

...your voice in health



for Queensland health consumers

Health Consumers Queensland

Consumer Representatives Program
Consumer Handbook

June 2009



Queensland Government

...your voice in health

Health Consumers Queensland

Consumer Representatives Program: Consumer Handbook

Information for health consumers about the Consumer Representatives Program: Ideas, tips and suggestions to support their participation in committees and other health consumer engagement initiatives.

**Health Consumers Queensland
Consumer Representatives Program**

Consumer Handbook

*Information for health consumers about the
Consumer Representatives Program:
Ideas, tips and suggestions to support their
participation in committees and other health
consumer engagement initiatives*

June 2009

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at the time of writing and review in May 2009.

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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 Queenslanders 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 Consumer Handbook, a companion Agency 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 Consumer Handbook, its companion Agency 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.

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 eleven 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 Handbook, sourced from Queensland Health and other organisation's 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', '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 on consumer engagement in Queensland, mentioning the *Australian Charter of Healthcare Rights*, the *Queensland Compact* and the role and function of Health Community Councils, the Health Quality and Complaints Commission (HQCC) and the HQCC Consumer Advisory Committee.

Section three outlines what HCQ expects of health agencies.

Section four discusses what is involved in being a consumer representative, why agencies want consumer representatives, and partnership arrangements between HCQ, consumer representatives and agencies.

Section five is about how to become a HCQ consumer representative, detailing the registration, nomination, selection and decision making processes that are required to put forward eligible consumers to requesting agencies for their committees and other engagement activities.

- Section six** provides information on the support available for consumer representatives. It also highlights HCQ's position on payment for consumer representatives and the need for consumers on committees to be involved in ongoing training and networking.
- Section seven** provides a useful checklist for getting involved in committee work and explains how a committee may work.
- Section eight** lists a range of tips and resources for consumers participating on a committee, with sections on self-care, personal challenges, responding to aggressive people, expressing anger and coping with stress. The section also provides tips for effective work on committees and terms used in committee minutes. The subjects of problem solving and conflict resolution are extensively addressed, with techniques provided to assist in the resolution of any issues as they arise.
- Section nine** 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 ten** provides an overview of the Australian Health System, 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 eleven** has a list of resources and links from Queensland and interstate for further reading.

Overall, the Handbook provides a range of useful ideas, tips and suggestions to support consumers' participation in committees and other health consumer engagement initiatives.

Background

What is Health Consumers Queensland?

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.

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, 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.

Community¹ 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.

Consumers² 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.

Carers³ 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. 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.

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.

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

The 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 consumers with information about the underlying principles of the program, an agency's process for requesting health consumer representatives, and the expectations of 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 The principles of the Consumer Representatives Program underpin its operation.

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

Further to this, HCQ's Consumer Representatives Program is underpinned by the Australian Charter of Healthcare Rights⁹ which reinforces the right of consumers to participate in decisions and choices about their healthcare; and the value and role of consumer engagement in the development of health policy, and in planning, service delivery and evaluation.

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.

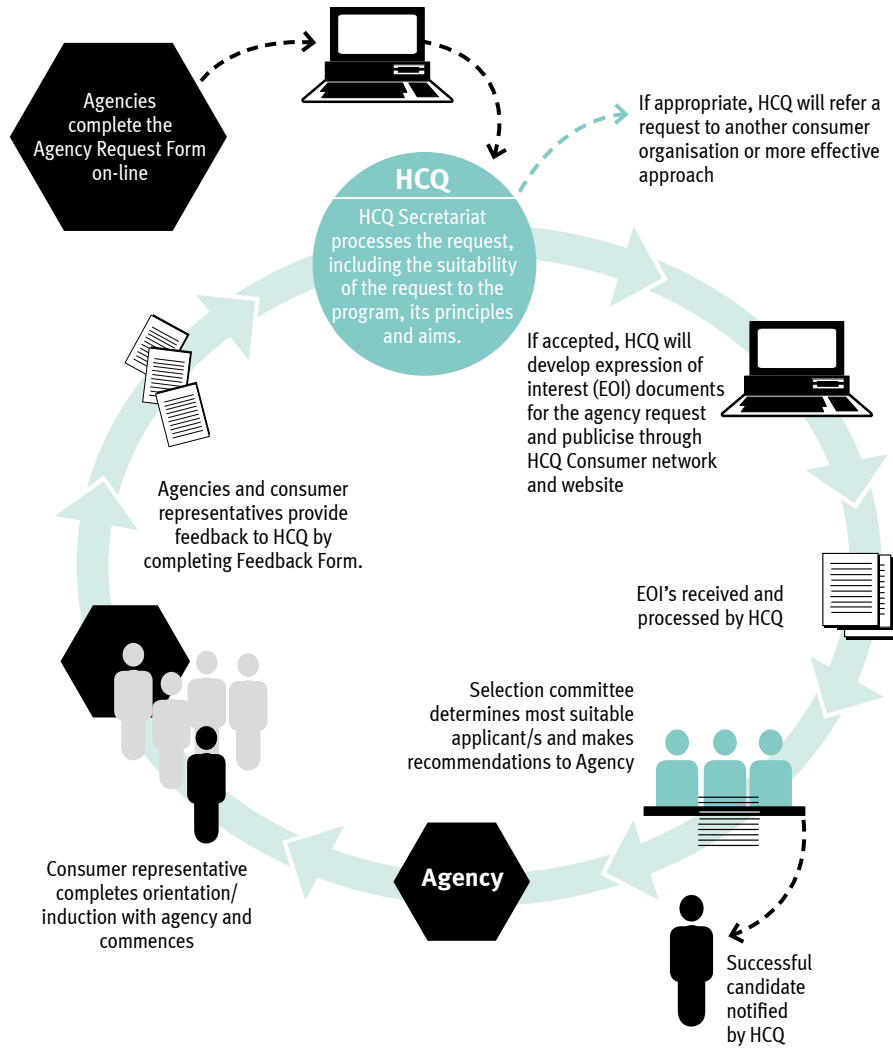
9 Australian Commission for Safety and Quality in Health Care. (2008). Australian Charter of Healthcare Rights. Canberra: Commonwealth of Australia

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 33 and 34 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.



Becoming a HCQ consumer representative

Join the Health Consumer Network

- » Register online to be a member of the Health Consumer Network at: www.health.qld.gov.au/hcq
- » To obtain a hard copy of the forms, please contact HCQ Secretariat on (07) 3234 0611

HCQ Secretariat advertises vacancies / calls for expressions of interest

HCQ Secretariat will send emails to members of the Health Consumer Network and post information on the HCQ website. HCQ's e-newsletters may also include calls for Expressions of Interest (EOI) for each committee as they arise.

Consumer representatives complete and submit documents

The process

- » Complete an *Expression of Interest Form (EOI)*
- » Submit a copy of his/her Curriculum Vitae

Selection and decision making process

A selection panel will review applications and make recommendations for successful consumer representative/s. Successful and unsuccessful applicants will be notified.

Orientation and support

HCQ encourages the agency to provide structured orientation to consumer representatives when they are appointed to a committee.

Information and feedback for HCQ

At the completion of their appointment to a committee, consumer representatives provide feedback about their experience and outcomes of their membership of the committee.

Section 2

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.¹⁰

The Australian Charter of Health Care Rights¹¹ reinforces health consumer engagement as a well-recognised component in quality, service delivery and its improvement, and as a right of the health consumer.¹² 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.

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*¹³ sets out expectations and commitments for the Queensland Government and the Non-profit Community

10 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.

11 See footnote 9.

12 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.

13 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>

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. The 36 councils are supported by the Manager, Health Community Council Coordination.¹⁴

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:

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

▶ *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.¹⁵

The Health Quality and Complaints Commission CAC's role is to advise the Commission on consumer concerns about 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.¹⁶

15 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>

16 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>

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.

HCQ does not seek to be the only source of consumer members for health sector bodies. HCQ's Consumer Representatives Program has been established to complement the work of existing consumer and community organisations and groups which regularly provide expertise and consumer representation on government 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, and in planning and service delivery.



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

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

Section 3

What does HCQ expect of health agencies?

HCQ requires agencies to make 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*,¹⁷ which strongly reinforces the right of consumers to be included in decisions and choices about their health care and in health service planning. These principles are consistent with HCQ's Information Paper, *Consumer and community engagement and patient involvement and participation in health service planning, delivery and evaluation*.¹⁸

HCQ recommends that consumers read this Information Paper, which is available on the website.

HCQ has nine principles, which underpin the Consumer Representatives Program. They are:

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.

17 See footnote 9.

18 See footnote 8.

4. Consumers should not be financially disadvantaged as a result of their participation in any engagement activity (refer to pages 33 and 34 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.

Health Consumers Queensland strongly recommends that consumers ascertain whether health agencies are responding to these principles and processes, using the questions provided in this guide, before agreeing to be a consumer representative.

Section 4

What is involved in being a consumer representative?

Registering for HCQ's Consumer Representatives Program opens opportunities for consumers, with a strong interest in the health system in Queensland, to become involved in a range of reform and quality and safety improvement activities, such as:

- » project reference or steering groups
- » advisory groups to Queensland Health or other Statewide health bodies
- » short term consultations on new health initiatives.

These can be quite different; for example, a one-off consultation meeting as opposed to a short-term working group, or an ongoing role such as an advisory committee member or a member of a technical research or quality improvement committee.

The committee's terms of reference might be mandated by Government or set by the health organisation or department. Some committees may meet only two or three times a year for three years; others may meet every month for six months. The committee may be comprised totally of consumers, or one consumer may be sitting around a table with managers, government bureaucrats, and clinicians.

Why do agencies want consumer representatives?

Agencies want to engage consumers because they can:

- » help to improve the quality of the agency's services, programs and projects
- » improve relationships with their community and the people who use their services
- » improve health outcomes
- » improve understanding of their patients'/clients' needs and any cultural or other considerations
- » provide a consumer perspective which identifies the strengths and weaknesses of service provision
- » provide important information about how an agency is perceived and received as well as the impact of their services/work/activities.

Further, a number of government policies, reporting and legislative requirements and accreditation standards mandate or guide the

health sector to involve consumers.¹⁹

In Queensland, the *Forster Report*,²⁰ *Q2*,²¹ and *Queensland Health's Strategic Plan*²² all point towards a more accountable and transparent health system, of which strong consumer engagement is a key component.

Partnership expectations – HCQ, consumer representatives and agencies

The consumer movement in health is part of a broader social movement that is based on the principle that the people affected by a decision have a right to participate in making that decision. Increasingly, the community expects greater involvement in decisions impacting on health and wellbeing and greater accountability and transparency from public health institutions.

Consumer representatives provide informed advice and feedback on health services, policy, systems and service reform and improvement from a consumer perspective. In undertaking this, consumers will work within the nine principles underpinning HCQ's Consumer Representatives Program, and HCQ's mission, guiding principle and aspirations.

HCQ's consumer representatives will receive information about their roles and responsibilities as a consumer representative. This will include the importance of community expectations about how health care is delivered - about accountability, transparency, sustainability and how the public interest is being met in relation to consumers' roles as consumer representatives.

Privacy and confidentiality of consumer and agency information

Once registered as part of the Consumer Representatives Program, consumers and agencies are asked for some confidential details. Consistent with the National Privacy Principles and national and state privacy legislation, HCQ only collect information that is necessary to the function of the Health Consumer Network and Consumer Representatives Program. For consumers this will include - name, contact details, age group, experience, and the health issues they are interested in. For agencies, this will include information about their request and interests.

19 Health Issues Centre. 2008. *Getting Started. Involving consumers on committees*. Melbourne

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

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

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

In response to consumers and agencies providing HCQ with this confidential information, HCQ will make sure their privacy is protected and their information is kept confidential. Consumer information can only be accessed by HCQ Secretariat staff responsible for responding to requests for consumers. Unless otherwise required by law, 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 HCQ's database at any time.

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 very clearly 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.

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.

Consumer representatives serving on committees

Consumer representatives serving on a committee should expect:

- » to be treated fairly and with respect
- » to receive 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,²³ or require taxi vouchers to travel to the meeting venue
- » financial resources to reimburse and remunerate consumers for their involvement
- » feedback on the outcomes and impact of their involvement in the committee.

The role and voice of consumer representatives

Once a consumer is invited to join a committee, they may bring a different perspective or contribution (e.g. sharing your experience of GP care or as a member of a specific committee). Consumers may sometimes represent the views of a particular organisation or association or of a particular health population. Alternatively, consumers may provide their own views as people who have experience of a service, as potential users of a service, or because of their knowledge and experience of a specific health condition (e.g. diabetes).

Consumers may also have different roles and may bring diverse

²³ Health Issues Centre. (2005). Getting involved. A kit for consumers interested in the Consumer representatives program. Melbourne: Author.

voices as members of a committee. Consumers should ask why they are on the committee; what role they want to play; and contrast and compare this with the role they were expecting to play. A consumer should reflect – is committee membership to:

- » ask questions
- » contribute consumer experience
- » ensure consumers' concerns are recognised
- » protect consumers' interests
- » gather consumers' views
- » present how consumers feel and think on a specific issue
- » gather information to then feed back to other consumers
- » make sure that the organisation remains accountable to consumers or community groups?

A consumer may play several roles on a committee. Clarifying these roles helps to differentiate between what he/she wants to do and what the committee asks or expects him/her to do.

It is important to receive information from the agency about the purpose and scope of the consumer representative role. This may include:

- » giving information to the consumer
- » receiving feedback and information from the consumer about a program, initiative, service etc
- » receiving advice to inform developing solutions or inform decision making from the consumer
- » receiving advice to direct future solutions/decision making from the consumer.

It is also important to receive information from the agency about the consumer's intended involvement, for example, is it to:

- » share personal experiences, family member's or carer's experiences of health?
- » share common perspectives of a community organisation, population or network?
- » represent a constituency?
- » express opinions as a member of the public?
- » express opinions as a past consumer of a particular service?
- » assess options for better health outcomes?
- » develop a clear understanding of the health system?

What do consumers bring to committees?

The consumer experience

Consumers, carers or community members have knowledge, understanding and a perspective about a health service or health condition that is crucial for improving the accessibility, safety, and quality of the health system. The consumer perspective and experience is of equal importance as the knowledge and perspective that clinicians, researchers, managers, and administrators contribute to the development of policy, planning and delivery of services.

Consumers bring these rich experiences to every situation that they find themselves in, including their work on reference groups or advisory committees. No matter how experienced, renowned or educated other people are, they do not have the consumer's unique experience.

That experience is not representative of anyone else's and it is not expected to be. It is simply meant to be another way of looking at things. Each person on the committee brings his or her perspective in exactly the same way. A doctor brings the perspective of a doctor (not all doctors), an administrator the perspective of an administrator and a consumer brings the perspective of a consumer.

At times, however, consumer representatives may be asked to represent knowledge and experience gained from a network or consumer group. Therefore, their contribution to the committee may involve expressing opinions of a particular network or consumer group, with which they are affiliated.

Consumer engagement – benefits and challenges

Many consumer representatives involved with health services find their involvement both empowering and satisfying. They can see how they are adding new consumer-focused information or issues to decision-making processes; how they are making a difference. However, it can also present a range of challenges. Consumers' expectations of their designated role, the project's timeframe or the actual change process may differ quite markedly from that of the agency. This should be defined at the start of engagement! Seeking information to clarify the purpose and expectations of their role on the committee will develop a mutual understanding about what, when, where, and how the consumer representative will be expected to contribute.

At times consumers report feeling that they are not being taken seriously or that they are there as a token consumer. These feelings

are not uncommon, but they may dissipate as other members get to know the consumer over several meetings and see the contribution they make, and as the consumer becomes more confident in their role.

However, if these feelings or experiences do not change, consumers need to discuss their concerns with the committee chair or committee secretariat staff, or HCQ.

Section 5

How to become a HCQ consumer representative

Registration

HCQ's Health Consumer Network is the pathway to the Consumer Representatives Program. Interested individual consumers can join the Consumer Network and register via a simple form online at: www.health.qld.gov.au/hcq It can be downloaded, completed online and submitted, by pressing the 'Submit' button. Alternatively applicants can contact the HCQ Secretariat on (07) 3234 0611 and ask for the form to be mailed out.

The process of nomination

Once a consumer is registered as part of HCQ's Consumer Network, he/she will be eligible to nominate for consumer representative engagement opportunities. They will receive regular emails to keep them up to date with emerging activities.

Health agencies seeking consumer representatives for a committee or other consultative process will submit a request online. HCQ may discuss the application with them to ensure their request is well-considered and clear.

HCQ will then advise its Consumer Network members of vacancies via email, and by posting the vacancy to the HCQ website. They may also be advertised in HCQ's e-newsletters.

Consumers can then respond by filling in the forms provided. These will include a simple *Expression of Interest* (EOI) form asking why he/she wants to join the committee and what relevant experience and skills they have. For some vacancies, a curriculum vitae (CV) may be required and a nominated individual or organisation (referee) will need to support the EOI.

Nomination checklist

- » ensure a *Health Consumer Network Registration* Form has been completed via HCQ's website
- » complete and submit the *Expression of Interest* (EOI) form via HCQ's website
- » enclose a copy of the CV (if required)
- » provide details on the *EOI* form of an individual or organisation to support the expression of interest (referee).

Eligibility for appointment as a HCQ Consumer Representative

To be eligible for appointment as a health consumer representative, a person will need to:

- » be registered on the Health Consumers Network
- » support the nine principles underpinning the HCQ Consumer Representatives Program
- » be able to represent consumer views about health services
- » meet the requirements of the selection criteria via responses to the Expression of Interest
- » support HCQ's mission, guiding principle and aspirations
- » provide a consumer voice to inform Queensland health policies, planning and service delivery
- » be 18 years of age or over.

Selection and decision making process

A register of applications will be kept by HCQ's Secretariat.

A selection panel will make recommendations to HCQ regarding the most suitable applicants for the request. This will be based on applicants' responses to the selection criteria and details in their CV.

If the agency wants to receive a shortlist of the applicants, HCQ will forward the selection panel's recommendation on to the agency for their consideration.

Alternatively, at the agency's request, HCQ will undertake the final selection and provide details of the successful applicant/s to the agency (with the applicants' consent).

Where the agency is making the final decision, they will need to notify HCQ's Secretariat about the successful applicant/s.

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

Privacy and confidentiality

See pages 24-25 for further information.

Section 6

Support for consumer representatives

As noted above, the role of a consumer on a committee can be challenging. It can help to talk to someone about how involvement with the committee is progressing (rest assured that the professional members seek similar support when they feel challenged!)

What support will the agency offer?

HCQ believes it is important that health agencies make a commitment to ensuring that consumers can participate effectively.

When HCQ talks to agencies about consumer engagement, it encourages them to consider individual needs and practical arrangements such as accommodating special needs to support participation (for example, considering health circumstances, or language needs or the need for disability support).

HCQ also encourages agencies to provide orientation about the committee's aims and processes, providing consumer representatives with relevant background information concerning aspects of the health sector that relate to the activity, and ongoing development opportunities.

When a consumer has any concerns about their function on a committee or the support they are receiving to participate, they should initially talk to the agency - the chairperson of the committee, the secretariat staff supporting the committee, or another supportive member.

Orientation HCQ recommends that the agency offers planned orientation or an induction process to new consumer representatives. Indeed this is helpful to all participants on committees to ensure a shared understanding of roles, terms of reference, procedures and the expectations of the participants, and of the health agency. For consumer representatives, this may involve receiving background reading, meeting the Chairperson or other members, and talking with them and the secretariat staff about the committee's work and aims, and the expected role of the consumer.

If such orientation is not provided for consumers as a member of a committee, he/she is quite within his/her rights to ask for one.

Ongoing development There may also be some ongoing or occasional development opportunities (e.g. to attend a relevant conference or workshop).

HCQ offers several types of support

Information

and advice HCQ's Secretariat can offer information, support or advice via telephone, email or in person. HCQ's Secretariat can also offer information and referral to other sources of information, which might be helpful in the consumer representative role.

There are a range of consumer peak bodies (a list is at Appendix 1) that might be useful for background information or ongoing support.

Useful sources of information and resources are available on the web (for example, www.healthissuescentre.org.au or www.chf.org.au).

HCQ's position on payment for consumer representatives

Most professionals attend committees as part of their salaried positions. Consumers, however, often have to take time off from other commitments to participate. This can place financial as well as physical strain on them, especially if they are not in full-time employment or on some form of income support. Each consumer representative's personal and financial circumstances will be different and should be addressed differently.

It is HCQ's position that no consumer should be financially disadvantaged as a result of their contribution to the Queensland health system. Therefore, at a very minimum, agencies should cover all out-of-pocket expenses (travel, accommodation, childminding or respite care costs, printing costs, as appropriate). HCQ also urges all agencies to give serious consideration to paying consumers a sitting fee for their expertise and contribution.

The agency may have developed a policy on such payment or reimbursement. Consumers have a right to be informed about the agency's policy before they take up membership of a committee. If no policy exists, the consumer may offer to assist the agency to develop such a policy.

Where consumers will receive a sitting fee, they may need to organise with the Australian Taxation Office to have an Australian Business Number (ABN), a very simple and relatively cheap matter. Further, if they are receiving Centrelink payments, they may need to consider the impact on those benefits. HCQ recommends consumers seek professional advice in this regard.

A range of articles on this issue and examples of policies and forms are available on the Health Issues Centre Inc website.²⁴

24 <http://www.healthissuescentre.org.au/search/results.chtml?search=payment>

Information, training and networking

In the fast-changing health sector, HCQ understands the value of networking, staying up-to-date and informed. HCQ will update its Health Consumer Network about emerging issues, engagement initiatives and opportunities to attend seminars, forums, conferences, and training.

Section 7

Checklist for getting involved

There are a number of issues to consider carefully before a person applies to join a committee. It is important for their level of satisfaction in the role, that they clearly understand their motivations as well as the needs and expectations of the health service or committee. Before applying to be involved, each person should consider the following questions.

- » Why am I interested in getting involved?
- » What do I expect to get out of it?
- » What is the committee's work and its terms of reference?
- » What are the committee's expectations of me as a consumer member?
- » How will the committee's expectations impact upon my role and work on this committee?
- » What skills and experience do I have that will help me?
- » What support do I need?
- » Is there any potential conflict of interest in my involvement (and does the committee have a policy on "conflict of interest" that will address this)?
- » Do the meeting arrangements suit me? (for example, where and when are the meetings held? How long do they run? How will I get there? Is there any support for me to access the meeting place (e.g. car parking, childcare)?)

Being clear about the answers to these questions will make the person more effective and satisfied in their role.

How does a committee work?

Most of the requests that come to HCQ are from a particular agency or organisation looking for consumers to join a committee (for example, a quality and safety panel looking at trends in sentinel events; a working group developing a policy on access to services; a ministerial council providing strategic advice about a research project).

Committee work is based around discussion and debate within a fairly structured framework. Committees have terms of reference, agendas, and time constraints. Good committees often have strategic plans or work plans as documents to show what is their agreed purpose and actions.

Often there will be only one consumer position on a committee. The rest of the committee will be comprised of health professionals and government staff. Some consumers will find this environment stimulating and challenging. Others may feel uncertain; that they are in unfamiliar territory. This is normal and the person may just need time to adjust.

Consumer representatives can also sometimes feel disappointed that the opportunity for them to contribute seems to be very limited. Approaching participation with eyes open and having a clear understanding from the beginning about the consumer role on the committee; what are the agency's expectations for the consumer's involvement; and the potential outcomes of his/her contribution are vital for a rewarding engagement experience.

It is important to note that committee work is not for everyone

After asking the questions outlined above and thinking about the responses, a person may think that committee work is not necessarily for them.

There are other equally valuable ways of making a contribution and working for change (for example, making submissions to consultation papers, attending a public forum on health matters, or joining an advocacy or self-help group).

In order to decide the preferred method of engagement, HCQ refers the reader to two Australian resources, which are full of stories and tips about serving on committees. The resources also detail the strengths, opportunities and challenges inherent in consumer engagement. They are as follows:

Adelaide Central Community Health Service. (2003). *The little purple book of community rep-ing: Not just a token rep project*. 3rd ed. Adelaide: Central Community Health, downloaded on 15 January 2008 from:
<http://www.participateinhealth.org.au/clearinghouse/Docs/littlepurplebook.pdf>;

Consumers' Health Forum of Australia. (1999). *Guidelines for consumer representatives*. 4th ed. Canberra: Author, downloaded on 14 January 2008 from:
http://www.chf.org.au/consumer_reps_program/chf_guidelines.asp.

Section 8

Tips and resources

for consumers participating on a committee

This fact sheet includes a series of tips, advice and resources for effective consumer participation on committees. It was prepared using mainly the following resources as well as drawing on the knowledge and expertise of Health Issues Centre Inc.

Although two of these resources were written a few years ago, they are still relevant, and are used by consumers all over Australia. Where verbatim quotations are used and where other literature was used, references are included. The three publications are:

Adelaide Central Community Health Service. (2003). *The little purple book of community rep-ing: Not just a token rep project*. 3rd ed. Adelaide: Central Community Health. Available at: <http://www.participateinhealth.org.au/clearinghouse/Docs/littlepurplebook.pdf>

Consumers' Health Forum of Australia. (1999). *Guidelines for consumer representatives*, 4th ed. Canberra: Consumers' Health Forum of Australia. Available at: http://www.chf.org.au/consumer_reps_program/chf_guidelines.asp.

Cancer Australia. (2009). *Consumer Participation Guide*. Canberra: Commonwealth of Australia. Available at: <http://www.canceraustralia.gov.au/consumer-support-and-information/resources/consumer-participation-resources.aspx>

HCQ highlights the following matters to support a consumer representative's journey through committee engagement.

Personal challenges Becoming a consumer representative is an exciting and positive experience and consumer representatives usually gain much from their working relationship with health agencies. Nevertheless, at the start, consumer representatives should acknowledge that active participation may be demanding; some of these demands may impact on their effectiveness. It is important that consumer representatives reflect on their individual capacities to be able to perform the new roles and not feel frustrated by the demands of the committee work. Below are a few tips on how to go about solving these problems.

What if I feel I'm not being taken seriously?

It is possible, sometimes, for busy committee members to forget that a consumer representative is not a staff member and so does

not have access to the same level of information about the health system as they do (for example, the consumer may not have a computer at home, so cannot receive emails or download large reports or documents). It may be that the consumer begins to feel ignored in meetings, or that their contributions are being routinely dismissed, or that they never get the agenda papers in time to read them.

If the consumer representative feels this is happening, they should try to develop some practical strategies for addressing the problem, based on the original reasons they were asked to join the committee, and their own expectations about what they wanted to achieve as a member of that committee. If they continue to have difficulties, Health Consumers Queensland's (HCQ) Secretariat is available to discuss their concerns further.

The Consumers' Health Forum of Australia (CHF) (1999, pp. 27–29) suggests that, in some circumstances, being a consumer representative can leave a person feeling demoralised. If this happens, the consumer may need to question their motivation for being a member of the committee, and review their expectations and goals of participating on the committee. In certain instances, it may be helpful to assess one's skills to see if they can be improved in some way.

Importantly, by seeking some immediate support and independent advice at such a time, the consumer representative will not have to face the concerns alone and may receive valuable insight into the situation.

Some advocacy activity is very demanding. You need to be honest with yourself about how much you are prepared to extend yourself. Decide what boundaries you are going to create for yourself before you commence. (*Mental Health Council of Australia 1998, p.3*)

Self-care

Self-care is a highly relevant issue for consumers participating in committees. From time to time, the role may be overwhelming for consumers and this may affect their effectiveness and their individual capacity to undertake the tasks. Alternatively, some consumers assume too many positions on committees or groups as the demand for their voice increases, which may become a tiring and frustrating burden.

As a consumer, knowing how to take care of oneself, will aid in managing the emotional stress that the consumer representative role may bring with it.

Being more assertive

Consumer representatives on committees need to be assertive to be able to face some challenging situations in the course of fulfilling their role. Assertiveness is viewed as the “open and appropriate expression of thoughts and feelings with due regard to the right of others” (*Mental Health Council of Australia. 1998. p.29*).

Some people find it difficult to confront others, even if facing disruptive or disrespectful behaviour. Being assertive is about standing up for personal rights but not necessarily about getting things one’s way.

A good technique to increase assertiveness is to role-play and rehearse the dialogue, posture and gestures that would be useful in a particular situation that may require a more assertive approach (for example, practice the technique when needing to ask for something from someone who can be intimidating).



Tip *Technique for responding to aggressive people*

- » If you are wrong, admit it.
- » Acknowledge the other person’s feelings.
- » Assert yourself about the other person’s aggression.
- » Quickly end the conversation.

Feelings

As a consumer representative, the work can be very satisfying and rewarding. Good relationships can be established with other members of the committee. Sometimes, however, the situation or task can feel overwhelming or contributions do not appear to be valued. Feelings of fear and anger are also sometimes present in the work that consumer representatives do.

It can be beneficial to acknowledge these feelings, and not just ignore them. Many people face fear, be it fear of saying the wrong thing, being inappropriate, stuttering and stumbling, or of making a fool of themselves. Recognising these feelings is a good starting point. Self-appreciation and focusing on goals assists in the self-management of those fears.



Tip *Managing fear*

The following tips for managing fear come from *The Kit*. In this context, the word ‘advocacy’ means the consumer representative’s role in influencing the committee.

- » You may not be afraid of the whole situation, only a part of it. Focusing on what the exact fear is will make it easier to overcome.

- » Plan and anticipate possible scenarios, assess the best and worst things that can happen, and consider possible strategies for achieving best outcomes.
- » Prepare well – gain as much information as possible and discuss the situation with your peers.
- » Be clear on the good things about yourself.
- » Undertake advocacy activities with which you feel comfortable.
- » Be clear about the advocacy activity – name the purpose, set clear goals, plan what you are going to do.
- » Rehearse your strategy with a trusted person.
- » Start by being involved in advocacy at a level that is comfortable to you – observe how others participate successfully. (*Mental Health Council of Australia 1998, pp. 3–4*)

As with fear, anger is a common human experience. Some people do not express anger at all, and others express it aggressively. Free expression of anger can get in the way of influencing others. Thus, it is often useful to find alternative ways to express feelings of anger within committee processes.



Tip *Alternate ways to express feelings of anger*

- » Verbalise your anger to yourself or write it down. Tearing your notes up afterwards might also make you feel better.
- » Collect people around you with whom you can talk through your anger.
- » Make it clear to yourself that it is your reaction to a situation, not the fault of the other person.
- » Avoid blaming the other person.
- » Try to remain rational about the situation. Consider whether your expectations of personal achievements are rational. Are you angry because you have not achieved your goals in a situation where success was never possible? Are you placing unrealistic expectations on other people? (*Mental Health Council of Australia 1998, pp. 4–5*)



Tip *Managing your anger and frustration*

- » Be focused and clear about what you are striving for.
- » Fully prepare yourself – focus on the task at hand.
- » Plan, organise and rehearse your strategies.
- » Be consistent, authentic and genuine.
- » Separate the issue from yourself, despite your passion.

- » Learn to actively listen.
- » Learn assertion over confrontation.
- » Take someone else with you whose role is to support you in avoiding anger.
- » Stick to the facts – avoid dragging out imagined evidence in desperation. (*Mental Health Council of Australia 1998, p. 5*)

Personal care

“Personal care” is understood in the literature as a sub-set of “self-care”. It refers to the specific actions a person takes to take care of themselves and their wellbeing.

Consumer involvement on committees requires a level of personal commitment and effort. It is good to organise time to create a balance between looking after oneself and participating in required activities. To promote personal wellbeing, have realistic goals and expectations of self and others. Sometimes the environment where a consumer works may be hostile, tense, stressful, or at extremes may be very uninviting. One of the main things to manage is ‘burn out’, and to ensure energy levels are high enough to face the demands of the work.



Tip *Taking care of yourself*

- » Maintain links with friends/family not involved in advocacy issues.
- » Eat a good diet.
- » Obtain sufficient rest and sleep.
- » Exercise (for example, go for walks with the dog; swim).
- » Take up a hobby and pursue it regularly.
- » Get emotional support from respected and trusted individuals.
- » Take ‘time out’ occasionally – be self-indulgent.
- » Understand that, despite all your advocacy work, there will always be issues to deal with and you are not responsible for resolving all these issues. Know your own limits. (*Mental Health Council of Australia 1998, p. 65*)

Among the most valuable tools included in the Mental Health Council of Australia’s *The Kit* is a “personal stocktake” to assess personal capacity to undertake consumer engagement activities. (*Mental Health Council of Australia 1998, pp. 10–23*)

This is aided by a worksheet that can be filled in once a year as a review of personal care needs and goals. The worksheet also includes a fitness worksheet to assess personal physical, social,

emotional, intellectual, and spiritual fitness. This section of *The Kit* also provides an example of a personal résumé, which would be useful for responding to requests for information or for preparing a personal introduction before giving a presentation.



Tip *Strategies to cope with stress*

- » Have a way of distracting yourself. Read a book, draw. Meditate.
- » Actively take a break. Walk around the block, pull up weeds. Visit a friend.
- » Pace yourself. Know when you are usually not at your best and when your energy is at its lowest. Organise your activities and establish routines around your knowledge of your own capacities. Stop rushing.
- » Focus on the task. Sort out what you are going to do and when you are going to do it. Put things in priority order.
- » Value yourself. Think positive thoughts. Praise yourself for what you are doing.
- » Look back and see how much you have achieved to reach this point. (*Mental Health Council of Australia 1999, p. 2*)



Tip *Effective work*

This section offers a range of tips for working as a consumer representative on a committee. These tips have been identified by Consumer's Health Forum of Australia (CHF).

I used to worry about sounding dumb when I asked questions. Then I realised that half of the rest of the Committee didn't understand the answers either. When everyone is an expert in different areas, each of us on the committee has things we don't know or understand. (*Consumer quoted in Consumers' Health Forum of Australia 1999, p. 14*)

Preparation time

To be a consumer representative on a committee, time needs to be set aside to do the job and to get things done. There is no 'one best way' to become an effective consumer member; much of it is learnt and practised. To improve skills, CHF recommends consumers seek out relevant books and workshops, and take every opportunity to talk to other consumers (*Consumers' Health Forum of Australia 1999, p. 23*).

Consumer representatives can also play an active part in a committee by preparing for the meetings and actively discussing issues, putting items on the agenda, and presenting papers for

discussion (*Consumers' Health Forum of Australia 1999, p. 26*).

Preparing for action is also important. CHF (1999, p. 24) recommends planning actions that will help when preparing to move a particular issue forward or aiming at winning an argument. Consumers should think about how to introduce a point, what facts/research they need to have, when it is a good time to raise a point, and who is likely to support the proposition (you might need to discuss tactics with them beforehand). Sometimes it is useful to write a paper on an issue as busy committee members will often respond well to written arguments.

The *Little Purple Book of Community Rep-ing* provides practical advice to consumers working on committees, and offers this insight: "It usually takes several meetings before a new rep feels comfortable and familiar with meeting procedures or issues, and is thus able to speak up" (*Little Purple Book of Community Rep-ing, p. 24*).



Tip *Questions are a powerful tool for consumers to use*

As the 'new kid on the block' ignorance can be used to advantage. Use every opportunity to ask basic questions.

- » Would you mind defining that term for me?
- » I don't know the background to that decision – could you fill me in briefly?
- » Why didn't that plan work?
- » What was the original intention?

(Consumers' Health Forum of Australia 1999, p. 14)

A word on influence

Do not underestimate the impact of being part of a committee. A consumer presence will influence how the committee considers issues and will raise awareness of thinking about consumer perspectives on all issues. Worrying about 'winning' on every issue is probably misplaced and anxiety provoking. People will not be persuaded on every issue. Being strategic means saving the strongest pitches and determination for the important issues.



Tip *Being effective on committees*

Some of the qualities that are important in ensuring the effective work of consumers are:

- » analyse an issue, and judge its effects on consumers.
- » move away from a personal opinion to a viewpoint that takes

- account of the diversity of experiences and needs of consumers.
- » present an argument rationally and convincingly.
 - » imagine the consequences of short-term and long-term decisions.
 - » negotiate for better health outcomes for all consumers.
 - » identify who you are representing.

(The Consumers' Health Forum of Australia 1999, p. 23)

Occasionally a committee will require the consumer representative to give an opinion or to vote on a motion when there has been insufficient time to consult with their constituency. This may happen occasionally to all committee members. If this happens:

- » give an interim opinion (and state that it is such) pending consultation.
- » defer the item briefly, to have an opportunity to consult with the nominating organisation (for example, a quick phone call). Ask for additional time to consult, if the matter is important. The item can then be deferred until the next meeting.

(Consumers' Health Forum of Australia 1999, pp. 17–18)



Tip *Working as a consumer member on a committee*

First impressions are crucial. CHF recommends that to create a positive first impression, consumers should try to avoid:

- » arriving late to the first meeting
- » leaving agenda papers at home
- » slinking in timidly at a meeting
- » talking at every opportunity, even when having nothing to say.

(Consumers' Health Forum of Australia 1999, pp. 23–24)

Health Consumers Queensland (HCQ) suggests the importance of consumer representatives building a relationship with committee chairs, so they understand the individual consumer's situation (for example, whether they are new to the role or very experienced) and get to know the consumer's strengths so they can actively draw you into relevant discussion. CHF suggests, some consumers deliberately sit opposite the chair, so he/she is always conscious of them, and so they can catch his/her eye whenever they wish to speak.

As a consumer representative on a committee, be a positive force by:

- » bringing the discussion back to the relevant issue

- » initiating new discussion
- » summarising major points
- » thinking laterally when discussion is not getting anywhere
- » blending various people's comments together
- » connecting two points
- » diagnosing a problem
- » inspiring others
- » relieving tension, or creating useful tension
- » remaining active even when the issue does not have consumer implications.

(Consumers' Health Forum of Australia 1999, pp. 25–26)

Meeting minutes

For most committees, a record of each committee meeting will be kept. These records are called minutes and reflect what was said, what decisions were made by the committee and what actions were prescribed for follow-up.

Some terms used in minutes

Present the names of everyone present

Apologies names of people who were unable to attend and have sent apologies

Previous minutes the minutes of the previous meeting are presented to the meeting; committee members need to ensure that they are a 'true and accurate' record of the meeting

Business arising the discussion of any business arising from decisions made at the last meeting to keep everyone up to date is useful for checking on the progress of projects and to remind members of the tasks they agreed to carry out

New business new items for discussion

Close the date and time that the chairperson officially closed the meeting (NB: On some committees, recording the time of opening and closing a meeting can be important to ensure no business is conducted in a member's absence). *(Consumers' Health Forum of Australia. 1999, p. 10)*

Identify allies

It is also important to identify any potential allies for specific critical issues. Some allies may support the consumer member

on some issues, and not on others. Anyone on the committee is a potential ally depending on the issues discussed. Sounding out issues with other committee members, will enable members to decide if the issues are worth raising with the full committee. (*Consumers' Health Forum of Australia. 1999, p. 24*)

Network It is especially important to talk with any other consumer/s on the committee, and on related committees, to see what their opinions are on a particular issue. It is vital to share ideas on important issues, discuss why they are important, and what outcomes are desirable.

If the consumer is on a committee that is part of a structure with many levels of sub-committees and working parties, it is extremely important to have a good set of contacts with other consumers within the structure. Ask the nominating organisation or the committee secretariat to provide a list of names of other consumers and a chart of the committee structure (*The Consumers' Health Forum of Australia. 1999, p. 25*).

Talk with former consumer members When taking over from a consumer who has previously served on the committee, it is wise to get a briefing from them. Ask them about: the wins and losses they had on the committee; who were their friends and opponents; what issues were the most crucial for consumers; was the committee Chair sympathetic to having a consumer member; was the committee secretary helpful; and did they have any problems with reimbursements? However, it is also important that new consumers make up their own mind once they have experience of the committee. (*Consumers' Health Forum of Australia. 1999, p. 25*)

Negotiation, finding solutions and conflict resolution

Negotiation is defined as an interactive process between two or more parties seeking to find common ground on an issue or issues of mutual interest or dispute, where the parties involved seek to make or find a mutually acceptable agreement that all concerned will honour (*The Negotiation Experts, 2007*).

Six steps in preparing to negotiate.

1. Preparation
2. Wants
3. Propose
4. Bargain
5. Agree
6. Follow-up

(Rose 1987)

A simple formula for prioritising wants.

- » Could get (what would be good but not necessarily reasonable)
- » Should get (what is reasonable)
- » Must get (bottom line).

(Rose 1987)

The negotiation may start with each party expressing their “could get” but it will not progress until both parties work from the point of “should get”. (Rose 1987, *Negotiate and Win*, viewed 15 Jan 2008, <http://www.negotiation.net.au/docs/colbook2005ed1.pdf>).

Clear steps to negotiation

Negotiate from interests not positions. Use the ‘principled negotiation’ process even when the other side is being unprincipled. Principled negotiation is contagious and is always the best alternative. (Fisher and Ury 1991, p. 11)

The principled negotiation process

1. Separate the people from the problem.
2. Focus on interests rather than positions.
3. Generate a variety of options before settling on an agreement.
4. Insist that the agreement is based on objective criteria.

Separate the people from the problem

Even while retaining a clear sense of the differences in positions, and an understanding that there are often real conflicts of interest, consumers should avoid projecting an ‘us’ and ‘them’ feeling. It is important to maintain a good working relationship in a committee as this is often more important for future decisions than the outcome of one particular negotiation. (*Consumers’ Health Forum of Australia 1999, p. 28*)

Problem solving and conflict resolution

Most interactions will be smooth. With appropriate communication skills, consumers can function well on a committee. Nevertheless, more effective communication skills may be required when the process of interaction with others is not running smoothly. To enable more effective conflict resolution and problem-solving, all committee members may benefit from some training in these techniques (further addressed in this section). There are some very useful sites dedicated to the creative resolution of conflict. In Australia, the Conflict Resolution Network (<http://www.crnhq.org/>) has been operating for over 20 years. Much of their material is free, including their conflict resolution training manual.

The principles of good conflict resolution have not changed over the years. There is still no substitute for using empathy, listening more than talking, managing emotions and focusing on the problem rather than on the person or their behaviour.

A very important part of conflict resolution and problem-solving is having clarity about the precise problem (defining the real problem). Often people focus on the effect rather than the cause. They will get upset with the person who is acting out their frustration rather than trying to see what is causing the frustration in the first place.



Tip *Listen. Put yourself in the other person's shoes. Discuss each other's perceptions. Ask questions so that you understand, and could explain the other's point of view. (Consumers' Health Forum of Australia. 1999, p. 28)*

Mapping the conflict The Conflict Resolution Network talks about “mapping the conflict”. By this, they mean looking at the issue to see what is going on and working out how to address it. This can involve trying to determine what needs or fears are motivating the other person or group of people. Guessing what these motivations are, in some part provides a basis on which to start resolving the issue. People appreciate attempts to understand their perspective and find it difficult to remain angry or obstructive under these circumstances.

Silence and reflection are also very effective tools in conflict resolution. If a meeting is getting heated, requesting the group remain silent and reflect on the conflict for two minutes can often produce the clarity that was missing in the midst of the struggle.

A source of growth and change

Conflict is often a source of growth and change and should not be viewed as something negative. Approached with curiosity rather than fear, creativity rather than stubbornness, and optimism rather than pessimism, conflict can create some wonderful opportunities for growth.

The Chinese symbol for “conflict” is made up of two separate symbols. One means danger, and the other one means opportunity. Conflicts always present us with obvious dangers but also with sometimes not-so-apparent opportunities for growth and development as well. (*John Kares Smith. 2007, cited in Northwestern University. Wage peace not war. Northwestener. Summer 2007, viewed 15 Jan 2008, <http://www.northwestern.edu/magazine/summer2007/cover/cover/sidebar4.html>*)

Summarising and clarifying

These two skills take time to develop. Each requires the ability

to retreat from the immediate situation and to look at the bigger picture, seeking connections or emerging trends and themes.

Clarifying is usually a process of enquiry and most often expressed as a question. Clarifying requires curiosity “so do you mean...?” or “Are you saying that if we...?”. It is not the same as asking a rhetorical question though the questions can often start the same way. The answer to a rhetorical question is already obvious to the questioner and it is frequently used to make a point. A question of clarification is an information-seeking question; the answer to which will build on knowledge or put a situation in sharper focus.

Often a person will summarise their understanding of a situation before asking for clarification by saying: ‘As I understand it, the situation is... So when you say... do you mean...?’

Critiquing Critiquing is not the same as criticising. Criticising is pointing out faults and is often a negative process (even though the term “constructive criticism” implies this is not always so, but this is debatable). Critiquing is the process of looking at something from all angles, not just from a person’s own point of view. It is harder to critique than to criticise because to critique something well entails trying to get inside the issue or the mind of the person presenting the idea to understand what else could be involved. The process is very subjective, fair and thorough. It is often formal, and requires presenting written findings and arguments to an audience. Nevertheless, a critique is still only a person’s opinion – albeit a well-considered one. However, offering a thoughtful critique to a committee is a significantly influential contribution.

Having a break from being involved

If the consumer representative feels the committee or program they are involved with is no longer meeting their expectations, or would like to take a break, speak first with the chair of the committee and explain the situation. Alternatively, contact Health Consumers Queensland’s (HCQ) Secretariat.

Dealing with feeling over committed or deciding to take a break could be a good opportunity to provide HCQ with feedback about involvement in the Program. Hearing back from consumer participants supports HCQ in our efforts to constantly improve our work with consumers in the health care system.

Section 9

Forms

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

Section 10

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 scheduled 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 AHCA 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

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- 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 11

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
- » Consumers' Health Forum of Australia website at: <http://www.chf.org.au/>

Appendix 1

Statewide organisations

Note that some of these peak bodies represent health agencies as well as consumers.

Organisation	Phone / TTY	email / web	Address
QCOSS Queensland Council of Social Services	<i>Ph</i> (07) 3004 6900 <i>Toll Free</i> 1800 651 255 <i>Fax</i> (07) 3004 6999	<i>web</i> www.qcoss.org.au <i>email</i> qcoss@qcoss.org.au	<i>Post</i> PO Box 3786 South Brisbane <i>Street</i> Ground Floor 20 Pidgeon Close West End Q 4101
CAGQ Combined Advocacy Groups of Qld	<i>Ph</i> (07) 3236 1122	<i>web</i> www.qai.org.au	<i>Street</i> Suite G2 Ground Floor Roma Street Transit Centre Q 4003
Maternity Coalition	<i>Ph</i> (07) 3256 8127 or 0424 493 201	<i>web</i> www.maternity coalition.org.au <i>email</i> qldpresident@maternity coalition.org.au	
QAHC Queensland Association of Healthy Communities Focus -Health and well- being of lesbian, gay, bisexual and transgender Queenslanders	<i>Ph</i> (07) 3017 1777 <i>Freecall</i> 1800 177 434 (outside Brisbane) <i>Fax</i> (07) 3852 5200	<i>web</i> www.qahc.org.au <i>email</i> info@qahc.org.au	<i>Post</i> PO Box 1372 Eagle Farm QLD 4009 Australia <i>Head Office</i> 30 Helen Street Newstead Q 4006

Organisation	Phone / TTY	email / web	Address
Council on the Aging Qld	<i>Ph</i> (07) 3316 2999	<i>web</i> www.cotaq.org.au <i>email</i> web@cotaq.org.au	<i>Street</i> Level 3 33 Queen Street Brisbane <i>Post</i> GPO Box 21 Brisbane Q 4001
QDN Queenslanders with Disability Network	<i>Ph</i> (07) 3252 8566	<i>web</i> www.qdn.org.au <i>email</i> qdn@qdn.org.au	<i>Street</i> 7 O'Connell Tce Bowen Hills Q 4006
Queensland Alliance of Mental Health Associations	<i>Ph</i> (07) 3832 2600	<i>email</i> admin@qldalliance.org.au <i>web</i> www.qldalliance.org.au	<i>Post</i> PO Box 919 Spring Hill Q 4000
Carers Queensland	<i>Ph</i> (07) 3843 1401 <i>Fax</i> (07) 3843 1403	<i>web</i> www.carersqld.asn.au	<i>Street</i> 15 Abbott Street Camp Hill <i>Post</i> PO Box 179 Holland Park Q 4121
Multicultural Development Association	<i>Ph</i> (07) 3337 5414	<i>email</i> mailbox@mdabne.org.au <i>web</i> www.mdabne.org.au	
QAIHC Queensland Aboriginal and Islander Health Council	<i>Ph</i> (07) 3328 8500 <i>Fax</i> (07) 3844 1544	<i>web</i> www.qaihc.com.au	<i>Street</i> 21 Buchanan Street West End <i>Post</i> PO Box 3205 South Brisbane Q
Qld Network of Alcohol and Drug Assoc.	<i>Ph</i> (07) 3834 0215	<i>web</i> www.qnada.org.au <i>email</i> info@qnada.org.au	<i>Street</i> Level 3, 133 Leichhardt Street Spring Hill Q 4000

Organisation	Phone / TTY	email / web	Address
Deaf Services Qld	<i>Voice</i> (07) 3892 8500 <i>TTY</i> (07) 3892 8501 <i>Fax</i> (07) 3392 8511	<i>web</i> www.deafsq.org.au <i>email</i> dsq@deafsq.org.au	<i>Post</i> PO Box 173 Annerley Q 4103
QADA Queensland Aged and Disability Advocacy	<i>Ph</i> (07) 3637 6000	<i>web</i> www.qada.org.au	<i>Street</i> 121 Copperfield Street Geebung Q 4034
Bundaberg Patient Support Network	<i>Ph</i> 0439 769 965	<i>email</i> god-love-ya@hotmail.com	
QSMA Qld Self- Management Alliance	<i>Ph</i> (07) 3857 4200	<i>web</i> www.qsma.org.au <i>email</i> info@qsma.org.au	<i>Post</i> PO Box 2121 Windsor Q 4030
Ethnic Community Council	<i>Ph</i> (07) 3844 9166	<i>web</i> www.eccq.com.au	<i>Post</i> PO Box 5916 West End Q 4101
YANQ Youth Affairs Network Qld	<i>Ph</i> (07) 3844 7713 <i>Fax</i> (07) 3844 7731	<i>web</i> www.yanq.org.au <i>email</i> admin@ynq.org.au	<i>Street</i> 30 Thomas Street West End Q 4101
Self-Help Queensland Inc.	<i>Ph</i> (07) 3344 6919	<i>web</i> www.selfhelpqld.org.au	<i>Post</i> PO Box 353 SunnyBank Q 4109
Health Consumers Network	<i>Ph</i> 5497 5786	<i>email</i> kathykendell@aapt.net.au	<i>Street</i> 9 Dylan Court Sandstone Point Q 4511
Women's Health Queensland Wide Inc	<i>Ph</i> (07) 3839 9962	<i>web</i> www.womhealth.org.au	<i>Street</i> 165 Gregory Terrace <i>Post</i> PO Box 665 Spring Hill Q 4004

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

Notes

...your voice in health

Health Consumers Queensland

Consumer Representatives Program: Consumer Handbook

Information for health consumers about the Consumer Representatives Program: Ideas, tips and suggestions to support their participation in committees and other health consumer engagement initiatives.

