...your voice in health

Health Consumers Queensland

Consumer Representatives Program

Agency Handbook

June 2009

Queensland Government

...your voice in health

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Consumer Representatives Program: Agency Handbook

A guide to the HCQ Consumer Representatives Program. Information and ideas for health agencies on how to invite, encourage and support consumer engagement on committees.

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Consumer Representatives Program

Agency Handbook

A guide to the consumer representatives program

Information and ideas for health agencies on how to invite, encourage and support consumer engagement on committees

June 2009

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HCQ commends the time, effort, expertise and experience that those organisations and people offered us in the development and review of the Handbooks and their associated information sheets.

The organisations and people who assisted HCQ included:

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HCQ Ministerial Consumer Advisory Committee
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Message from the Deputy Premier

Engagement with the general public provides us with the necessary information to improve the provision of health care to Queenslanders.

One of the Queensland Government's aims, under *Toward Q2: Tomorrow's Queensland,* is to make Queenslander's Australia's healthiest people. Some of the challenges we need to overcome to achieve this include population growth, the ageing of our population, entrenched disadvantage and unhealthy lifestyles.

But every challenge is also an opportunity to empower people with purpose and the knowledge to make changes that create a better future. In acting as 'your voice in health', Health Consumers Queensland (HCQ) seeks to strengthen the consumer perspective in health policy, systems and service reform.

HCQ's Strategic Plan 2008-10 underpins the ongoing work of this important Statewide consumer body, focusing on the areas of advocacy support, consumer engagement and capacity building.

HCQ is committed to promoting and informing individual and broader health consumer and community engagement and representation, towards better health outcomes for all Queenslanders.

I congratulate HCQ's Chairperson, Mr Mark Tucker-Evans, all 13 Committee members and the HCQ Secretariat on this initiative and encourage health consumers to use this body as their voice in health.

Paul Lucas MP
Deputy Premier
Minister for Health

Message from the Chairperson Health Consumers Queensland

Good health is critical to well-being and to ensure healthy life opportunities for everyone, health consumers need to be engaged in the decision-making processes that affect them and their loved ones. Consumers are the experts in their personal and family experiences of accident and illness. Recognising consumers as having unique needs, values, preferences, social circumstances and lifestyles, will ensure more meaningful dialogue between health professionals, service providers and consumers.

Engagement of consumers in the development of health policy, planning, service delivery and review can assist Queenslanders to have a more accessible and acceptable health system and better health outcomes. Well-structured, well-resourced and competently facilitated deliberative engagement processes work to create a conversation between consumers, service providers and Government, ensuring effective collaboration and partnerships. This results in individual and collective reflection, new ideas and learning, and better solutions to the health challenges of the 21st Century.

Health Consumers Queensland's (HCQ) mission is to support the voices of Queensland health consumers to achieve better health outcomes. Our aim is to strengthen the consumer perspective at all levels of the health system. HCQ's key functions, in line with its terms of reference, encompass the provision of ministerial advice on key health policy and initiatives, enhancing consumer participation, building consumer capacity and advocacy support.

As part of HCQ's consumer engagement framework, our Consumer Representatives Program has been developed to ensure effective partnering between requesting health agencies and consumers who want to have a say in health matters. To support the Program and assist health consumers and Government and non-Government health professionals and service providers to have a rewarding engagement experience, HCQ developed a resource kit, comprising this Agency Handbook, a companion Consumer Handbook, an Information Paper and comprehensive information sheets.

I encourage all consumers and agencies to read this Handbook and the other information available in the resource kit and to invest in collaborative, comprehensive and integrated action for the good health of all Queenslanders.

The other documents in the kit can be accessed on our website at www.health.qld.gov.au/hcq
or by phoning HCQ's Secretariat on (07) 3234 0611.

Mark Tucker-Evans
Chairperson
Health Consumers Queensland

Introduction

Health Consumers Queensland (HCQ) has developed this Agency Handbook, its companion Consumer Handbook and associated information sheets as part of a community engagement resource kit for health consumers, government, and community and private health agencies to support their mutual engagement for better health outcomes.

HCQ comprises a 14-member Ministerial Consumer Advisory Committee and Secretariat supported by the Office of the Director-General, Queensland Health. It was established to contribute to the continued development and reform of health systems and services in Queensland, by providing the Minister for Health with information and advice from a consumer (patient) perspective and by supporting and promoting consumer engagement and advocacy.

HCQ aims to strengthen the consumer perspective in health services policy, systems and service reform and improvement. In acting as your voice in health, HCQ supports consumer, community and patient involvement in all aspects and stages of their individual and collective health care journey. HCQ's term of reference two 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."*

As part of HCQ's consumer engagement plan and framework, HCQ developed an information paper, *Consumer and community engagement and patient involvement and participation in health service planning, delivery and evaluation.* The information paper is the first in a two-part series of papers. It is based on a review of the literature and current practices within Australia and other international contexts. The second paper will reflect the consumer perspective and be informed through Statewide consultation with health consumers, and their carers and family members, and health professionals and government and community organisations.

A further component of HCQ's plan and framework includes HCQ's Consumer Representatives Program, which has been established to promote and enable levels of health consumer engagement within Queensland and respond to requests by health agencies for consumer representatives at state and national levels.

This Handbook, as part of HCQ's resource kit, underpins HCQ's Consumer Representatives Program. The resource kit is a collaborative effort between individual health consumers, a

number of consumer, health and community sector groups, the Health Issues Centre Inc., Victoria (HIC) and HCQ.

This Handbook provides background information about consumer and community engagement and HCQ's Consumer Network, which is the pathway to the Consumer Representatives Program.

The Handbook is divided into six sections, with two appendices on Statewide health-related organisations and the Australian Charter of Healthcare Rights.

Initially, the Handbook offers definitions of the terms used in the document, sourced from Queensland Health and other organisations' documents. Being familiar with our definitions will provide a clear understanding of what HCQ means by the term, 'consumer engagement' and how HCQ describes a consumer, carer, committee, consumer representative, health agency and community.

Section one details HCQ's Consumer Representatives Program and processes. It highlights the nine principles of HCQ's Consumer Representatives Program, which HCQ believes provide a useful framework for mutual collaboration between agencies and health consumers.

Section two offers some useful information for agencies about consumer engagement, including why agencies engage consumers, and what consumer representatives expect from being involved in committees.

Section three has frequently asked questions and their relevant answers.

Section four directs the reader to HCQ's website, www.health.qld.gov.au/hcq to find all relevant forms to register for the HCQ Consumer Representatives Program, either as a health consumer or a health agency.

Section five details the Australian Health System, a comprehensive overview compiled by the Health Issues Centre Inc, in Victoria. It discusses the health system at the Federal, State, Territory and Local Government level; Medicare Australia; the Pharmaceutical Benefits Scheme; health service delivery; private health insurance; and current research initiatives.

Section six has a list of resources and links from Queensland and interstate for further reading.

The Handbook provides a range of useful tips, information and ideas for agencies that choose to engage with HCQ's Consumer Representatives Program or recruit independently.

HCQ expects agencies to give a committment to upholding HCQ's mission and principles and to engage in respectful working partnerships. The Agency Request Form and copies of both handbooks and information sheets, along with other information on the history and work of HCQ can be accessed on HCQ's website.

Background

What is consumer and community engagement?

Consumer and community engagement is a catalyst for change. It is the process by which the aspirations, values, needs and concerns of 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.

HCQ's Consumer Network

The HCQ Consumer Network is a register of health consumers, community organisations and statutory bodies, who are interested in providing input into health policies and initiatives from a consumer perspective. As part of the Network, members will receive information and can provide information and feedback to inform HCQ's work in relation to health policy, planning and service provision within Queensland and nationally.

The HCQ Consumer Network is the pathway to the Consumer Representatives Program. Being a Consumer Network member entitles members to:

» receive HCQ e-newsletters

» receive emails about opportunities for consumer representative committees

» receive invitations for Expressions of Interest (EOI) for specific committees

» respond to invitations and opportunities to provide feedback to HCQ

» identify and raise emerging issues from a health consumer perspective

» link with other interested health consumers about similar areas of interest and share information and ideas, within an online environment

» receive information about and invitations to HCQ events and other Government and community health events

» receive information about opportunities for training, conferences, and workshops.

Terms used in this handbook

The following definitions of the terms used in the document were sourced from Queensland Health and other organisations' documents. HCQ acknowledges there are many alternate definitions available in the relevant literature.

For the purposes of this handbook, HCQ has adopted those definitions, to provide readers with a clear understanding of what HCQ means by the term, 'consumer engagement' and how HCQ describes a 'consumer', 'carer', 'committee', 'consumer representative', 'agency' and 'community'.

Agency In this handbook, "health agency" or "agency" refers to any health organisation, or Queensland Health unit or service provider that is seeking consumer representatives through the HCQ Consumer Representatives Program.

Community[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.

Consumers[2] HCQ identifies consumers as 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.

Carers[3] Within the context of this definition, a carer is a person of any age who, without being paid, cares for another person who needs ongoing support because of a long-term medical condition, a mental illness, a disability, frailty or the need for palliative care.

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

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

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

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.

Committee For the purpose of this handbook where we use the word "committee" we are describing any reference group, advisory group, board, consultation forum, committee, working group, and so forth, where a consumer representative is sought through the HCQ Consumer Representatives Program.

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.[4]
- 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.[5]
- 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.[6]

Consumer Representative

A HCQ Consumer Representative is a consumer, including family members and carers, who is nominated by and accountable to HCQ to represent the voices of Queensland's health consumers.

4 See footnote 1.

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

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

Section 1
About HCQ's Consumer Representatives Program

Health Consumers Queensland has established the HCQ Consumer Representatives Program to promote health consumer engagement within Queensland and respond to requests for consumer representatives at state and national levels.

HCQ's Consumer Representatives Program receives requests from Statewide health agencies to nominate health consumer representatives to health related committees, reference and focus groups, advisory bodies and panels (committees). Through their membership of these committees, consumers provide input from a consumer perspective into health policies, systems, planning, services and initiatives.

The Program works collaboratively with other key government and community agencies and links closely with local, state and national consumer networks (and other non-government groups).

This section of the handbook provides health agencies with information about the underlying principles of the program, the process of requesting health consumer representatives, and the expectations of both agencies and health consumers who participate.

Underlying principles

HCQ's Consumer Representatives Program operates within nine principles. The principles relate directly to the mission, guiding principle and aspirations of HCQ, as stated in its *Strategic Plan 2008 - 2010*[7] and *Information Paper, Consumer and Community Engagement and patient involvement and participation in health service, planning delivery and evaluation*[8] .

Each of these documents can be accessed through HCQ's website at: www.health.qld.gov.au/hcq.

Further to this, HCQ's Consumer Representative's Program is underpinned by the Australian Charter of Healthcare Rights[9] which reinforces the right of consumers to participate in decisions and choices about their healthcare; and the value and role of consumer

7 Health Consumers Queensland, (2009). Health Consumers Queensland Strategic Plan 2008–2010. Brisbane: Author.

8 Health Consumers Queensland, (2009), Consumer and community engagement and patient involvement and participation in health service planning, delivery and evaluation. Brisbane: Author.

9 Australian Commission for Safety and Quality in Health Care. (2008). Australian Charter of Healthcare Rights. Canberra: Commonwealth of Australia.

engagement in the development of health policy, and in planning, service delivery and evaluation.

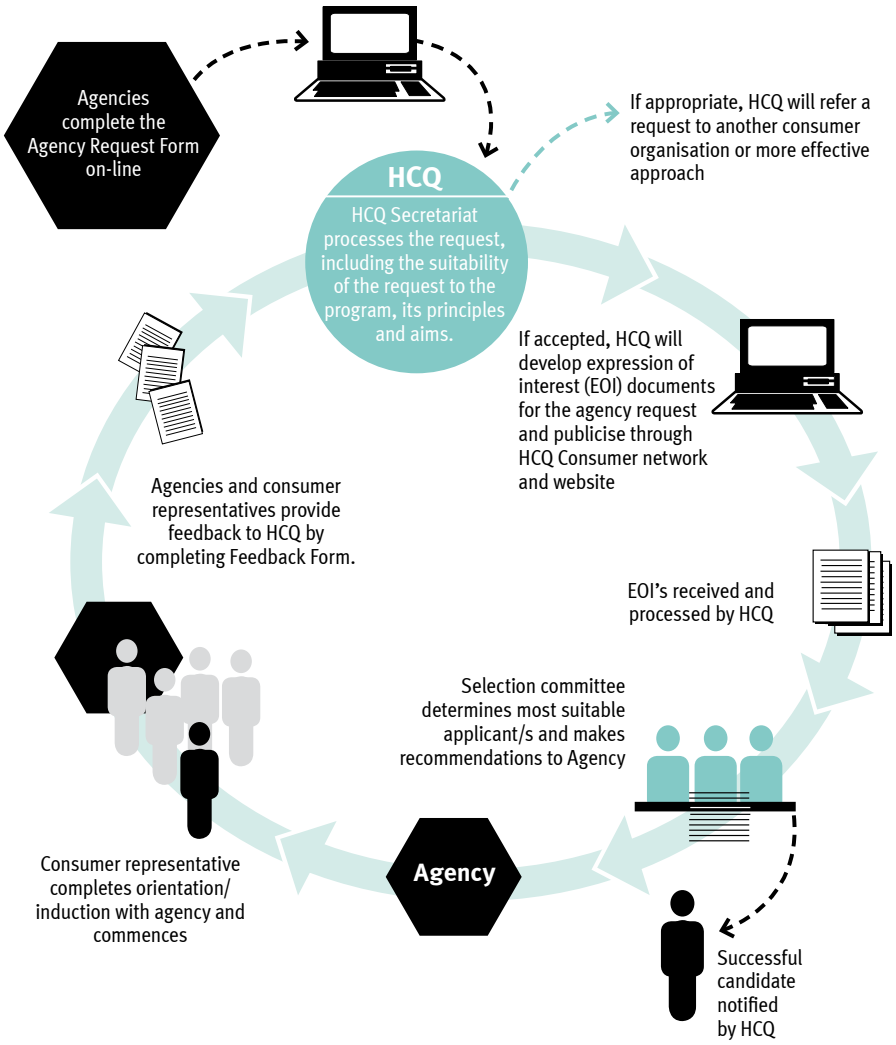
To be eligible to access HCQ's Consumer Representatives Program, HCQ requires that agencies agree to working within the nine principles of the program.

HCQ's nine program principles

1. HCQ acknowledges the right of all consumers to be involved in the planning, implementation and evaluation of health policy, programs and services and their individual care arrangements.
2. Engagement activities should utilise an appropriate range of skills, expertise, knowledge and strategies relevant to each engagement situation.
3. Consumer engagement should be supported by all levels of the consulting organisation and sufficiently resourced so that involvement is a positive and meaningful experience for consumers, carers, community representatives and organisational staff.
4. Consumers should not be financially disadvantaged as a result of their participation in any engagement activity (refer to pages 31 and 32 of this handbook).
5. Consumers should be engaged from the beginning of any engagement activity.
6. Appointments to any consultation process should be equitable, transparent, accountable and efficient.
7. Consumers and the consulting organisation should consider and value each other as equal contributors to the engagement process and act in a mutually respectful manner.
8. All aspects of consumer engagement should recognise and be supportive of the diversity of Queensland health consumers.
9. The Consumer Representatives Program complements and promotes the role of existing consumer and community organisations and networks.

How the program works

The following table depicts the process for agencies requesting consumer representatives through HCQ's Consumer Representatives Program.



HCQ's Consumer Representatives Program

The process

Step 1: *Agencies complete the Agency Request Form on-line.*

Agencies seeking a consumer representative via HCQ's Consumer Representatives Program are required to complete an online *Agency Request Form* via HCQ's website: www.health.qld.gov.au/hcq

The *Agency Request Form* covers the committee's purpose and aims, and the skills, knowledge base and experience the agency is looking for in a consumer representative.

Tip *Think about these details when planning to recruit a consumer representative:*

- the purpose, aims and scope of committee's work
- the terms of reference
- the number of consumer representatives sought
- the time commitment and where the activity is located
- the skills, experience and knowledge base the consumer representative needs
- the specific target group or health population being sought
- the scope of the consumer representative's role
- the agency's experience of consumer engagement
- the agency's expectations from consumer engagement
- whether the agency will pay a sitting fee to consumer representatives
- whether the agency has the capacity to reimburse expenses incurred by consumer representatives in the course of their representative roles
- the potential barriers to consumer engagement
- the range of supports needed by consumer representatives.

Tip *How many consumer representatives does a committee need?*

HCQ recommends that agencies invite TWO consumers onto a committee for several reasons. Two consumers participating provide an opportunity for each to support the other during meetings; in preparation and debriefing. Having two consumers involved will facilitate succession planning. It also safeguards continuity should one be unable to fulfil their responsibilities for some reason.

Tip *When to involve consumers on committees*

Involving consumers at the beginning of any process is better than seeking consumer involvement once a process has commenced, as better outcomes will be achieved than if consumer involvement is sought once a process has begun.

If an agency is recruiting consumer representatives to an existing initiative, it may need to address any consumer concerns about the value of their participation.

Step 2: *HCQ Secretariat Processes the request*

HCQ will consider the request against the principles and aims of the program. This includes considering if there is an existing consumer group, which may be better placed to assist with the nomination of a consumer representative. If there is, HCQ may refer the agency to such a group as an alternative to the Consumer Representatives Program.

Given HCQ's Statewide focus, it will refer local or district requests on to Health Community Councils, as these bodies undertake consumer and community engagement at a health district level.

HCQ will also negotiate with agencies about making a referral to consumer and community groups, which might more effectively and appropriately respond to requests for consumers with specific experience or from defined health populations.

Tip *Think about asking other groups*

HCQ works to complement the roles of existing consumer and community organisations and peak and statutory bodies. It recognises that other consumer groups may more appropriately or effectively assist with the recruitment of consumers with specific experience, skills or perspectives, where this is needed.

(For example, an agency seeking consumers with knowledge and expertise specifically around Deaf Community health issues would be referred to organisations like Deaf Services Qld, which have an interest and expertise in this area.)

(For example, a regional Division of General Practitioners wanting consumer representatives for a committee developing a funding proposal for a district project to assist consumers to self-manage their chronic disease and lifestyle, would be referred on to a Health Community Council or a local consumer or community organisation.)

Step 3: *HCQ develops expression of interest (EOI) documents*

Where HCQ does not refer the agency to other groups, the Secretariat will develop an *Expression of Interest Form* (EOI) relevant to the agency request.

The vacancy will be promoted through HCQ's state-wide Consumer Network and the *Expression of Interest Form* will be posted to the website with other relevant documentation.

Consumers can then respond by completing and submitting the EOI form online, then submitting their curriculum vitae .

Step 4: *EOI's received and processed by HCQ*

HCQ's Secretariat will receive and register all completed *Expression of Interest Forms*. The secretariat will determine the eligibility of each candidate and maintain confidential records.

To be eligible for consideration, health consumers must meet the following requirements:

- be registered on HCQ's Consumer Network
- demonstrate they are able to represent consumer views about health services
- demonstrate they meet the requirements of the selection criteria
- support Health Consumers Queensland's mission, guiding principle and aspirations
- agree to work within the nine principles of HCQ's Consumer Representatives Program
- be 18 years of age or over.

Ineligible applications will not proceed to the next stage.

Step 5: *Selection committee determines most suitable applicant/s and makes recommendations to Agency*

HCQ will convene a selection panel. The panel will determine the most suitable candidate/s in line with the selection criteria and applicants' responses.

Recommendations will then be made to the agency for their consideration.

The agency will notify HCQ of their decision.

Step 6: *Notification to applicants*

The Secretariat will notify applicant/s of the outcome of the selection process.

With the agreement of the successful candidate/s, their contact details will be provided to the agency.

Step 7: *Consumer representative completes orientation / induction with agency and commences*

Committees need to provide consumers with information that will give them a sense of the organisation and their role on the committee. Orientation packages can include fact sheets, annual reports, terms of reference, background reports, information about

the services provided by the agency, a list of contacts and any forms needed to claim reimbursement or provide feedback. In addition, it is also extremely useful for both consumer and agency to conduct a face-to-face orientation meeting. This should involve the key person servicing the committee but can also valuably involve the Chair.

Tip *Structured orientation*

Structured orientation for all members should be built into the work plan of a committee. It is a useful strategy which ensures a shared understanding of the role, scope and functions of the committee and each person on it. It is also an opportunity to clarify goals, working relationships and expectations across the whole committee.

The HCQ secretariat can provide support and referral to sources of information which might be helpful to both consumer representatives and agencies.

Step 8: *Information and feedback for HCQ*

Agencies are to provide feedback following the completion of the consumer's appointment. HCQ recognises that it is important to receive feedback and information about outcomes of consumer engagement. This informs HCQ's strategic goals, helps identify emerging issues and trends, and informs program evaluation processes.

HCQ respects the private nature of committee work. In obtaining feedback, HCQ will not seek details of the work or deliberations of the committee.

Agency Feedback Forms are on the HCQ website.

Program conditions

HCQ supports and promotes consumer engagement which is consistent with contemporary best practice. As participants in the program, HCQ has expectations of both agencies and consumer representatives, which reflect a mutually respectful approach to collaboration for better health outcomes.

What does HCQ expect of health agencies?

HCQ requires agencies to give a commitment to:

- support the mission, guiding principle and aspirations of HCQ
- support the nine principles underpinning the HCQ Consumer Representatives Program
- meaningful and respectful engagement with consumers
- provide information to consumers about the scope of their role, expectations for engagement in the committee, and terms of appointment
- provide consumers with orientation and induction to the agency and the committee
- provide assistance with administrative needs as required.

HCQ's Consumer Representatives Program principles build upon the principles, which underpin the Australian Charter of Healthcare Rights.[10] They strongly reinforce the right of consumers to be included in decisions and choices about their health care and in health service planning. The principles are consistent with HCQ's Information Paper, *Consumer and community engagement and patient involvement and participation in health service planning, delivery and evaluation.*[11]

HCQ recommends that health agencies read this Information Paper, which is available on its website.

10 See footnote 9.

11 See footnote 8.

What does HCQ expect from consumer representatives?

As participants in the program, consumers are required to be eligible to become a HCQ consumer representative and need to:

» support HCQ's mission, guiding principle and aspirations

» support the nine principles underpinning the HCQ Consumer Representatives Program

» be registered on the HCQ Consumer Network

» be able to represent consumer views about health services

» meet the requirements of the selection criteria via responses to the EOI

» be willing to provide a consumer voice to inform Queensland health policies, planning and service provision

» be 18 years of age or over.

HCQ requires that its consumer representatives are familiar with and work according to the following guidelines.

Ethical practice

In accepting the role of consumer representative, consumers need to be provided with clear information about their role and responsibilities so they can understand what is expected of them. Expectations include the responsibilities outlined below.

Commitment – to attend meetings, to read papers, notes and other information as required, to participate, question, and contribute.

Confidentiality – issues of a confidential nature will often arise in health committee meetings. Consumer members are bound by the same level of confidentiality as other members in relation to committee matters.

Conflict of interest

A conflict of interest can occur when there is a real or perceived conflict between a person's duties and responsibilities and their private interests or the interests of other roles they may hold in the community. A conflict of interest may prejudice or be seen to prejudice a person's ability to perform their duties and responsibilities objectively. A conflict of interest can also be based on a perception or an appearance that a participant's own interests could improperly influence the performance of their duties, and whether or not this is in fact the case.

While conflicts of interest cannot always be avoided, they do need to be identified, disclosed, and effectively managed. The minimum

requirement for all conflicts of interest is that they must be openly and formally disclosed.

Tip *Consumers, like any other members of the committee, should declare when they have an interest — financial or personal — in a certain outcome, and in such circumstances should be prepared to remove themselves from the decision-making process if asked.*

Complaints

Any complaints consumer representatives might have which relate to or stem from their experiences within a committee, must be raised appropriately. In the first instance, any concerns should be discussed with the Chair of the Committee and if not resolved, should be directed to the relevant complaints mechanism within the organisation.

Information that may be sourced while participating on a committee relating to individuals' healthcare experiences should firstly be discussed with the Committee Chair. This may include the need for onward referral to an appropriate health service complaints mechanism, the Health Quality and Complaints Commission or a health professional board.

Note — HCQ does not receive or manage complaints.

HCQ's commitment to consumers

Information provision

HCQ consumer representatives will receive information about their roles and responsibilities as a consumer representative and tips, advice and resources for effective consumer participation on committees. This will include the importance of community expectations about how health care is delivered; about accountability, transparency, sustainability and the public interest also being met in relation to consumers' roles as consumer representatives.

Privacy and confidentiality of agency and consumer information

Once registered as part of HCQ's Consumer Representatives Program, agencies and consumers are asked for some confidential details.

Consistent with National Privacy Principles and national and state privacy legislation, HCQ will only collect information

that is necessary to the function of the Consumer Network and Consumer Representatives Program. For agencies, this will include information about their request and interests while for consumers, it will include – name, contact details, age group, experience, and the health issues they are interested in.

In response to agencies and consumers providing HCQ with this confidential information, HCQ will make sure their privacy is protected and their information is kept confidential. No consumer information will be passed on to agencies, without a consumer's consent. Consumers can also amend their registration details or withdraw their name from the database at any time.

Section 2:
Consumer engagement.
Some useful information for agencies

HCQ recommends that agencies refer to its information paper on consumer engagement, *Consumer and community engagement and patient involvement and participation in health service planning, delivery and evaluation*[12] for further detail. This information will support agencies to make their engagement experience and that of health consumers a positive and effective one.

Health consumer engagement in Queensland

The establishment of HCQ is in line with a broader social movement for consumer engagement in health service policy, planning and delivery, in Australia and overseas. Consumer and community participation is now a common element of much of the health care approach in Australia, although it is still evolving. Community and consumer engagement promotes the active involvement of consumers, carers and community members in decision-making, not only about their individual treatment and care, but also in health services and health care planning decisions. It is an active process that takes place within a health service at individual, program, hospital ward, and organisation levels. It is a process that aims to more accurately orient systems and structures towards the needs of consumers and carers.[13]

The Australian Charter of Health Care Rights[14] reinforces health consumer engagement as a well-recognised component in quality, service delivery and its improvement, and as a right of the health consumer.[15] The common national accreditation regimes such as EQuIP ™ and the Quality Improvement Council also include standards for participation. The role of consumer engagement is reinforced through a range of current national and state reforms at individual, service and systems levels, including policy and planning.

12 See footnote 8.

13 Victorian Department of Human Services. (2006) Doing it with us not for us. Participation in your health service system 2006-09: Victorian consumers, carers, and the community working together with their health services and the Department of Human Services. Melbourne: Rural and Regional Health Services, Department of Human Services.

14 See footnote 9.

15 Australian Commission for Safety and Quality in Health Care. (2005). Achieving safety and quality improvements in health care. Canberra: Commonwealth of Australia; Victorian Quality Council. (2005). Better quality, better health care. Melbourne: Author; Metropolitan Health and Aged Care Services Division. Melbourne: Victorian Department of Human Services.

HCQ's Consumer Representatives Program is one mechanism for consumer engagement in Queensland, and works collaboratively with established systems and stakeholders, nationally and at state and local levels.

The Queensland Compact[16] sets out expectations and commitments for the Queensland Government and the Non-profit Community Services Sector to work together in a respectful, productive, forward-looking relationship that benefits the community. The Compact aims to create practical improvements in the relationship between the Queensland Government and the Non-profit Community Services sector. It underpins and aims to strengthen the engagement of consumer and community organisations and the Queensland Government toward building stronger communities.

Queensland Health currently has a number of community and consumer engagement activities at district and regional levels to inform decision making and respond to consumer needs. At a broader level, the Clinical Practice Improvement Centre and the Patient Safety Centre have a number of consumer members on high level committees across their programs.

Health Community Councils (HCCs) and the Health Quality and Complaints Commission (HQCC) and its Consumer Advisory Committee (CAC) are two other mechanisms for consumer engagement in health in Queensland.

The current 36 HCCs across Queensland are statutory authorities with guiding legislation that underpins their operations and key functions within their local health districts. The HCCs are advisory bodies established under the provisions of the Health Services Act 1991. They work in partnership with Queensland Health to strengthen community input and ensure that the delivery of public sector health services is highly responsive within their local district. Councils undertake community and consumer engagement activities; monitor the quality, safety and effectiveness of health services delivered within the district; enhancing community education about the delivery of health services; and advise and make recommendations to their District CEO. District CEOs provide administrative and funding support to each of the councils to undertake their role, functions and activities.

16 Queensland Department of Communities. (2008). About the Queensland Compact. Retrieved on 25 May 2009 from: http://www.communities.qld.gov.au/department/about/corporate-plans/queensland-compact/about.html

The 36 councils are supported by the Manager, Health Community Council Coordination.[17]

It should be noted that on 31 March 2009, the Premier released the report and recommendations from the independent review of Queensland Government boards, committees and statutory authorities by Simone Webbe and Professor Patrick Weller (the Weller Review). The review recommended the HCCs be abolished. The Government's response, announced on 22 April 2009, regarding the HCCs was that,

> *Community Health Councils provide important community input at the local level and will be retained. However, Government accepts that the alignment of Councils with service delivery areas should be reviewed to ensure maximum effectiveness. Government will engage with Councils on the options prior to making a final decision.*

The Deputy Premier and Minister for Health has subsequently approved that Queensland Health undertake a review of HCCs' structure and their alignment with local health service districts. The review is expected to be completed in August 2009.

The HQCC is an independent statutory body with guiding legislation and principles.

HQCC was established under the *Health Quality and Complaints Commission Act 2005* and has responsibility for monitoring, reviewing and reporting on the quality of health services and recommending actions to improve quality; establishing and monitoring standards; receiving and managing complaints about health services including helping users and providers to resolve complaints; and preserving and promoting health rights through information sharing and other activities. As part of its statutory responsibilities, HQCC is responsible for advertising and nominating to the Minister for Health, persons it considers suitable for appointment as members of the 36 state-wide HCCs. The Commission is supported by the Office of the Commission, which is led by a Chief Executive Officer appointed by the Governor in Council. It also has a Consumer Advisory Committee and a Clinical Advisory Committee.[18]

The Health Quality and Complaints Commission CAC's role is to advise the Commission on consumer concerns about

17 Queensland Health. (2008). Health Community Councils. Downloaded on 27 October 2008 from: http://www.health.qld.gov.au/hcc/

18 Health Quality and Complaints Commission. (2009). About us. Downloaded on 1 May 2009 from: http://www.hqcc.qld.gov.au/home/inner.asp?pageID=53&tsnav=0

health services and other matters referred by the Commission; provide strategic advice from a consumer, carer and community perspective, in relation to health services; and facilitate communication between consumer, carer and community groups and the Commission. In addition, the CAC participates in the monitoring and evaluation of the Commission's engagement of health service users; and advises on education needs for consumers, carers and the community in relation to the Commission.[19]

Apart from the above bodies, non-government consumer and community organisations have a long history in Queensland playing a key role in enabling health consumer engagement. Many of these organisations have well-established processes and programs for consumer engagement at national, state and local levels.

Many non-government organisations receive either State or Federal funding and offer developmental, information, networking and other capacity building opportunities to their members. They also select representatives to sit on other health bodies.

The implementation of HCQ's Consumer Representatives Program builds on previous and current initiatives, which support consumer engagement in the government and community sectors. It is HCQ's goal to work with HCCs, HQCC, CAC, and government agencies, and community and consumer organisations, to increase the scope and effectiveness of health consumer engagement in Queensland.

Why agencies engage consumers

Engagement is a valuable tool in delivering quality governance, services and programs. A study from Vancouver[20] 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* happens by building up the capacity of consumers in their communities to interact effectively in the system that affect their lives

19 Health Quality and Complaints Commission. (2009). Advisory committees: Consumer advisory committee. Downloaded on 27 May 2009 from: http://www.hqcc.qld.gov.au/home/inner.asp?pageID=266&tsnav=0

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

- *expertise and energy* emerge from individuals' and communities' own lived experiences for good solutions to their local issues
- *improved outcomes* for individuals and communities happen as the consumer perspective helps to ensure policies are informed, relevant, appropriate and targeted and services are delivered effectively and efficiently
- *improved relationships* develop between health professionals, service providers and consumers
- *political purpose* is served by reducing political risk and increasing public confidence in the policy process and the legitimacy and credibility of decisions.

Further, a number of government policies, reporting and legislative requirements and accreditation standards mandate or guide the health sector to involve consumers.[21]

In Queensland, the Forster Report,[22] Q2,[23] and the Queensland Health's Strategic Plan[24] all point towards a more accountable and transparent health system of which strong consumer engagement is a key component.

What do consumer representatives expect from being involved in committees?

Because consumers are the 'receivers' of health care, they often experience the best and the worst of care and can identify systemic success and failure. Consumers want to be involved in having a say about their own care and treatment, or the care and treatment of someone they care for. Consumers also often want to be involved in decisions about the planning of services, how services are delivered and how services are evaluated, because of their experiences.

Most consumers seeking to be involved want things to be better for others and they want to use their own experiences as a conduit for improving things. Some consumers may have had a negative experience with their health care and want to share that experience so it doesn't happen to someone else. Some consumers view participating in such ways as an opportunity to contribute to the system in positive and practical ways.[25]

21 Health Issues Centre. (2008). Getting Started. Involving consumers on committees. Melbourne: Author.

22 http://www.health.qld.gov.au/health_sys_review/default.asp

23 http://www.towardq2.qld.gov.au/tomorrow/index.aspx?kwc=KNC- adwords_Q2&tgclid=CKrInuWJnJgCFZEtpAodzXWKng

24 http://www.health.qld.gov.au/about_qhealth/strategic.asp

25 Health Issues Centre. (2005) Getting involved. A kit for consumers interested in the consumer representatives program. Melbourne: Author.

Consumer representatives serving on a committee expect:

- to be treated fairly and with respect
- to receive appropriate information in time to be able to read and prepare for meetings and have medical terminology/acronyms/complexities explained in plain English
- information about the terms of their appointment, length of commitment, time required, etc.
- to be able to ask questions before, during, and after the meetings
- access to administrative and financial support; for example, having relevant details so they can contact staff members if required, or if they need debriefing after a meeting.[26]
- financial resources to reimburse and remunerate consumers for their participation
- feedback on the outcomes and impact of their involvement in the committee.

Other approaches to engaging consumers

HCQ is not the only source of consumer representatives for health sector bodies. HCQ's Consumer Representatives Program has been established to complement the work of existing consumer and community organisations and groups. These regularly provide expertise and consumer representation on government and community committees and other bodies, especially in relation to their specific social and health stakeholder group (e.g. financially disadvantaged, Indigenous, mental health, chronic illness/disease). The involvement and contribution of these groups is important and necessary in the formulation of policy, in planning, and service delivery.

Tip *HCQ encourages agencies seeking consumer representatives for their committees to consider their stakeholder groups and to approach them directly to take part.*

Included in the appendices is a list of state-wide consumer and community networks and organisations across a range of social and health population groups. This is not an exhaustive list, but is intended to provide one simple guide to assist agencies to connect with relevant consumer networks.

26 See Footnote 25.

Inviting consumers onto committees

Most agency committees are predominantly comprised of health professionals or health administrators. They bring considerable experience and knowledge to the table but do not bring the full spectrum of experiences on health care. Involving consumers on committees will bring new views, new ideas and new questions to discussions. As a by-product, it will also assist in developing ongoing dialogue between consumers and health professionals and administrators.

A committee structure provides an opportunity to move beyond one-off consumer feedback to a more interactive approach, and allows consumers to have direct input into decision-making processes.

Inviting consumers onto a committee makes sense when:

» the committee will meet at least several times to review and progress its work

» the outcomes will affect consumers

» it is developmental and the consumer perspective will add to the creative effort; it will bring non-professional perspectives and challenges to the table

» only consumers are likely to have some of the information the committee requires to complete its tasks.

Clarifying expectations with consumer representatives

One of the most common complaints of consumers involved in health sector committees is that their role is not clear enough. Being clear about the expectations agencies have of consumer representatives is a crucial foundation for effective participation and good outcomes.

It is important that the requesting agency clarifies with the consumer representative the scope of their role, including expectations by both parties about the degree of influence the consumer representative may have upon the outcomes of the project/initiative. With lack of clarity, a consumer representative may believe themselves to be part of a decision making body, when the committee is advisory in nature only, for example.

Agencies should be clear about whether the initiative is an information giving or gathering activity, a consultation, or if the consumer representative will have an active role in decision-making or the activities of the body. These distinctions indicate the degree of empowerment of the consumer in the process or committee.

For example, do you want consumer representatives to:

» share their own experiences of care or those of their family members?

» share what they perceive as being common perspectives of members of their community organisation, population group, or networks?

» represent a constituency of some sort (and report back to them etc.)?

» express opinions as a member of the public?

» express opinions as a past consumer of service?

» assess options having a clear understanding of the health system?

» be able to see the big picture?

» be able to think strategically?

» be part of decision-making?

» be able to challenge assumptions of the providers?

» be able to "hold their own" with senior professionals?

These are quite distinct roles and some will fit your requirements and others may not. You need to be very clear about which are relevant, so you can identify and target consumers with particular perspectives, experiences or skills. It will help you to be clear about what you want them to do.

In keeping with good practice, HCQ encourages all agencies to be prepared and have undertaken adequate planning when they invite consumer representatives onto their committees, and provide the consumer with the information they require to understand the expectations of their role.

Offering support

Effective consumer participation requires ongoing commitment, organisational leadership and resources from an agency. Make sure that you consider and have supports in place as needed that will enable consumer representatives to fulfil their roles.

Supports may include, but not be limited to:

» travel and / or accommodation

» language interpreters

» out of session contact to answer questions or discuss matters relating to the committee work

- timely receipt of papers, minutes, and other reading
- sufficient notice of meetings and other deadlines
- physical accessibility of meeting venues for people with disabilities
- support workers for people with disabilities
- printing and forwarding large documents
- information and explanation of technical terms and acronyms in use
- child care
- at home or other support in the case of carers
- cultural considerations
- awareness of and planning to address potential barriers to engagement.

Tip *Each individual consumer representative will have individual needs. The best approach is to negotiate directly with each consumer representative as to the best and most effective ways their membership of a committee can be supported.*

Section 3
Frequently asked questions

How can one consumer represent all consumers?

The role of consumer representatives is not to provide answers on behalf of all consumers, but to raise issues and prompt the committee to debate matters from a different experience base and range of perspectives. Similarly, doctors on committees are not expected to put forward the views of all doctors.

What if a consumer representative breaches confidentiality requirements?

Consumer representatives are subject to the same confidentiality requirements as other members of a committee, and held accountable to the committee for maintaining confidentiality and protecting privacy. Committee representatives who breach these provisions will lose the trust of their fellow committee members, which may jeopardise their effectiveness on the committee. Additionally, they may be removed or have more formal action taken against them, depending on the nature of the committee (for example, an advisory council or a statutory committee).

To whom are consumer representatives accountable?

Consumer representatives are accountable to the agency that recruited them and to the nominating organisation, if they are a formal representative of that organisation. They must operate within the conditions of the invitation covering their appointment (including the Terms of Reference) to which they agreed when accepting the position.

Does 'conflict of interest' apply to consumer representatives?

As with any other committee members, conflicts of interest also apply to consumer representatives. Therefore, conflict of interest requirements and protocols need to be included in orientation information, and also listed as a standing item on the agenda.

What if the agency/committee cannot afford to pay consumer representatives?

As consumer engagement becomes more integrated into the work of health services, the costs of consumer engagement need to be identified and built into forward budgets. Consumer representatives

should not be out of pocket through their involvement and the organisation should always cover such expenses.

While many consumers are prepared to carry out reading and research of papers voluntarily, most consumers require reimbursement of any expenses they incur through their involvement in the committee.

Additionally, payment of a sitting fee broadens the pool of potential consumer representatives and minimises individuals' financial disadvantage.

Section 4
Forms

All forms can be completed online at www.health.qld.gov.au/hcq

Section 5
The Australian health system

This section was compiled by the Health Issues Centre Inc, Victoria with further input from Queensland Health. Health Consumers Queensland (HCQ) gratefully acknowledges the work of both agencies and their in-depth knowledge of the Australian health system.

Overview

Australia has a very complex health care system with many types of services, providers and funding arrangements. Few consumers are aware of all the services, organisations and funding responsibilities in the Australian health system (it is confusing for many health professionals too). The following information may be useful for consumers participating in high-level committees. A very useful text for a more detailed overview is Dr Stephen Duckett's, *The Australian Health Care System* (2007).

In Australia, both public and private sectors provide health care and all levels of government are involved. Very broadly, the federal government has responsibility for national health care funding, broad policy decisions and funding for general practitioners (GPs) and aged care, while the States And Territories are responsible for the delivery of other health services, including public hospitals and community health services.

There is free access to some but not all health care in Australia. Public hospital care is free. Medicare is the national public health insurance scheme funded by taxation and it subsidises GP and medical specialist care and some other services in some circumstances. GP care is sometimes provided free for those on lower incomes with a Health Care Card, but most other consumers pay a fee, which varies greatly from one practice/clinic to another. This is also true for many, but not all, services from medical specialists operating outside hospitals. Pathology and optometry

services are often free (i.e. paid for directly by Medicare), but not always. There are also some consumer charges for most other services such as dentists, radiology and allied health (e.g., physiotherapists and counselling). Fees at community health services will be very small but are generally only available to Health Care Card holders. Outside this, fees can be quite high for private practitioners.

Health care is funded by three main sources: the federal government, state governments and consumers' own ("out-of-pocket") payments via gap fees and private health insurance. This consumer contribution amounts to about one-third of the whole budget, so is very significant. government funding comes naturally from general taxation revenue (including the Medicare Levy) collected mainly by the Commonwealth Government, some of which is passed onto the states for the hospital systems. Information about the health funding system is available from the Department of Health and Ageing (2005).

Federal level

The federal government funds and administers the Medical Benefits Scheme (MBS; the part of Medicare which partially pays for GP services), the Pharmaceutical Benefits Scheme (PBS; which partially pays for medications) and the Australian Health Care Agreements (which gives funds to the states to run public hospitals). The Department of Health and Ageing is the national health agency (www.health.gov.au), and is responsible for national policy, funding public health programs, research, and information management. However, there is not actually a national health policy or framework, as such, around which all governments base their policies and funding.

Medicare Australia

Medicare was introduced in 1984 to provide eligible Australian residents with affordable, accessible and high-quality health care. Medicare is based on the understanding that all Australians should contribute to the cost of health care according to their ability to pay. It is financed mainly through progressive income tax while a smaller proportion comes from an income-related Medicare levy of 1.5 per cent that is charged on individuals earning more than $50,000 p.a.

Medicare Australia is responsible for administering government health programs including:

» Medicare

- Pharmaceutical Benefits Scheme (PBS)
- Australian Childhood Immunisation Register (ACIR)
- General Practice Immunisation Incentives Scheme (GPII)
- Practice Incentives Program (PIP)
- 30 per cent Private Health Insurance Rebate
- Hearing Services
- Compensation Recovery Program
- Australian Organ Donor Register
- Rural Retention Program
- General Practice Registrars' Rural Incentive Payments Scheme
- Family Assistance Office in partnership with Centrelink, the Australian Taxation Office (ATO) and the Department of Families, Community Services and Indigenous Affairs (FaCSIA)
- Claims processing and payments for the Department of Veterans' Affairs (DVA) treatment
- accounts.

The professional services that attract Medicare benefits (MBS) are listed in the following four schedules:

- Medicare benefits (includes oral and maxillofacial surgery)
- Optometric
- Cleft lip and cleft palate
- Allied health and dental services.

A series of MBS items has been included in recent years to encourage GPs to use certain best practice approaches or to provide specific services. These have focused on: chronic disease management; diabetes; annual cycle of care; asthma care plans; health checks for 45-year-olds; older people and refugees; GP mental health care; pregnancy support counselling; medication management; multidisciplinary cancer care; allied health services; and psychological therapy, among others. For more details on the MBS, see Department of Health and Ageing 2007, The November 2007 MBS, viewed 16 Jan 2008,

http://www.health.gov.au/internet/mbsonline/publishing.nsf/Content/Medicare-Benefits-Schedule-mbs-publications-Nov07)

The schedule fees for items are uniform across Australia and are determined by the Department of Health and Ageing in consultation with professional bodies. Medicare benefits are based on a percentage of the scheduled fee for each service as listed in

the Medical Benefits Schedule (75 per cent for inpatients, 85 per cent for outpatients and 100 per cent for GP services). Practitioners are able to charge fees they consider suitable for the services they provide which are very often higher than the schedule fee. By contrast, because of the undertaking that optometrists make with the Department, they cannot charge an additional fee above the schedule fee. Exceptions to this rule are detailed in the Schedule of Medical Benefits for Consultations by Optometrists. For up-to-date information see Medicare Australia 2007, About Medicare Australia, viewed 16 Jan 2008, http://www.medicareaustralia.gov.au/about/index.shtml

Pharmaceutical Benefits Scheme (PBS)

The Pharmaceutical Benefits Scheme (PBS) subsidises approved medications to Australians. About three-quarters of medications dispensed by Australian pharmacies are included on the PBS. The Scheme is regarded internationally as one of the most effective in the world and has successfully balanced access to reliable, effective interventions with controlling the continual pressures of rising costs. More information is available at Department of Health and Ageing 2006, Pharmaceutical Benefit Scheme, viewed 16 Jan 2008, http://www.health.gov.au/pbs

State and Territory level

State and Territory governments are primarily responsible for delivering health care services and funding the gaps left by Medicare. For example, States And Territories provide funding to, and regulate, public hospitals. Funding for hospitals is currently based on five-yearly agreements between the States And Territories and the Commonwealth called the Australian Health Care Agreements (AHCA, pronounced 'aka').

From 1 July 2009, the AHCAs will be replaced by a new broader National Healthcare Agreement (NHA) which will encompass the collective efforts of Commonwealth, State and Territory governments on prevention, primary and community care, hospital and related care and aged care. The NHA will provide States and Territories with a single broadband Specific Purpose Payment that replaces former funding agreements for public hospitals, public health, organ and tissue donation and youth health services. In addition, Commonwealth funding will also be provided under National Partnership (NP) Agreements on Hospitals and Health Workforce Reform, Preventative Health and Closing the Gap in Indigenous Health Outcomes.

States directly fund mental health services and community services,

plus a range of community and public health services such as community health services, dental care and child health programs.

Local Government level

Local health services are responsible for some public health services, for public health surveillance but not for clinical medical services. They are a significant provider in some states of Home and Community Care (HACC) services using mostly federal, some state and some of their own funding. Local governments in some states (especially Victoria) are also involved in immunisation programs; they run Maternal and Child Care Centres and undertake some health promotion activities.

Health service delivery

A mix of public and private sector providers deliver health care services. Some public hospitals are run and funded by state or territory governments (e.g. NSW, Queensland) while others are independent organisations with their own boards (Victoria). Private hospitals can be owned by for-profit or not-for-profit organisations such as health insurance companies or charitable organisations.

The majority of GPs and many specialists are self-employed and engaged in private practice, although many of the latter may also be employed part time or full time by hospitals. In reality, nearly all receive a considerable proportion of their private practice income from Medicare.

Private health insurance

Private health insurance is a significant source of funding of health care. Consumer contributions pay for private health insurance, and about half of the population has such cover. The Commonwealth Government subsidises 30-40 per cent of insurance premiums through the Private Health Insurance Rebate (although this is a contentious issue in health circles). Private insurance covers care in private hospitals / clinics (or private care in public facilities) and will pay some (but not necessarily all) of the gap in medical costs for inpatient services (i.e. the difference between the doctor's fee and the Medicare rebate). It may also cover some of the costs of attending private practitioners; for example, seeing allied health workers such as podiatrists or psychologists. It can allow consumers more opportunity to choose their doctor, hospital and timing of procedure. However, private hospital care can still involve significant out-of-pocket expenses ("gap fees").

Research

The National Health and Medical Research Council (NHMRC) is the main funding body for health and medical research. For more information see National Health and Medical Research Council 2007, General public information portal, viewed 16 January 2008, http://www.nhmrc.gov.au/users/gpublic.htm

The Commonwealth Government provides funding for public health research to continually improve the evidence for public health interventions and to contribute to a reduction of future health care costs.

References

Department of Health and Ageing. (2005). *Overview of the Australia healthcare system*, viewed 16 Jan 2008, http://www.health.gov.au/internet/wcms/publishing.nsf/Content/healthsystem-overview-3-funding

Department of Health and Ageing 2006, *Pharmaceutical Benefit Scheme*, viewed 16 Jan 2008, http://www.health.gov.au/pbs

Department of Health and Ageing. (2007). *MBS online*, viewed 16 Jan 2008, http://www.health.gov.au/internet/mbsonline/publishing.nsf/Content/Medicare-Benefits-Schedule-mbs-publications-Nov07

Duckett, S. (2007). *The Australia Health Care System,* 3rd ed, Oxford University Press, Sydney NSW.

Medicare Australia. (2007). *About Medicare Australia*, viewed 16 Jan 2008, http://www.medicareaustralia.gov.au/about/index.shtml

Section 6
Further reading

HCQ recommends the following articles or web page links for further reading

Queensland resources

» Health Consumers Queensland. (2009). Consumer and community engagement and patient involvement and participation in health service planning, delivery and evaluation. Brisbane: Author.

» Health Consumers Queensland website at: www.health.qld.gov.au/hcq

National resources

» Health Issues Centre website at: www.healthissuescentre.org.au (this site holds the largest collection of material on health consumer engagement in Australia).

» Consumers' Health Forum of Australia website at: http://www.chf.org.au/ (this site features the national peak body for health consumers in Australia).

Appendix 1
Statewide organisations

Note that some of these peak bodies represent health agencies as well as consumers. If seeking consumer input, we suggest you make this very clear in your requests.

Organisation	Phone / TTY	email / web	Address
QCOSS Queensland Council of Social Services	*Phone* (07) 3004 6900 *Toll free* 1800 651 255 *Fax* (07) 3004 6999	*web* www.qcoss.org.au *email* qcoss@qcoss.org.au	*Postal* PO Box 3786 South Brisbane Q 4101 *Street* Ground Floor, 20 Pidgeon Close West End Q 4101
CAGQ Combined Advocacy Groups of Qld	*Phone* (07) 3236 1122	*web* www.qai.org.au	*Street* Suite G2 Ground floor Roma Street Transit Centre Q 4003
Maternity Coalition	*Phone* (07) 3256 8127 or 0424 493 201	*web* www.maternitycoalition.org.au *email* qldpresident@maternitycoalition.org.au	
QAHC Queensland Association of Healthy Communities *(focus – health and well-being of lesbian, gay, bisexual and transgender Queenslanders)*	*Phone* (07) 3017 1777 *Freecall* 1800 177 434 (outside Brisbane) *Fax* (07) 3852 5200	*web* www.qahc.org.au *email* info@qahc.org.au	*Postal* PO Box 1372 Eagle Farm Q 4009 Australia *Head Office* 30 Helen Street Newstead Q 4006
Council on the Ageing Qld	*Phone* (07) 3316 2999	*web* www.cotaq.org.au *email* web@cotaq.org.au	*Street* Level 3, 33 Queen Street GPO Box 21 Brisbane Q 4001

Organisation	Phone / TTY	email / web	Address
QDN Queenslanders with Disability Network	*Phone* (07) 3252 8566	*web* www.qdn.org.au *email* qdn@qdn.org.au	*Street* 7 O'Connell Terrace Bowen Hills Q 4006
Queensland Alliance of Mental Health Associations	*Phone* (07) 3832 2600	*web* www.qldalliance.org.au *email* admin@qldalliance.org.au	*Post* PO Box 919 Spring Hill Q 4000
Carers Queensland	*Phone* (07) 3843 1401 *Fax* (07) 3843 1403	*web* www.carersqld.asn.au	*Street* 15 Abbott Street Camp Hill PO Box 179 Holland Park Q 4121
Multicultural Development Association	*Phone* (07) 3337 5414	*web* www.mdabne.org.au *email* mailbox@mdabne.org.au	
QAIHC Queensland Aboriginal and Islander Health Council	*Phone* (07) 3328 8500 *Fax* (07) 3844 1544	*web* www.qaihc.com.au	*Street* 21 Buchanan Street West End *Post* PO Box 3205 South Brisbane
Qld Network of Alcohol and Drug Assoc.	*Phone* (07) 3834 0215	*web* www.qnada.org.au *email* info@qnada.org.au	*Street* Level 3 133 Leichhardt Street Spring Hill Q 4000
Deaf Services Qld	*Voice* (07) 3892 8500 *TTY* (07) 3892 8501 *Fax* (07) 3392 8511	*web* www.deafsq.org.au *email* dsq@deafsq.org.au	*Post* PO Box 173 Annerley Q 4103
QADA Queensland Aged and Disability Advocacy	*Phone* (07) 3637 6000	*web* www.qada.org.au	*Street* 121 Copperfield Street Geebung Q 4034

Organisation	Phone / TTY	email / web	Address
Bundaberg Patient Support Network	*Phone* 0439 769 965	*email* god-love-ya@hotmail.com	
QSMA Qld Self-Management Alliance	*Phone* (07) 3857 4200	*web* www.qsma.org.au *email* info@qsma.org.au	*Post* P.O. Box 2121 Windsor Q 4030
Ethnic Community Council	*Phone* (07) 3844 9166	*web* www.eccq.com.au	*Post* PO Box 5916 West End Q 4101
YANQ Youth Affairs Network Qld	*Phone* (07) 3844 7713 *Fax* (07) 3844 7731	*web* www.yanq.org.au *email* admin@ynq.org.au	*Street* 30 Thomas St West End Q 4101
Self-Help Queensland Inc.	*Phone* (07) 3344 6919	*web* www.selfhelpqld.org.au	*Post* PO Box 353 Sunnybank Q 4109
Health Consumers Network	*Phone* (07) 5497 5786	*email* kathykendell@aapt.net.au	*Street* 9 Dylan Court Sandstone Point Q 4511
Women's Health Queensland Wide Inc	*Phone* (07) 3839 9962	*web* www.womhealth.org.au	*Street* 165 Gregory Terrace *Post* PO Box 665 Spring Hill Q 4004
Micah Projects Inc./ Homeless Alliance	*Phone* (07) 3844 9122	*web* www.merivale.org.au *email* micah@merivale.org.au	*Street* St Mary's House 20 Merivale Street *Post* PO Box 3449 South Brisbane Q 4101

Statutory authority	Phone / TTY	Email / web	Postal
HQCC Health Quality and Complaints Commission Consumer Advisory Committee	*Phone* (07) 3870 3659 *Toll free* (07) 3120 5999 *TTY* 1800 077 308 *Phone* (07) 3120 5997 *Fax* (07) 3120 5998	*email* info@hqcc.qld.gov.au	*Post* GPO Box 3089 Brisbane Q 4001
Public Advocate	*Phone* (07) 3224 7424	*email* public.advocate@justice.qld.gov.au	*Post* GPO Box 149 Brisbane Q 4001
OAG Office of the Adult Guardian	*Phone* (07) 3234 0870 or 1300 653 187	*email* adult.guardian@justice.qld.gov.au	*Post* PO Box 13554 Brisbane George Street Q 4003
HCC Health Community Councils	*Phone* (07) 3234 1561	*email* HCC-Coordination@health.qld.gov.au	*Post* PO Box 48 Brisbane Q 4001

Appendix 2
Australian Charter of Healthcare Rights

In 2008, the Australian Commission on Safety and Quality in Healthcare developed the Australian Charter of Healthcare Rights. The document describes the rights of patients and other people using the Australian health system. It can be accessed on their website at: www.safetyandquality.gov.au

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.

What can you expect from the Australian health system?

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

Notes

...your voice in health

Health Consumers Queensland

Consumer Representatives Program: Agency Handbook

A guide to the HCQ Consumer Representatives Program. Information and ideas for health agencies on how to invite, encourage and support consumer engagement on committees.