planning, to make good policy and to deliver on programs and services. It is a powerful tool for bringing about behavioural and environmental changes towards improving the health of communities and its members, through coalitions and partnerships which can mobilise resources, influence systems and change relationships between partners.²

1 Aslin, H.J. and Brown, V.A. (2002). *Terms of engagement: A toolkit for community engagement for the Murray-Darling Basin*. Canberra: Bureau of Rural Sciences.


2 Health Consumers Queensland. (2009). *Consumers representatives program: Consumer handbook*. Brisbane: Author.

The framework reflects international and national charters and principles, especially the Australian Charter of Healthcare Rights and aligns with approaches by the World Health Organization and the International Association of Public Participation to community participation and engagement.

The consumer engagement framework comprises:

- a set of eight principles
- a model
- an eight-step process for meaningful and responsive consumer engagement.

The development of the consumer engagement framework

 *most consumers want to engage with health services and the broader system*

HCQ has worked with health consumers, health practitioners and government and community agencies to develop this framework that is underpinned by HCQ's vision, mission, guiding principle and aspirations. Consumer engagement forums were held in Townsville and Brisbane in June 2009. From these consultations with health consumers, it was identified that most consumers want to engage with health services and the broader system because they want to:

- make informed decisions about their healthcare
- have access to reliable healthcare and treatment delivered by trusted health practitioners in a safe, quality environment close to home
- ensure their needs and the needs of their communities of interest are considered when limited resources are available
- be involved with the broader health system and in the decisions being made about that system
- improve the relationship between consumers and health practitioners towards better understanding of each other's perspectives
- be part of improving the health system.


In responding to this feedback, HCQ has developed this consumer engagement framework to support Queensland health consumers to achieve meaningful engagement with their own healthcare and the health system.

 *participate in the processes used to make good policy and to deliver on programs and services*

Consumer engagement

The reform and future of the Queensland and Australian health systems recognise the importance of public participation and community engagement to improve the responsiveness of the

health system to deliver better health outcomes. 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. Communities have multiple stakeholders, including the consumers of programs and services. Health consumers are a key stakeholder within the area of health, and engagement with this key stakeholder group is fundamental to public participation and to ensuring that health services remain consumer and family/carer centred.

 Consumer engagement involves a shared responsibility of all participants

HCQ recognises that consumer engagement is a process that can involve individual health consumers, and groups of health consumers engaging in a variety of ways with health practitioners, peers, and health agencies. Consumers in their engagement may represent their own individual views, the views of family members and care recipients, as well as the views of consumer groups, organisations and consumer bodies.

Consumer engagement involves a shared responsibility of all participants – for consumers to engage and represent themselves or the views of others in a clear and open way, and for health practitioners and health agencies to be transparent and supportive during the processes and accountable to consumers about how their input may influence the final outcome. While consumers have choice in deciding how, when and if they will engage with their healthcare and the health system, it is important to recognise that consumer engagement may not always have the influence that consumers wish or result in the exact changes they may have put forward.

A chronic pain self-management group hosted a forum to get feedback on the proposed priorities that they were wishing to put forward to government on key policy areas. All members, community people who could be affected by their decisions, and funding body representatives were invited to attend and provide input. In the invitation to attend the forum, everyone was provided with clear information that the group were seeking feedback on five key proposed priorities. Everyone's viewpoint was important, recorded and considered in developing the draft priorities. The attendees were invited back to consider the priorities and make additional comment before the final submission was made to government.

HCQ believes consumers will choose to engage depending on the nature and integrity of the activity; their life, health and social circumstances at the time; and their perceptions of whether the activity will improve health outcomes. Additionally, HCQ also



Get to know more about what is happening and have input into matters and be able to influence final decisions”

HCQ Consumer Network and Consumer Representatives Review April 2010

acknowledges there are some consumers who are particularly disadvantaged due to a range of cultural, social and economic factors that impact on their ability to engage with agencies around their overall health and well-being. These consumers often need a range of physical, financial, emotional, information and administrative supports to enable them to engage. It is important that consumer engagement ensures the involvement of consumers and/or their representatives from Indigenous; rural and remote; culturally and linguistically diverse (CALD) backgrounds; younger and older people; persons with disability; adults with impaired decision-making capacity; members of the lesbian, gay, bisexual and transgender communities; and the financially disadvantaged and homeless.

The actual process of engagement and participation should inherently empower individuals and communities to understand their own health situations, provide positive input into local health activities and feel a greater sense of influence over the health services they use. Consumer engagement should not be random; rather it should be purposeful, structured, rigorous and responsive.

Consumer engagement may involve:

- health consumers seeking information from health practitioners and services
- health consumers giving and sharing their information, experiences and viewpoints with health practitioners
- interactive processes between consumers and health agencies, services or practitioners
- individual and community involvement in the decision-making processes that affect individual and collective health and wellbeing.



As a consumer I was not satisfied with the health services that are provided and feel the need to keep going back to make a difference”

HCQ Consumer Network and Consumer Representatives Review April 2010

Why do consumers become involved in health matters?

Consumers become involved:

- as a result of their own individual experiences with the health system, both positive and negative and because they want to work towards bringing about change in their own health and the broader system
- because they want to ensure the consumer perspective is brought to the table to influence improvements in health services and programs
- to gain more health information and knowledge to improve their own individual and collective health outcomes and to be better able to self-manage their own healthcare



Information is power”

HCQ Consumer Network and Consumer Representatives Review April 2010



*Keep whole group
focused on why we are
here and what we are
doing”*

HCQ Consumer
Network and Consumer
Representatives Review
April 2010

- to clarify health news they read or hear about
- to dispel myths³
- to influence state and national health reform initiatives.

What are the benefits of engagement for consumers?

Consumers can benefit by being involved in and engaged with their health systems through:

- developing greater understanding of health services and issues
- getting to know health decision-makers at a local, regional or state level
- seeing improvements in health outcomes and in responsive, quality and safe care
- increasing their capacity to contribute to health service and systems review
- feeling their voice is valuable and heard, leading to greater confidence when engaging with health practitioners and agencies.

What do health consumers say contributes to meaningful and responsive consumer engagement?

- To be and feel included
- A shared role in achieving and interpreting the results
- Informal gatherings to share perspectives to inform views on issues prior to a more formal engagement activity
- Their viewpoint to be heard and respected
- Adequate support and access to be able to participate, including information, tools and resources (for example, financial support to attend a meeting)
- Leadership development
- Feedback on what happened as a result of their input and engagement.

3 Nilsen, E., Myrhaug, H., Johansen, M., Oliver, S. and Oxman, A. (2006), *Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material*. Cochrane Database of Systematic Reviews 2006, 3.

Why do agencies engage consumers?⁴

- It is a valuable tool in delivering quality governance, services and programs.
- It contributes to:
 - the identification of needs and priorities for effective decision-making
 - open and transparent processes
 - better informed and more confident consumers
 - improved outcomes for individuals and communities
 - improved relationships between health practitioners, service providers and consumers
 - service credibility
 - system sustainability
 - health practitioners being more aware of consumers' cultures, values and needs.

The principles

When people are involved in making the decisions which affect their lives, their self esteem and self confidence rise, in turn improving their health and wellbeing.⁵

The following principles provide the foundation for health consumers, individually or collectively to be involved and have a say in their healthcare and the health system, and for health practitioners and agencies to engage consumers in a meaningful and respectful way.

The eight principles reflect and support international and national health charters and principles which reinforce the importance of health consumers in the development, implementation and review of the health services they receive.

The 1978 World Health Organisation's *Declaration of Alma Ata* and the 1986 Ottawa Charter for Health Promotion identified that health practices require the involvement of consumers and communities in health-related initiatives. This right of civic participation is also enshrined in international human rights instruments, like the International Covenant on Economic, Social and Cultural Rights. Australia is a signatory to these documents.

4 Health Consumers Queensland. (2009). *Consumer representatives program: Agency handbook*. Brisbane: Author.

5 Campbell, F., Hughes, L. and Gilling, T. (2008). *Reaching out: Community engagement and health*. London, UK: Improvement and Development Agency.

Nationally, the Australian Charter of Healthcare Rights, launched by the Deputy Premier on 17 March 2010 in Queensland, and currently being implemented across public and private health services in Queensland, strongly reinforces the right of health consumers to be heard and included in decisions and choices about their individual healthcare and in local, regional, state and national health initiatives. The Design and Governance Principles which are contained in the National Health and Hospitals Reform Commission Report, *A Healthier Future For All Australians: Final Report June 2009* also recognise the importance of seeking input and involving the community and the people who use health services, in the development and delivery of their healthcare and the health system.

Principles

1	Consumer participation	Consumers have the right to engage, be engaged and participate
2	Consumers are the central focus	Consumers are central to the engagement process
3	Consumer potential	Consumers have the potential to engage with the health system
4	Consumer choice	Consumers choose how they participate in the engagement process
5	Support to consumers	Consumers are supported to engage with the healthcare system
6	Shared responsibility	Consumer engagement processes involve participants working together in an open way, and sharing ownership and responsibility for outcomes
7	Mutual respect and value	Consumer engagement involves participants showing mutual respect and valuing each other's contributions
8	Diversity	Consumer engagement processes recognise and support diversity

Principle		Explanation of principle	Consumer questions
1	Consumer participation	Consumers have the right to engage, be engaged and participate	<p>Everyone has a right to have their say and be heard. The Australian Charter of Healthcare Rights and international human rights instruments and other health-related agreements, as outlined above reinforce Queensland health consumers' right to be engaged in health policy development and in service planning, implementation and evaluation.</p> <p>Can I ask my doctor about getting medications that don't leave me out of pocket?</p> <p>Can I have a say about what is happening in my community?</p> <p>Can our consumer group have input into the health policy which affects us?</p> <p>What if I get it wrong?</p>
2	Consumers are the central focus	Consumers are central to the engagement process	<p>Consumers experience the health system firsthand and it is important that their experiences and knowledge inform and shape service delivery. It is vital that consumers are central to any engagement process. This may involve the development, planning, implementation and evaluation of their own individual healthcare, and may also include the broader health policy, service and system reform.</p> <p>Do I get asked about things that matter to me?</p> <p>Can our group of health consumers interested in this particular health service area be asked to provide feedback?</p> <p>Will my needs be met?</p>
3	Consumer potential	Consumers have the potential to engage with the health system	<p>Health consumers have the potential to be active participants in their personal healthcare and broader health matters. However, consumers may require information and support to engage in a meaningful way. For consumers, this engagement process can be influenced by factors outside their control, such as the willingness to take on the consumer view. It is important to recognise that everyone has the potential to have a say and put forward their views about their own healthcare. It is also important to have input into the development, planning, implementation and review of the health system and services.</p> <p>Will I be able to understand the information and process and have the confidence to talk to doctors, public servants and other health consumers?</p> <p>How can I go about joining a consumer network or consumer group?</p> <p>What can I/we do to become active contributors to improvements in the health system?</p>
4	Consumer choice	Consumers choose how they participate in the engagement process	<p>Consumers may choose to engage in different ways and at different times or at different points with the health system. This can depend on what is happening for someone, their particular circumstances and their needs, or the issue at hand. The actual engagement process with a particular individual or agency can also influence how accessible the process is for health consumers.</p> <p>Can I step back and get involved again further down the track?</p> <p>Will it affect my service if I say no?</p>

Principle		Explanation of principle	Consumer questions	
5	Support to consumers	Consumers are supported to engage with the healthcare system	<p>It is important that consumers are provided with the information, tools and support that they need to engage and that the engagement process is accessible for everyone. To ensure accessibility, support may be provided to consumers to enhance their knowledge of the health system and health terminology. It is also important that consumers have the necessary support to navigate the health system and to engage with health agencies and practitioners; and to have opportunities for leadership roles. Very importantly, consumers should be supported physically and financially to be involved in engagement activities (for example, travel and accommodation; signing or language interpreters; personal care support and reimbursement of out-of-pocket expenses).</p>	<p>Will I get paid for travel costs to get to the session and home again?</p> <p>What if I've got good ideas that aren't on the form?</p> <p>Is there any training available to help me be effective on the reference group?</p> <p>Will my ideas really influence decisions?</p> <p>Will I get information about how I can influence what is going to happen and feedback?</p>
6	Shared responsibility	Consumer engagement processes involve participants working together in an open way, and sharing ownership and responsibility for outcomes	<p>Consumer engagement works best when there is mutual agreement about the engagement processes and productive working relationships. As such, consumers should be involved from the beginning of any engagement activity, as active partners in deciding on terms of reference; the expectations, purpose and points of engagement; and roles, responsibilities and information needs of participants. This provides for a mutual value exchange — health agencies being open and honest throughout the engagement process and identifying how consumers will benefit from the activity and health consumers providing honest input into the process for better health outcomes.</p>	<p>Are the people asking the questions comfortable with me not agreeing?</p> <p>Some of this is complex – will there be a chance to discuss and debate it before I decide on a point of view?</p> <p>Will I be listened to?</p> <p>Will I get feedback on what others said?</p> <p>Will I get to hear what the outcome was?</p> <p>Is this a genuine opportunity for me to influence decisions or are they wasting my time?</p>

Principle		Explanation of principle	Consumer questions
7	Mutual respect and value	Consumer engagement involves participants showing mutual respect and valuing each other's contributions	Consumers and the consulting agency will consider and value each other as equal contributors to the engagement process and as 'experts' in their particular aspects of health, treat each other with mutual respect.
			<p>Will I be patronised or treated with dignity and respect?</p> <p>Will there be retribution if I complain?</p> <p>Will having a say potentially make me more vulnerable in the system?</p>
8	Diversity	Consumer engagement processes recognise and support diversity	<p>Consumer engagement will recognise and be supportive of the diversity of Queensland health consumers, responding to people from Indigenous, rural and remote, and culturally and linguistically diverse (CALD) backgrounds, younger and older people and persons with disability, adults with impaired decision-making capacity, members of the lesbian, gay, bisexual and transgender communities and the financially disadvantaged and homeless.</p> <p>What if they don't have a signing interpreter at the forum?</p> <p>Will they provide halal food for lunch?</p> <p>Will the venue be accessible?</p> <p>What support will they provide to help with my visual impairment?</p>

The model

The model builds upon the Vancouver Coastal Health (VCH) model, reflecting the World Health Organization and International Association of Public Participation's approach to community participation.⁶ It focuses on individual consumers, and their families and carers as central to any engagement process. The intent of the model is to develop and enhance public participation in health service policy, planning and decision-making, and to raise awareness within the health system about community issues and concerns that may not otherwise be apparent.⁷

This model embodies HCQ's mission and term of reference two - that diverse voices can contribute to better decisions and that engagement extends beyond the general practice clinic or hospital bedside to formal dialogue between health consumers and their representatives, and health practitioners, health agencies and government.

HCQ's model of consumer engagement acknowledges that:

- health consumers are central to the engagement process
- consumers have the potential and the right to choose whether they want to engage in health-related activities or not. However, they may need information, tools and support to meaningfully participate
- there are multiple players, including health consumers and/or their representatives; health practitioners; health agencies; and government
- those involved in the engagement process want to engage on specific health issues
- there is no one best way to undertake consumer engagement. For consumers and/or their representatives, each episode of engagement is situation and context specific. They may be engaging in their personal healthcare or working towards systemic change.

6 Vancouver Coastal Health. (2008). *Community engagement framework*. Retrieved on 3 November 2008 from: www.vch.ca/ce

7 Davis, S., Nicol, V. and Dwyer, L. (2009). *Community engagement: Supporting improvement and innovation learning series*. Retrieved on 1 May 2010 from: http://www.impactbc.ca/files/SII_WebConf_-_Community_engagement_7_07_09.ppt#21

The HCQ Consumer Engagement Model

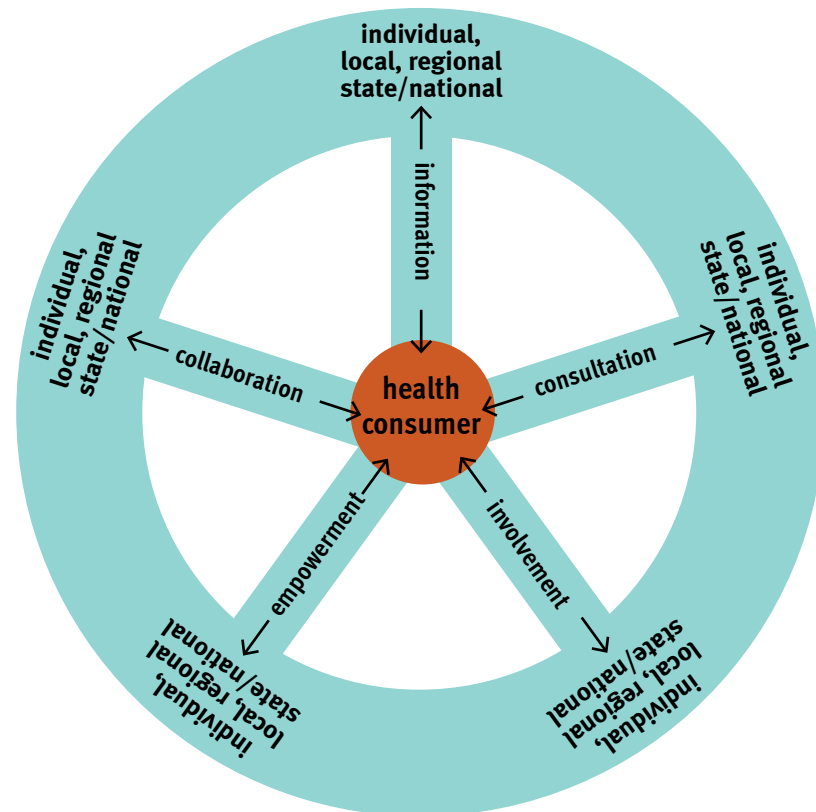


Diagram 1

Health Consumers Queensland: Consumer Engagement Model

About the model

The consumer engagement model:

- provides five elements of consumer engagement – information, consultation, involvement, collaboration and empowerment, which can happen at any of four points – individual, local, regional and state/commonwealth
- aims to represent different ways of engaging, with different points of involvement and influence over the process and its outcomes.

For health consumers

- Consumers may choose to engage across the five elements and four points depicted in the model, depending on the issue they are interested in and the information, tools and support available to assist their engagement. Sometimes consumers may only want information, and sometimes they want a partnership in, or indeed to drive an engagement process and the resulting decision-making.

- As consumers become better supported and informed, and more engaged, they may choose to adopt more formal consumer representative roles in pursuing their health rights; the defining of health policies and procedures; and in the planning, monitoring and evaluating of health services and programs; and the allocation of resources.

A local community health organisation is running a media campaign around swine flu vaccinations. It has a range of language-specific brochures on the vaccination program available in each of the member medical centres. Ah Rhong heard about the vaccination program from her local radio station and went to her local medical centre to pick up one of the brochures so she could learn more about the program and about the risks and benefits of having a vaccination. As Ah Rong is Korean and a member of a large population of Koreans in the local area, she was concerned that there were no brochures available in the Korean language. She mentioned her concerns to the receptionist who raised the matter with the multidisciplinary team who commissioned an environmental scan of languages spoken in the service area. The outcome was the brochure was translated into four other languages, including Korean.

For health practitioners and health agencies

- Consulting health practitioners and agencies may plan to use any or all of the five elements across the four points of consumer engagement (refer to Table 1, page 22 for some examples). This will depend on the messages they are trying to convey and the amount of feedback they need from consumers and/or their representatives and other stakeholders to inform their planning and decision-making. Different approaches may be appropriate for different agency goals and varying levels of commitment and resourcing.
- Certain agency goals will require more active involvement by consumers through shared decision-making and solution-focused activities. At other times, the health practitioner or agency may require information to be disseminated in the most accessible, user-friendly manner to inform health populations about a new or revised health initiative. Additionally, the health practitioner or agency may want to test draft plans, documents, policies or procedures with a representative sample of consumers, before publishing a finalised document or moving forward with a new program.

A pharmacy group heard their opening times were not meeting the needs of the community. Members of staff developed a survey which was distributed to health consumers and other citizens through their network of pharmacies. About 100 people returned the completed surveys. When the survey results were collated, the pharmacy group saw a very clear message that consumers and citizens wanted access to their pharmacies one hour earlier and one hour later than current opening times. After evaluating their financial and personnel resources, the pharmacy group extended their opening hours.

Other examples of engagement between consumers and their representatives, health practitioners and agencies, and government across the five elements and four points can be found at Table 1, page 22 – Examples of the Elements and Points of Consumer Engagement.

An explanation of the five elements of the model and the corresponding four points of consumer engagement follows.

The five elements

1. Information (*information exchange; low consumer/public involvement and influence*)

Timely, fit-for-purpose information supports effective consumer engagement. The flow of information between consumers and/or their representatives and health practitioners and agencies should convey facts, feelings and perspectives. The information provided by health practitioners and agencies to consumers and/or their representatives should convey facts, agency decisions, and inform consumers and the wider population about services, programs, activities and other health matters. This information should assist consumers to understand health issues, problems, alternatives and policy directions. Alternatively, consumers may request information from health practitioners and agencies to extend their knowledge and understanding or to inform their decision-making around personal and community health matters.

To engage in the other four elements of the model, consumers require relevant information from consulting health practitioners and agencies to inform their dialogue. In more formal engagement processes, agencies should provide this information to consumers and their representatives well in advance of the planned engagement activity.

2. Consultation (*information gathering; discussion; some consumer/public involvement and influence; but no agency commitment to change*)

Consultation involves some dialogue between health consumers and/or their representatives, and health practitioners and agencies. From the consumer perspective, consultation provides them with the opportunity to share their health journeys, views, needs, interests and aspirations with health practitioners and agencies about a particular health topic or issue. From the agency perspective, consultation activities seek consumers' and/or their representatives' reactions to, views on and lived experiences of the health system, policy, service, program or agency proposals. The consultation is usually for a defined period. Consumers' feedback may be incorporated into changes in health policy, plans or service delivery.

3. Involvement (*shared consumer/public and health practitioner and agency agenda-setting; some influence over differing options*)

Involvement requires consumers to be 'at the table' with health agencies and/or health practitioners and/or community organisations and/or government around the planning, delivery and evaluation of health services and programs and the development and/or revision of health policies. Consumers potentially can assist to shape decisions around these matters while raising their concerns or needs.

This work may be on an ongoing basis, on a single health issue, or on a range of health issues or policy matters. It encompasses continuing dialogue that is described as purposeful talk involving openness, active listening, making meaning of, and learning together.

4. Collaboration (*high consumer/public involvement and influence*)

Health consumers and/or their representatives and other stakeholders work together to develop innovative and/or preferred solutions, which are implemented for better health outcomes. In the process, all stakeholders make the decisions and each individual stakeholder owns the process and its outcomes. Consumer engagement is coordinated through partnership and dialogue that is continuous and high-level. Innovation comes from collaboration and conversation.

5. Empowerment (*consumer/public control*)

Decision-making within a specified framework is handed to consumers and/or their representatives by health practitioners, agencies or government. The consulting practitioner or agency stands at arms length, while giving a commitment to implementing consumers' and/or their representatives' priority setting and decisions. This ensures policy, service and program options are formulated by consumers and/or their representatives who are the end-users of health delivery.

The four points

1. Individual

Consumers and/or their representatives have the opportunity to be actively involved with their health practitioner in their personal healthcare and treatment or the support of a family member or care recipient. Additionally, it is about consumers and/or their representatives having the confidence to ask questions about their health condition, understand medical advice, find relevant support groups, and become active in their healthcare. At this point, consumers and/or their representatives may engage individually in health services planning and priority setting that is carried out close to them.

2. Local service

Consumers and/or their representatives may reactively or proactively engage with a health practitioner or agency at a service, program or hospital point within their local community.

3. Regional

Consumers and/or their representatives may be involved in regional or district health matters to better meet local area needs or to monitor the performance of local health agencies.

4. State/national

Consumers and/or their representatives may be involved in conveying their perspectives or in decision-making around state and national health legislation, policy review, reform initiatives or resource allocation with the intent of better health outcomes for their fellow Queenslanders and Australians.

Participation in a health agency's strategic planning workshop

A health agency providing services to people with a specific health condition requested a consumer representative to participate in their strategic planning workshop to provide a consumer perspective and inform the planning of the organisation's activities for the next three years. They approached the relevant state-wide consumer support body for people to submit an expression of interest outlining their experience and skills in this area. Following a selection process, one consumer was nominated to the health agency to participate in their workshop. A representative from the health agency met with the consumer to provide them with background information about the agency, discuss the agenda and talk about what they were hoping to achieve on the day. The consumer was able to provide valuable feedback to the agency from the consumer perspective.

*Carers meeting –
aged care nursing
home*

At a nursing home in Brisbane, the carers meeting was held bi-monthly to talk about the issues that arise in relation to supporting the people they care for. At this meeting, some carers raised concerns about the way their family member's health needs were being met in their aged care nursing home. There had been an outbreak of flu and some of the residents were transferred to hospital by ambulance. At the meeting, some of the families said they had not been notified before their family member was transported to hospital. They were aware that an after hours medical service could come and visit the residents in the nursing home, and bulk bill them, resulting in them being able to remain in their own familiar environment and still receive the medical treatment they required. The nursing home developed a procedure for staff about the need to ask families about the options of an after hours service or transfer to hospital. In the event the person was critically unwell, they would be transferred to hospital immediately.

Gaining state-wide consumer feedback on the proposed national health reforms

Health Consumers Queensland (HCQ) provided an interim feedback paper to the Federal Minister for Health and Ageing in October 2009 around the National Health and Hospitals Reform Commission's final report. The paper represented HCQ's perspective, which was informed by a HCQ state-wide consumer forum on the final report and feedback from our Consumer Network and HCQ's Committee. To further inform our response in a final position paper to the Queensland Deputy Premier and the Federal Minister for Health and Ageing, HCQ encouraged more feedback from our state-wide Consumer Network; hosted a focus group with health consumers from culturally and linguistically diverse backgrounds; and spoke with representatives of Indigenous health consumers and health agencies. Throughout the feedback process, consumers and their representatives were provided with information outlining the proposed reforms, and were encouraged to give their perspectives on what the Federal Government was proposing and HCQ's interim response.

Some key messages were delivered to the Queensland and Commonwealth Governments, about the future direction of health services and systems in Australia. HCQ suggested consumers wanted patient-focused, affordable, accessible, timely and responsive health services for Queenslanders and their fellow Australians. HCQ also suggested changes to the Australian health system should reflect the Australian Charter of Healthcare Rights and the needs and interests of Australia-wide health consumers and their representatives, along with the interests of governments, health practitioners and health programs and services. HCQ was keen to have consumers and their representatives included in further dialogue on national health reforms. Further to this, Queensland health consumers have had opportunities to attend a number of consultation activities, including discussion on the National Health and Hospitals Network, Medicare rebates, the Pharmaceutical Benefits Scheme and patient safety in Queensland.

The following table gives some examples of how consumer engagement can work across the five elements and four points of consumer engagement. There are many more examples in real life settings, however, consumer engagement opportunities and the ability to influence health matters and systems may narrow as consumers and/or their representatives move through the various elements and points of the model.

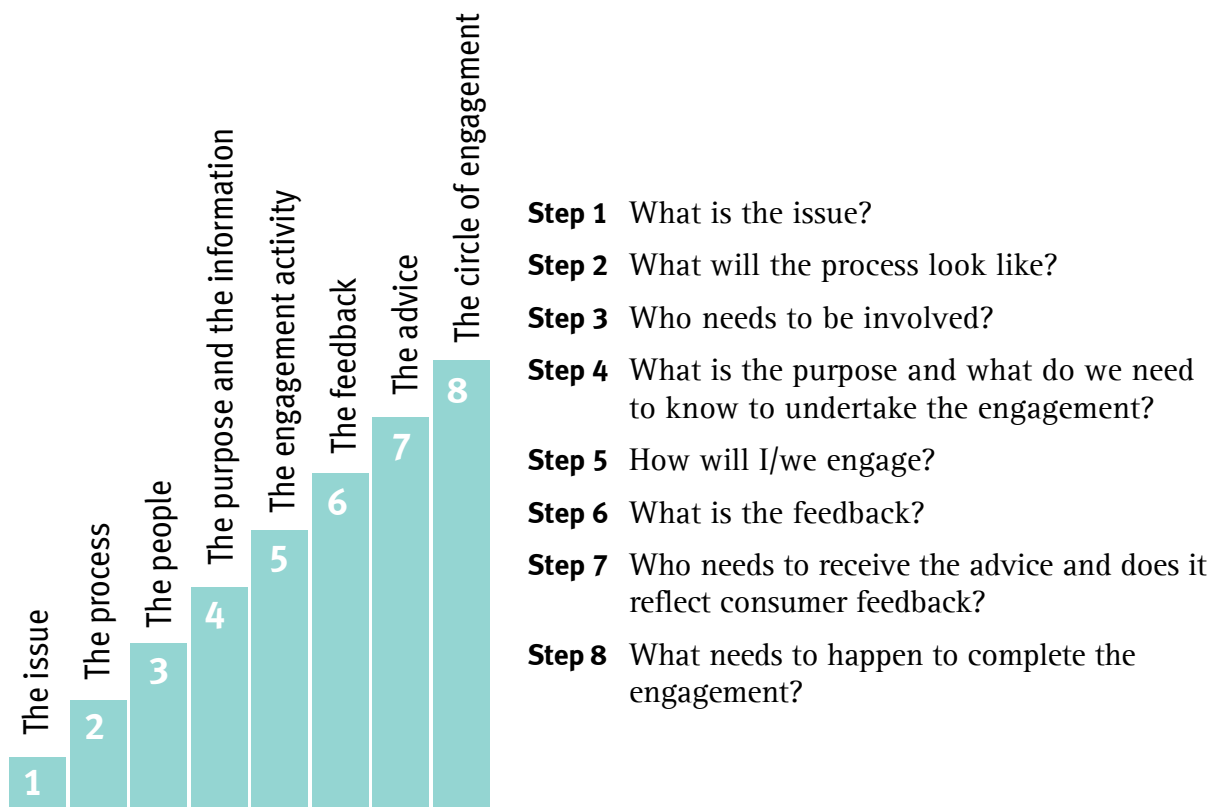
*Table 1
Examples of the Elements and Points of Consumer Engagement*

Four points of engagement	Five elements of engagement				
	Information	Consultation	Involvement	Collaboration	Empowerment
Individual	Flu vaccination brochure	Consumer satisfaction survey	Homelessness forum participant	Participant at a health agency’s strategic planning workshop	Advance health directive
Local service	Local mental health services directory	Consumer needs analysis	Carers meeting – aged care nursing home	Hospital refurbishment working group	Chronic illness steering committee
Regional	Maternity and children services regional expo	Regional focus group on Culturally and Linguistically Diverse communities needs and issues	Health Community Council	Member of Dental Board Queensland	Consumer Community Cooperative
State/national	National Health and Hospitals Reform Commission reports	State-wide public meetings on Closing the Gap initiative	State-wide consumer workshop to gain feedback on proposed national health reforms	Joint letter by the Australian and state/territory peak health consumer bodies in relation to changes to social security payments	Australia-wide referendum on a state and national health reform

The eight-step process

The eight-step process has been developed to support meaningful and respectful consumer engagement. It is based upon what health consumers have told HCQ about how their engagement with health practitioners and agencies can work most effectively and promotes best practice for consumer engagement. This process relates to formal consumer engagement activities, individually or collectively between consumers and/or their representatives, and health practitioners and agencies, and between consumers and/or their representatives and decision-makers. Examples of formal engagement activities include focus groups, forums, panels, committees, etc.

The process reflects the eight principles for consumer engagement and the five elements of the consumer engagement model across the four points. HCQ acknowledges individual and collective consumers, health practitioners and agencies may have different perspectives on the process.



The following table provides information about each of the eight steps written for consumers and their representatives and for health practitioners and agencies. It is written to support engagement that may be initiated and driven by health consumers as well as engagement that is initiated by health practitioners and health agencies. This may include an individual or group of health consumers identifying an issue in relation to their own healthcare or in the health system around which they wish to engage. Alternatively an individual consumer or group of consumers may be interested in engaging in regards to an issue that a health practitioner or health agency has initiated.

Table 2
The eight steps for consumers and agencies

Step 1 What is the issue?	
For consumers and their representatives	For health practitioners and agencies
<p>The following provides some useful questions to begin the engagement process to look at what is the issue that I/we are wanting to engage about.</p> <ul style="list-style-type: none"> • I/we have a health issue – what can I/we do about it? • How can I/we get all of the information I/we need? • Who can help me/us to access the information or resources I/we need? • How can I/we contribute to the discussion around the issue? 	<p>The health agency may require feedback on a particular health issue or require assistance with a needed decision. The clear aims and objectives of the engagement activity should be developed by the consulting agency in consultation with consumers and/or their representatives.</p> <p>At other times, consumers and/or their representatives may drive the issue, the consultation question and the resulting process.</p> <p>At this first stage of the engagement process it is important to define the:</p> <ul style="list-style-type: none"> • terms of reference, purpose, aims and scope of the proposed engagement activity • number of consumer representatives required • skills, knowledge and experience of consumer representatives for the proposed engagement activity.

Step 2 What will the process look like?	
For consumers and their representatives	For health practitioners and agencies
<p>As a consumer or a consumer representative, it is important that the engagement activity is well-planned and responsive to the diversity of potential consumer perspectives. When thinking about what the process will look like, it is important to involve consumers from the beginning and look at the following key areas:</p> <ul style="list-style-type: none"> • the most suitable engagement activity, venues and times • the risks and benefits of involvement in the activity • how participants with special and support needs will be accommodated • proposed roles and responsibilities • the skills needed to ensure discussion with health practitioners to fully communicate consumers' views and experiences • assistance to better engage. What extra supports do I/we need to assist to better engage? • role expectations – for consumers, health practitioners and consulting agencies • the most relevant information • how the ongoing flow of information will be channelled between you, other participants and the consulting agency • how the outcomes of the engagement activity will be communicated to government, service providers and health practitioners for decision-making. 	<p>This stage seeks to look at the best process to achieve the stated purpose within the health practitioner or agency's capacity – funding and human and information resources.</p> <p>Consumers need to be involved in exploring suitable communication options to ensure consumer participants, consulting agency staff and facilitators are well-informed and engaged from the start of the engagement activity.</p> <p>At times, consumers and/or their representatives may drive the process and initiate the engagement activity with health practitioners and agencies.</p> <p>At this stage, it is important that consideration is given to:</p> <ul style="list-style-type: none"> • an evaluation of the consumer population to be engaged • a risk and benefits analysis • the best engagement activities – short-term and long-term • timeframes to achieve the desired aims • the available budget and resources • suitable and accessible venues for intended participants.

Step 3 Who needs to be involved?	
For consumers and their representatives	For health practitioners and agencies
<p>If the engagement activity is one that is consumer driven, it is important to ask questions such as</p> <ul style="list-style-type: none"> • Who needs to be involved? • Who are the key stakeholders that I/we need to talk to? • Who do I/we need to invite into this process to be involved in what we are doing? <p>If the engagement activity is one that is agency driven, consumers may be invited to participate in an engagement activity through:</p> <ul style="list-style-type: none"> • a personal invitation from a health practitioner or agency • a personal invitation from a peak health body or a community organisation • a public notice in a newspaper • a health-related website • an email from an agency or peak health body • membership of a personal or professional network. <p>Sometimes, the process may be as informal as agreeing to participate in the engagement activity. At other times, a formal expression of interest (EOI) may be required to apply to participate in the engagement activity. This may involve addressing selection criteria or submitting a copy of your curriculum vitae (resume) or the names of people who could support your application.</p> <p>Alternatively, you may be selected by a consulting agency based on your relevant experience, skills and knowledge of the issue up for discussion. In this case, the agency should make appointments based on responses to the selection criteria and/or suitability for consumer representative roles.</p> <p>HCQ has a number of resources available, including a consumer handbook and an information paper on consumer and community engagement. To access these documents, please visit HCQ's website at: http://www.health.qld.gov.au/hcq</p>	<p>Matching consumers to an engagement activity and its desired outcomes is vital for any planned, successful engagement activity. Consideration should be given to what point of the health system the consumer and/or his/her representative will engage with — local service, district, state or national — and the specific health-related population.</p> <p>It is important to consider the demographics in the planned area of engagement (for example, state-wide or South West Queensland) to ensure representation from diverse consumers.</p> <p>Consumers may be recruited by personal invitation or through a consumer network; key stakeholder organisations; or via advertised calls for EOI for particular engagement activities. If the health practitioner or agency is using a formal EOI process, relevant consumers may be interviewed for the available position/s. The selection of consumers and other stakeholders should be transparent. Successful and unsuccessful applicants should be advised of the outcomes of their EOI.</p> <p>Consumers and/or their representatives should be advised of the health practitioner or agency's expectations of them, relevant codes of conduct, confidentiality agreements and be provided with opportunities to convey their expectations of the proposed engagement activity.</p> <p>HCQ has a number of resources available, including an agency handbook and an information paper on consumer and community engagement. To access these documents, please visit HCQ's website at: http://www.health.qld.gov.au/hcq</p>

Step 4

What is the purpose and what do we need to know to undertake the engagement?**For consumers and their representatives**

In undertaking any engagement, whether developing or participating, it is important that every person involved is clear on the purpose of the activity and receives all of the information that is required to ensure everyone can participate in a meaningful way. This may include:

- receiving an orientation to the organisation
- relevant written and verbal information about the roles, responsibilities and expectations of stakeholders
- background information concerning aspects of the health sector that relates to the activity
- a copy of any pertinent legislation and operating protocols
- administrative procedures.

For further information please visit HCQ's website at: <http://www.health.qld.gov.au/hcq>

For health practitioners and agencies

For agency-led engagement activities, consumers and other participants, including health agencies and practitioners should be acquainted with the history, governance arrangements, processes, membership, activity schedules, administrative support and current opportunities and challenges inherent in the planned engagement activity.

The information provided should assist the engagement process and give each participant:

- an understanding of the health agency
- the objectives of the engagement activity
- awareness of fellow participants' skills, knowledge and areas of expertise
- clarification of agency, consumer and other stakeholder role expectations

Where relevant, an orientation package could include, but is not limited to:

- fact sheets
- annual reports
- terms of reference
- background reports
- information on agency services
- a list of contacts
- photo consent forms
- codes of conduct
- confidentiality agreements
- administrative forms.

For further information please visit HCQ's website at: <http://www.health.qld.gov.au/hcq>

Step 5 How will we/I engage?	
For consumers and their representatives	For health practitioners and agencies
<p>At this stage, consumers may consider what is the best way for them to engage to achieve the best outcomes. This may be in a formal or informal way.</p> <p>For individual consumers, for example, this may be attendance at a clinical handover or case conference.</p> <p>More formal activities include interviews, focus groups, forums or workshops on a single or systemic health matter. This may be between consumers and consumers, or between consumers and health agencies and/or practitioners.</p> <p>A more formal activity provides an opportunity:</p> <ul style="list-style-type: none"> • to represent your individual or the collective views of a specific health population • provide relevant information • listen to the voices and views of other participants • engage in a conversation with other participants and agency staff • contribute to expanding the knowledge of other participants • in certain circumstances, collaboratively make decisions. <p>Having consumers involved and engaged can:</p> <ul style="list-style-type: none"> • influence how the agency considers issues • raise awareness of thinking about consumer perspectives on issues • possibly, find collaborative solutions for better health outcomes. <p>This is a time when you may like to consider:</p> <ul style="list-style-type: none"> • who you are representing and the diversity of their needs and experiences • the issue, major discussion points and their potential effect on consumers • blending various viewpoints • presenting your arguments rationally and convincingly • initiating new discussion if the current discussion is not going anywhere. 	<p>For agency initiated activities, this step builds on the earlier four steps. It is the culmination of all planning to date and should respond to the engagement principles. It is the physical activity that:</p> <ul style="list-style-type: none"> • links consumers and their representatives to relevant health practitioners and agencies • seeks to answer research questions • allows consumers and other stakeholders to share their views, needs and interests • provides participants with relevant information and/or options • hears what consumers and other participants have to say • provides an opportunity to share information, network and build ongoing working relationships. <p>It is important to have skilled facilitators who can enable participants to feel heard, and to have their viewpoints captured.</p> <p>Consumers should not be financially disadvantaged because of their involvement. Where required, they should be supported:</p> <ul style="list-style-type: none"> • to attend the activity (for example, travel and accommodation, cab vouchers) • during the activity (for example, a support worker to facilitate participation for a person with a disability, a carer etc, information in alternate formats, language interpreters). <p>Consumers should be provided with:</p> <ul style="list-style-type: none"> • an agenda and reading materials • writing equipment • an evaluation form • information about relevant health services and programs.

Step 6 What is the feedback?	
For consumers and their representatives	For health practitioners and agencies
<p>Whether this is a consumer-led activity or an activity that health agencies and practitioners arrange for consumers and/or their representatives, it is important that:</p> <ul style="list-style-type: none"> • the feedback from the activity is collated and a summary developed • each participant has an opportunity to provide further comment before a final document is developed • everyone learns from the feedback • recommendations reflect everyone's viewpoints. 	<p>Where the activity is agency-led, verbal and written feedback received during the engagement activity should be analysed. Then a summary should be drafted containing:</p> <ul style="list-style-type: none"> • a précis of the information received • any health-related issues or key findings which arose during discussion • future recommendations. <p>This summary/report should then be made available to each participant, including consumers and their representatives, for further comment, prior to drafting a final document.</p>
Step 7 Who needs to receive the advice and does it reflect consumer feedback?	
For consumers and their representatives	For health practitioners and agencies
<p>Reflecting on the summary of the feedback provides an opportunity to decide who needs to see/hear the advice/recommendations. The consumer perspective should be highlighted. Relevant agencies that may be influenced by the summary may include:</p> <ul style="list-style-type: none"> • other health consumers • the Queensland Minister for Health • the Commonwealth Minister for Health and Ageing • Queensland Health • peak consumer bodies • health-related consumer and community organisations. <p>At this stage of the engagement process, consider if:</p> <ul style="list-style-type: none"> • the engagement was worthwhile • meaningful dialogue occurred • the decision-makers were influenced • an ongoing engagement pathway was created. 	<p>Strategically targeted advice should maximise health outcomes. If recommendations made in an engagement activity report are relevant to a particular policy or reform area, it can be forwarded to relevant parties to inform their decision-making. These parties could be:</p> <ul style="list-style-type: none"> • the Queensland Minister for Health • the Commonwealth Minister for Health and Ageing • Queensland Health • peak consumer bodies • health-related consumer and community organisations. <p>At this stage, it is important for the agency to also evaluate the engagement approach used and note any areas for improvement or refinement at future events. Reporting on successful engagement activities and quality outcomes also builds support for future consumer engagement in government and non-government health-related planning and decision-making.</p>

Step 8 What needs to happen to complete the engagement?	
For consumers and their representatives	For health practitioners and agencies
<p>This is the concluding stage. Other opportunities to engage may arise from this instance, however, at the end of this particular engagement activity, it is important for all participants to:</p> <ul style="list-style-type: none"> • receive information about any decisions arising out of the engagement activity. • ensure this information and outcomes are conveyed to the consumers and/or organisations being represented. 	<p>This is the concluding stage as specific engagement activities inevitably come to an end. At the end of this particular engagement activity, it is important to:</p> <ul style="list-style-type: none"> • receive any further feedback from participants, including consumers and/or their representatives and decision-makers. • provide each participant, including consumers and/or their representatives with a copy of the final summary/report.

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Health Consumers Queensland definitions

Key definitions

Health consumer

Health consumers are people 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.

Carer

The Carers (Recognition) Act 2008 identifies a carer as an individual who provides, in a non-contractual and unpaid capacity, ongoing care or assistance to another person who, because of disability, frailty, chronic illness or pain, requires assistance with everyday tasks.

Agency

Agency refers to any health organisation, or Queensland Health unit or health service provider or health practitioner that chooses to engage with consumers.

Other relevant definitions

Agents of change

Agents of change are individuals and/or their representatives who want to engage in health-related activities to improve their personal circumstances, or the healthcare and treatment of their care recipient/s, family member/s and communities, or to tackle the wider social determinants of health and systemic disadvantage.

Community

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

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. It is a powerful vehicle for bringing about environmental and behavioural changes that will improve the health of the community and its

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

members through partnerships and coalitions that help mobilise resources, influence systems and change relationships among partners.⁹

Consumer engagement

Consumer engagement informs broader community engagement. It is about health consumers being involved in their own healthcare and treatment and in the planning and development of health policies and service planning, implementation and evaluation. It can be seen as a broad way to cover the range of activities used by governments, organisations and individuals to generate consumer input in or discussion about policy.¹⁰

Consumer representative

A consumer representative is a health consumer, including family members and carers, who is nominated by and accountable to an organisation like HCQ to represent the voices of health consumers.¹¹

Healthcare

The provision of services that help individuals achieve an optimal state of wellbeing, in any setting or stage in the human life cycle.¹²

Health champions

Health champions are individuals who possess the experience, enthusiasm and skills to encourage and support other individuals and communities to become involved in health engagement activities. These champions also work to ensure health issues facing individuals, communities, the state or nation remain high on the agenda of organisations that are in a position to effect change.

Health engagement

Health engagement happens between health consumers and agencies for the mutually beneficial exchange of knowledge, ideas, viewpoints and resources in a context of partnership and reciprocity.

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

10 Gregory, J. (2008). *Consumer engagement in Australian health policy: Final report of the AIHPS research project*. Melbourne, Victoria: Australian Institute of Health Policy Studies.

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Health policy

It is the laws, rules and financial and administrative decisions made by governments and other relevant organisations to influence the management of and planning for the health system and the provision of health services.¹³

Lived experience

Lived experience relates to individual's life health activities, encounters, wisdom and knowledge gained from a personal, family and/or community perspective. It is the care, treatment, emotions and relationships we go through during our health journey.

Rights

Rights refers to those fundamental rights that humans have by the fact of being human, and which are neither created nor can be abrogated by any government. Broadly defined, rights are about what is just, good or proper, conforming with or sitting comfortably with justice, law or morality.¹⁴

Social determinants of health

The social determinants of health are the circumstances in which people are born, grow up, live, work and age and the systems in place to deal with illness, which are all shaped by wider societal factors.¹⁵

Wellbeing

Wellbeing is a state of complete physical, mental, social and emotional wellbeing, which is not merely the absence of disease or infirmity.

13 Nilsen et al cited in Gregory (2008).

14 United Nations. (1948). *The Universal Declaration of Human Rights*. Retrieved on 15 April 2010 from: <http://www.un.org/en/documents/udhr/index.shtml#a1>

15 Department of Health and Ageing. (2009). *Development of a new national women's health policy consultation discussion paper 2009*. Canberra: Author.

Attachment A The Australian Charter of Healthcare Rights

Australian Charter of Healthcare Rights

Supported by **Queensland Health**

The Australian Charter of Healthcare Rights describes the rights of patients and other people using the Australian health system. These rights are essential to make sure that, wherever and whenever care is provided, it is of high quality and is safe.

The Charter recognises that people receiving care and people providing care all have important parts to play in achieving healthcare rights. The Charter allows patients, consumers, families, carers and services providing health care to share an understanding of the rights of people receiving health care. This helps everyone to work together towards a safe and high quality health system. A genuine partnership between patients, consumers and providers is important so that everyone achieves the best possible outcomes.

Guiding principles

These three principles describe how this Charter applies in the Australian health system.

1 Everyone has the right to be able to access health care and this right is essential for the Charter to be meaningful.

2 The Australian Government commits to international agreements about human rights which recognise everyone's right to have the highest possible standard of physical and mental health.

3 Australia is a society made up of people with different cultures and ways of life, and the Charter acknowledges and respects these differences.



For further information please visit www.safetyandquality.gov.au

AUSTRALIAN COMMISSION ON SAFETY AND QUALITY IN HEALTHCARE



What can I expect from the Australian health system?

My rights	What this means
Access	
I have a right to health care.	I can access services to address my healthcare needs.
Safety	
I have a right to receive safe and high quality care.	I receive safe and high quality health services, provided with professional care, skill and competence.
Respect	
I have a right to be shown respect, dignity and consideration.	The care provided shows respect to me and my culture, beliefs, values and personal characteristics.
Communication	
I have a right to be informed about services, treatment, options and costs in a clear and open way.	I receive open, timely and appropriate communication about my health care in a way I can understand.
Participation	
I have a right to be included in decisions and choices about my care.	I may join in making decisions and choices about my care and about health service planning.
Privacy	
I have a right to privacy and confidentiality of my personal information.	My personal privacy is maintained and proper handling of my personal health and other information is assured.
Comment	
I have a right to comment on my care and to have my concerns addressed.	I can comment on or complain about my care and have my concerns dealt with properly and promptly.

Health Consumers Queensland

...your voice in health

Consumer engagement framework

