

...your voice in health



*for Queensland health consumers*

## Health Consumers Queensland

# Annual Report 2009-10

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

**Toward**   
Tomorrow's Queensland

 **Queensland  
Government**

## **Terms of reference**

*The following terms of reference were endorsed by the former Queensland Minister for Health on 7 May 2008.*

### **1. Purpose**

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 perspective, supporting consumer engagement and promoting advocacy development.

### **2. Outcome**

The strengthening of the consumer perspective in health services policy, systems and service reform and improvement.

### **3. Terms of reference**

#### *3.1 Term of reference one*

Provide timely, high level, strategic advice to the Minister on government health policies and proposals, other matters the committee identifies, or as referred by the Minister, from a consumer perspective, and recommend priority areas of action to improve the quality and responsiveness of health services.

#### *3.2 Term of reference two*

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.

#### *3.3 Term of reference three*

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

#### *3.4 Term of reference four*

Working collaboratively with government, health sector and community stakeholders, develop and promote an advocacy framework to inform and strengthen individual and systems consumer health advocacy activities in Queensland.

#### *3.5 Term of reference five*

Provide quarterly reports to the Minister, a published annual report at the end of the financial year in line with the Strategic Plan and Terms of Reference and advise the Minister on the future priorities and governance of the Ministerial Consumer Advisory Committee.

## About Health Consumers Queensland's Annual Report 2009-10

Health Consumers Queensland's (HCQ) 2009-10 annual report highlights our key achievements during our second year of operation. The report delivers on HCQ's commitment to accountability to government, consumers and the community around our performance as Queenslanders' *voice in health*. The report reflects the major aspects of our work, which encompass engaging with statewide Queensland health consumers and listening to their perspectives on proposed state and national health reforms and other health matters. Consumer feedback is then incorporated into formal advice to the Deputy Premier and Minister for Health, the Commonwealth Minister for Health and Ageing and their relevant departments, health practitioner networks, non-government peak bodies and community agencies.

### Who we are...

In 2008, HCQ was established to be *your voice in health*. HCQ comprises a Ministerial Consumer Advisory Committee (Committee) and a small Secretariat supported by the Office of the Director-General, Queensland Health. HCQ's current 12-member Committee was appointed until August 2010, as an interim arrangement to be reviewed before the end of its 2-year term, to assess the preferred model and governance arrangements for a peak health consumer body into the future. HCQ's Committee represents the diversity of Queensland health consumers, covering a range of life stages, health populations and social groups (for example, Indigenous, culturally and linguistically diverse, disability, women and rural, regional and remote communities).

### What we do...

HCQ's *Strategic Plan 2008-10* underpins our work. It details how we will deliver on HCQ's five terms of reference, including our mission, guiding principle, aspirations, goals and strategies and three priority areas for action - quality and safety; equitable access and targeted responses; and participation and engagement. HCQ:

- provides advice to the Deputy Premier and Minister for Health on health policies and initiatives and through the Deputy Premier, to other State and Federal Departments, health practitioner networks, peak bodies and community agencies
- supports health consumers to build their knowledge and confidence to engage with, and advocate to, government and community on health issues
- coordinates a Consumer Network and Representatives Program comprising consumer representatives interested in hearing about and providing feedback around health policy, planning and service initiatives
- facilitates initiatives to strengthen individual, family and systems health advocacy and proactively works towards systemic change within the health system
- works collaboratively with Health Community Councils to strengthen consumer participation in district health services.

### What we do not do...

Some activities are beyond HCQ's terms of reference. HCQ does not:

- provide health treatment and prevention services. These are provided by health professionals in public and private services
- receive or manage complaints. Complaints are dealt with by health service providers, the Health Quality and Complaints Commission or health professional boards
- deliver individual advocacy support. However, HCQ will provide consumers with information about advocacy organisations to contact.



### **Chairperson's Review 2009-10**

2009-2010 has been another eventful year for Health Consumers Queensland (HCQ). We have worked hard to promote and support consumers engaging in the health system at the individual, local, regional, State and Commonwealth levels, for better health outcomes. I am proud of the achievements of the Ministerial Consumer Advisory Committee and Secretariat, in delivering on our terms of reference and strategic priorities. This has included engaging with consumers and key stakeholders across the state around a wide variety of key health initiatives, encompassing state and national health and hospital reforms. In particular, HCQ enabled consumers and their representatives to provide input into matters relating to health system integration, patient safety, clinical governance arrangements, Queensland Health's end-of-life documents, the Blue Skies Scenario, medication safety, quality use of pathology, advance care planning and Advance Health Directives, clinical handover, open disclosure, eHealth and the *National Health and Hospitals Network for Australia's Future* reform paper.

I am pleased that statewide Queensland consumer feedback provided by HCQ to the Commonwealth on the reform paper along with feedback from other state consumer bodies and Consumers Health Forum of Australia has been reflected in the April 2010 Council of Australian Governments (COAG) agreement, highlighting the Commonwealth Government's commitment to consumer engagement and participation in the development of health policy and the planning, implementation and evaluation of health reforms.

I believe a key milestone in our work this year was HCQ's co-hosting with Queensland Health's Clinical Practice Improvement Centre of the Deputy Premier and Minister for Health's launch of the Australian Charter of Healthcare Rights on 17 March 2010. The launch demonstrated Government's commitment to the rights of health consumers in the provision of public and private health services in Queensland and the display of the Charter across all Queensland Health facilities. The Charter recognises that people receiving care and people providing care all have important roles to play in achieving their healthcare rights towards a safer, high quality health system.

Consumer engagement is an integral part of the development and delivery of quality health services and ensures a viable, responsive and effective health system. HCQ has established a strong Consumer Network which is the gateway to our Consumer Representatives Program. We have been able to provide consumer representatives to numerous health-related consultation activities arranged by Government and Non-Government agencies. We have also included consumers from across Queensland in face-to-face forums and workshops and used their feedback to provide informed comment on State and Commonwealth discussion papers. I would like to take this opportunity to thank all our consumers and representatives from consumer organisations for their support throughout the year and for their selfless individual and collective sharing of views, experiences and opinions with HCQ.

HCQ is currently finalising a Consumer Engagement Framework and a Health Advocacy Framework to provide health consumers and their representatives, and health agencies with models, principles, tools, and resources to strengthen consumer engagement and advocacy. In supporting Queensland consumers to have a stronger voice in health, we will continue to work towards more consumer-focused, safe, quality, affordable, accessible, timely and responsive health programs and services for Queensland. I believe the future will provide further opportunities for consumers to share in the decisions needed for positive change in our health system. I look forward to continuing this vital work in partnership with Queensland health consumers, consumer and community groups, key health professional networks and the Queensland State Government.

#### **Mark Tucker-Evans**

Chairperson  
Ministerial Consumer Advisory Committee  
Health Consumers Queensland



### **Director's Review 2009-10**

HCQ supports universal access to healthcare and a health system that is consumer-centred, safe, affordable, accessible, timely and responsive to the needs of Queenslanders.

This year has seen further significant reforms in health at state and national levels. Consumers have played an important role in informing HCQ's formal advice and work. I would like to thank all those consumers, carers, health practitioners and agencies and consumer and community organisations who have informed our work during 2009-10.

In collaboration with HCQ's Committee, the Secretariat has organised a diverse number of consumer and community engagement activities this year, in response to state and national health issues. HCQ has been able to provide submissions to the State and Commonwealth Governments grounded in the consumer perspective. Submissions included formal responses to the National Health and Hospital Reform Commission: Final Report 2009; the national health reform paper, A National Health and Hospitals Network for Australia's Future; and on issues relating to patient safety, health practitioner law reforms, open disclosure and complaints management standards.

HCQ has three key priority areas which underpin the work of the Committee and Secretariat. These are quality and safety; equitable access and targeted responses; and participation and engagement. This year HCQ undertook pioneering work in the area of health consumer engagement and is currently finalising HCQ's Consumer Engagement Framework. The Framework comprises a model, eight principles and an eight-step process to support health consumers and health agencies to achieve stronger consumer engagement, and ensure that consumers have positive input into the health policies, programs and services which impact on their lives.

Strengthened individual and systems health advocacy has been another key area of work for HCQ this year. The finalisation of HCQ's Health Advocacy Framework and Health Advocacy Toolkit builds Queensland health consumers' capacity to better engage with the health system and advocate around their healthcare and improvements to the overall health system.

HCQ has continued to maintain strong collaborative working relationships this year with the national peak consumer body, Consumers Health Forum of Australia and other State and Territory consumer bodies. This has enabled us to provide a united consumer perspective, particularly in regards to the changing landscape of national health reforms.

The rights of patients and health consumers were reinforced this year with the launch of the Australian Charter of Healthcare Rights by the Deputy Premier. HCQ looks forward to working collaboratively with all stakeholders in the delivery of a health system which is underpinned by consumer rights and safe, quality healthcare.

I especially extend my sincere thanks to members of HCQ's Consumer Network for their invaluable participation in our consultations and their informed feedback on State and Commonwealth health reform matters. I would also like to thank HCQ's Chairperson, Mark Tucker-Evans, the Committee and the Secretariat, for their hard work and dedication to achieving improved health outcomes for Queenslanders.

#### **Paige Armstrong**

Director, Secretariat  
Health Consumers Queensland

## Achievements against HCQ's terms of reference 2009-10

### Term of reference one – providing formal advice on government health policies and proposals and matters identified by the committee

HCQ continues to undertake work in the three key priority areas of **quality and safety**; **equitable access and targeted responses**; and **participation and engagement**. In supporting the voices of Queensland health consumers to achieve better health outcomes, HCQ has undertaken systemic advocacy across a number of key state and national health reform initiatives and delivered strategic advice to government on health quality and safety matters, from the consumer perspective.

HCQ has also worked collaboratively with the national peak consumer body, Consumers Health Forum of Australia (CHF) and the other State and Territory bodies to deliver joint position papers and responses to the Commonwealth Government and Prime Minister.

**Advance care planning and Advance Health Directives** have emerged as a key area of work for HCQ in 2010, with engagement with consumers and other key stakeholders to inform the development of a consumer information and discussion paper.

Our other achievements included:

- In March 2010, HCQ and the Queensland Health Clinical Practice Improvement Centre co-hosted the Deputy Premier's launch of the Australian Charter of Healthcare Rights and related matters at the Parliamentary Annexe.



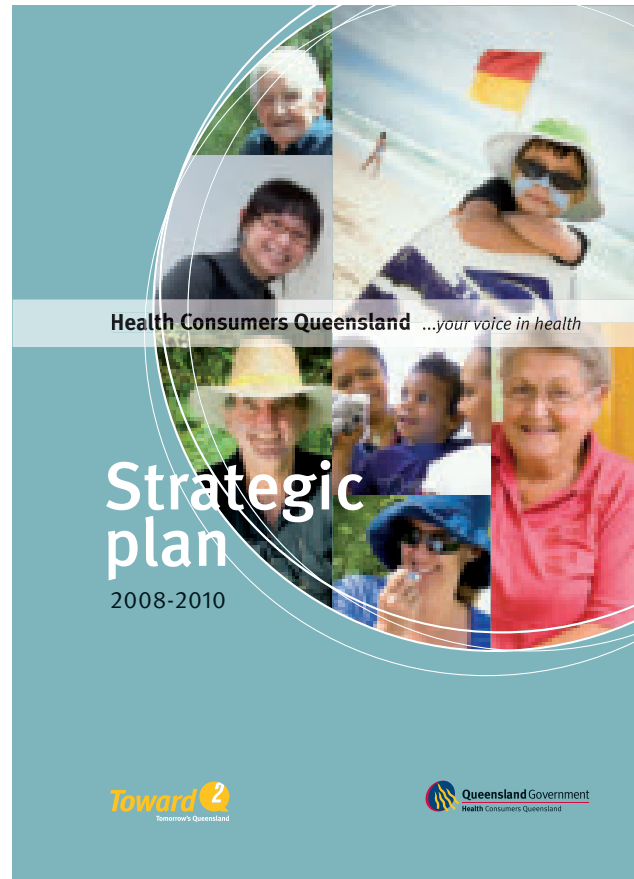
Mark Tucker-Evans with Deputy Premier

- Continuing to maintain effective working relationships with a wide variety of state and national organisations which ensure advice is grounded in the consumer experience. Effective working relationships have been sustained with members of HCQ's Consumer Network; Queensland Health; the Health Quality and Complaints Commission; the Australian Commission on Safety and Quality in HealthCare; the Queensland Council of Social Service; Consumers Health Forum of Australia and associated State consumer bodies; the Offices of the Public Advocate and Adult Guardian; and General Practice Queensland.
- Maintaining an Issues Register, based on feedback from Queensland health consumers which is incorporated into the advice provided to the Deputy Premier, Queensland Health and other relevant health bodies. The following details some of the key areas that consumers have identified this year:

- » Perth Declaration – Perth Patients for Patient Safety Forum
- » Pathology bulk billing arrangements
- » Private health insurance rebates
- » Oral health issues
- » National Health and Hospitals Network
- » Implementation of COAG health reforms
- » eHealth
- » Advance care planning
- » Advance Health Directives
- » Patient assisted travel.
- HCQ’s Chairperson continues as a member of the Queensland Clinical Senate Executive.
- HCQ Committee Members have been formally appointed to the following committees:
  - » Queensland Plan for Multicultural Mental Health Reference Group
  - » Cancer Screen Services Quality Management Committee
  - » Queensland Health eHealth Stakeholder Reference Group
  - » Sexual Assault Expert Advisory Group
  - » School of Medicine Consultative Committee
  - » UQ School of Medicine Consultative Committee.
- HCQ developed a total of 10 submissions around the following initiatives:
  - » National Health and Hospitals Reform Commission: Final Report 2009
  - » A National Health and Hospitals Network for Australia’s Future
  - » Queensland Health Patient Safety Centre Clinical Handover – A Strategy Options paper
  - » Consumer information and discussion paper on advance care planning and Advance Health Directives
  - » Queensland Health’s Allied Health Clinical Governance Framework discussion paper
  - » The Exposure Draft of the Health Practitioner Regulation National Law 2009
  - » Health Quality and Complaints Commission: Complaints management standard
  - » Draft Indicators of Effective Open Disclosure.

## Health reforms and the consumer voice

The national health reform agenda aims to deliver better quality healthcare for all Australians. HCQ committed a major part of its work to the reform agenda during the year. Consumer feedback informed all HCQ submissions and the joint papers developed in partnership with the other peak health consumer bodies in regards to those reforms. HCQ undertook a number of initiatives to gather this feedback. In particular, in developing HCQ's submission to the *National Health and Hospital Reform Commission: Final Report June 2009*, HCQ invited feedback from HCQ's statewide Consumer Network and hosted a statewide forum attended by 40 health consumers; two targeted focus groups for culturally and linguistically diverse people; a discussion with Indigenous health consumer representatives, and a workshop with HCQ's committee. In acting as Queenslanders' *voice in health*, HCQ has collaborated with Consumers Health Forum of Australia and the other State consumer bodies to advocate for rigorous consumer engagement mechanisms as central to ongoing health reform matters. HCQ supports strong consumer engagement as part of the national reform implementation process to promote the delivery of safer, patient-focused, affordable, accessible, timely and responsive health services for Queenslanders and their fellow Australians.



*“Your invaluable contribution to the panel discussion provided a strong foundation for the group work and the recommendations that were proposed”*

(To a HCQ Committee Member, from the Chair, Queensland Clinical Senate)

## Term of reference two – fostering consumer engagement and capacity building

HCQ works to support and promote meaningful opportunities for Queensland health consumers to engage with health services and the health system and have input in health policy development and service planning, implementation and evaluation. Access to information and resources which build the capacity of consumers and their representatives to engage with the health system are vital to positive consumer engagement activities.

A key component of HCQ's consumer engagement work has been the development of HCQ's Consumer Engagement Framework which comprises a set of eight principles, a model and an eight-step process. The Framework will assist health consumers to better engage with their health care and the health system in achieving better health outcomes at an individual, service and broader agency level. The Framework provides a tool that can be used at a state and national level to support consumer engagement within the public policy arena. HCQ is using the Consumer Engagement Framework as a foundation for its future strategic planning initiatives with the Queensland Government.

HCQ also undertook an external review of its Consumer Network and Consumer Representatives Program, examining the effectiveness of both programs in engaging with consumers and agencies and recommending improvements to support the ongoing sustainability of the initiatives. The review report concluded:

- 94 per cent of consumer respondents said the Consumer Network provided them with relevant information about health policy, initiatives and reforms and opportunities to engage.
- 80 per cent of consumer respondents felt the Consumer Network provided them with adequate opportunities to provide feedback to inform policy, initiatives and service provision and put forward their health consumer voice and views.
- 95 per cent of consumer respondents and 93 per cent of agency respondents were either satisfied or very satisfied with their Consumer Representative Program experiences.

### Our other achievements included: Consumer Network and Consumer Representatives Program

HCQ's statewide Consumer Network had 183 individual and organisational members registered as at 30 June 2010. Network membership has grown by up to 60 per cent since last financial year.

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



Consumer workshop

During 2009-10 the HCQ Consumer Representatives Program received 69 agency requests and matched 192 consumer representatives to agencies' requests (at Attachment 1).

HCQ assisted statewide Queensland health consumers to actively participate in an additional 146 engagement activities hosted by health-related agencies and other professional bodies and tertiary institutions (at Attachment 1).

*Being a cancer survivor, having a mother in aged care with dementia and with a husband suffering from a chronic condition, I thought I had negotiated the health system pretty well. I had not been aware of the plight of a vast number of other health consumers who had not been as fortunate as I. Wasn't that about to change! I joined Health Consumers Queensland (HCQ). The HCQ website and related sites opened up the world of health consumerism to me. To have the opportunity to contribute to improvements for consumers within our health system is invigorating and humbling (HCQ Consumer Network Member and Consumer Representative from North Queensland).*

*"I have learnt a lot and met so many wonderful people, all with the same passion as myself, to see a new healthcare system come into being"*

(Brisbane North health consumer).

*"Thanks for all your help organising the conference. We were very happy with how the consultation went – the organisation and venue were very good, and we also appreciated the active participation of those who attended"*

(Senior Project Officer, Australian Commission on Safety and Quality in Health Care)

### **Supporting and promoting consumer engagement**

HCQ undertook a total of 14 focus groups, forums and workshops with statewide health consumers and key stakeholders during the year, to gather feedback in relation to the:

- National Registration and Accreditation Scheme for Health Professionals Bill B – exposure draft legislation Health Practitioner Regulation National Law 2009 (two focus groups)
- Australian Commission on Safety and Quality in Health Care National Safety and Quality Framework for Australia and the National Safety and Quality Health Care Standards (two workshops jointly hosted by HCQ and the Commission)
- National Health and Hospitals Reform Commission's Final Report statewide forum
- Blue Skies Scenario – A vision for an inclusive community (for people with disability) focus group

- Queensland Health draft End-of-life documents (two focus groups)
- National Health and Hospitals Reform Commission's Final Report (two focus groups with the Ethnic Communities Council of Queensland and Indigenous representatives)
- National Health and Hospitals Network statewide forum
- National Health Reform Forum with Mark Butler, Parliamentary Secretary to Hon Nicola Roxon, Minister for Health and Ageing (jointly hosted by HCQ and Consumers Health Forum of Australia)
- Final draft of HCQ's Consumer Engagement Framework statewide forum
- Advance care planning and Advance Health Directives forum in Toowoomba.

*It was early 2009 when I received an invitation to become involved with HCQ. When I answered an email invitation to apply to be a member of HCQ's Consumer Network, I did not fully realise what my involvement was going to mean.*

*I need not have worried. My first involvement was a seminar, one of many I have now attended. Being a part of HCQ opened up a whole new world of interest for my wife and I.*

(HCQ Consumer Network Member and Consumer Representatives from Brisbane North).



*Consumers engaging*

*“The Thursday forum was very interesting and informative [and] highly organised and conducted very professionally. I really enjoyed the company of the consumer forum. They are such skilled professionals and truly caring about consumer needs. The input from the participants was received in a very encouraging manner“*

(Associate Professor, School of Medicine & Dentistry, James Cook University),

### Consumer capacity building initiatives

HCQ circulated information to consumers, their representatives and other key stakeholders, including:

- The Australian Charter of Healthcare Rights
- HCQ's eight principles for consumer engagement
- HCQ's brochure and Consumer Engagement Resource Kit – Consumer and Agency Handbooks
- HCQ information updates, information papers, summaries of key health reform papers and e-bulletins.

HCQ's website at <http://www.health.qld.gov.au/hcq> is regularly updated, providing consumers, stakeholders and the community with current information on HCQ's activities and consumer representation opportunities.

### Presentations

HCQ delivered presentations to health-related audiences to develop the skills and capacity of health agencies and professionals to engage with health consumers. Audiences have included:

- the Queensland Clinical Senate
- General Practice Queensland
- Health Services students at University of Queensland
- 15th Medication Safety Workshop
- Centre for Research Excellence in Patient Safety at Monash University
- The Power of Apology Symposium
- Queensland Health's Clinical and Statewide Services: Radiology Support.

### Consumer Engagement

HCQ's Consumer Network comprises a statewide register of health consumers and community organisations who are interested in health matters and in providing input into health policies and initiatives from a consumer perspective. Members of the Network collaborated with HCQ in the development of its HCQ Consumer Engagement Framework. Information, discussion papers and draft documents have regularly been provided to the Network during the development of the framework. Consumers and their representatives were invited to provide feedback to inform HCQ during the developmental stages of the document. They participated in forums in Townsville and Brisbane and focus groups in Brisbane during the initial stages of this work then provided verbal and written feedback and attended another Brisbane forum to debate the final content of the Framework, comprising a model, eight principles and an eight-step process. The finalised Framework reflects this informed advice. HCQ believes the Framework will deliver a user-friendly tool to foster and build the capacity of Queensland's health consumers, their carers and supporters, and health and community agencies to engage effectively for better health outcomes.

### Term of Reference three – *collaborating with Health Community Councils*

HCQ's work on statewide health matters has been greatly informed by Health Community Councils (HCCs), who bring a localised or district perspective to inform HCQ's activities. HCQ continues to collaborate with HCCs across the state in working towards better health outcomes for Queenslanders.

#### **Our collaborative activities with HCCs**

- Members of a number of HCCs are also members of HCQ's Consumer Network, giving them opportunities to engage in HCQ facilitated forums, focus groups and workshops around state and national health reform matters.
  - Two of HCQ's Committee are members of their local HCCs (Bundaberg and Mount Isa). They brought insight about the role and work of their HCC and a wealth of knowledge to HCQ around their local health service districts and the needs, aspirations and interests of their local communities.
  - HCQ provided input into Queensland Health's response to the Weller Report, which reviewed Government boards and bodies, including HCCs.
  - HCCs receive copies of HCQ's submissions and other published materials to assist them in their district engagement activities.
  - HCQ collaborated with the HCC in Central Queensland to promote the launch of the Australian Charter of Healthcare Rights.
  - HCQ continues to promote HCCs' important role and functions during HCQ events.
- HCQ identifies requests through our Consumer Representatives Program which are more relevant to the work of a local HCC and then refers those requests to the relevant HCC.
  - HCQ planned and co-hosted an advance care planning forum in Toowoomba with South Burnett and Toowoomba HCCs.
  - HCQ is currently working in partnership with the Mount Isa HCC to facilitate a consumer and community forum around the Patient Travel Scheme and patient assisted travel in Mount Isa in August 2010.



*Health Community Council Members with  
HCQ Committee Member*

*My sincere thanks to you and all concerned for giving me the opportunity to attend this symposium. It was very interesting with a great line up of guest speakers and presenters. Again many thanks.*

*(A Central Queensland Health Community Council member).*

### Joint HCC and HCQ Toowoomba Advance Care Planning Forum 25 June 2010

HCQ collaborated with the South Burnett and Toowoomba Health Community Councils (HCCs) to explore rural and regional health consumers' views in relation to advance care planning and Advance Health Directives (AHDs). The project sought to obtain consumer perspectives around solutions and strategies for improvement and reform of laws and health policies, practices and service delivery, in order to advise the Deputy Premier and Minister for Health. Forum participants acknowledged the issues underpinning these topics are complex and often confusing, and for rural and remote consumers, there are additional challenges specific to their location and region. Forum participants also identified people living in rural and remote areas are often separated from family and socially-isolated. The tyranny of distance, costs of travel and caring can impact on consumers' and carers' commitment to or ability to develop Enduring Powers of Attorney or Advance Health Directives with health, allied health or human service professionals, legal representatives and Justices of the Peace. Forum participants suggested simplification of existing forms and the development of a national register so that documents can be readily developed then accessed easily in times of need and their existence and validity can be checked by treating health professionals. Overall, consumers supported a consumer-centred approach to advance care planning and AHDs, considering AHDs valuable tools for providing directions about the care and treatment they wished to receive in the event they lost the capacity to make decisions for themselves. Four strong themes – information and support for consumers around AHDs and advance care planning; improving access to AHDs through ehealth; the role of health practitioners and advance care planning; and national legislative reform – emerged throughout the consultation.



HCQ Committee Member with Health Community Council Member

*“I write as Acting Chair of The Prince Charles Hospital Health Community Council to provide a brief comment on certain aspects of [HCQ’s] work. Over recent months, The Prince Charles Hospital Health Community Council (TPCH HCC) has received, read and considered a variety of reports and submissions generated from HCQ. Our HCC members have asked me to thank you for the work you are doing to promote the perspective of health consumers in state-wide and nation-wide deliberations currently being undertaken. We commend you for your work and state that we endorse the feedback provided by HCQ on reports such as, The National Health & Hospitals Reform Commission Final Report [and] The Code of Conduct for Doctors produced by the Australian Medical Council. While we cannot say that we totally agree with every single detail of your comments and submissions, members of TPCH HCC acknowledge the excellent work you are doing, and state our endorsement of the direction in which your comments are seeking to influence the delivery of improved health services to consumers. We wish you well in your ongoing work in this important area of provision of health services to the Australian public.”*

### **Term of reference four – *informing and strengthening individual and systems health advocacy***

Health advocacy is an important part of delivering improved health outcomes for consumers and is vital in driving positive cultural change at both individual and systems' levels. HCQ believes health advocacy is about speaking, acting or writing with minimal conflict of interest to support a health consumer or group's wellbeing, and to promote, protect and defend their right to accessible, safe, quality healthcare. It can be undertaken by the consumer themselves, or by an independent advocate loyally representing the individual or group's perceived interests.

Our achievements included:

- **Launch and promotion of the Australian Charter of Healthcare Rights**  
The Australian Charter of Healthcare Rights (at Attachment 2) underpins and informs HCQ's health advocacy work. The Charter reinforces the fundamental rights of health consumers when accessing and using public and private healthcare in Australia. HCQ was pleased to co-host the Queensland launch of the Charter with Queensland Health's Centre for Healthcare Improvement in March 2010. In his speech at the Charter launch, HCQ's Chairperson said the Australian Charter of Healthcare Rights promotes health consumers and providers working together to create a safe and quality health system. Further, he said HCQ had been actively promoting the launch of the Charter along with a clear implementation process for the Charter. He said the Charter publicly committed to the provision of safe, quality and accessible healthcare for all consumers in an atmosphere of dignity, respect and consideration, and that it encouraged consumers to participate fully in their own healthcare.

- **Health Advocacy Framework and Toolkit**  
HCQ is in the process of finalising a Health Advocacy Framework for Queensland and a Health Advocacy Toolkit to inform and strengthen individual and systemic health advocacy through providing an overarching framework and the tools and resources to assist consumers. The Framework was informed through consumer and community engagement, a comprehensive research paper developed by the Queensland Council of Social Service and a statewide forum in September 2009. In particular, HCQ heard the perspectives of the Queensland Combined Disability Advocacy Groups, health advocacy organisations, key community organisations, Queensland Health and Department of Communities' staff, and the Offices of the Public Advocate and Adult Guardian on the topic.

In developing the Health Advocacy Toolkit, HCQ hosted four focus groups in Brisbane in May 2010 to obtain consumers' views on a user-friendly toolkit for health consumers and their families and carers to assist them to advocate around their healthcare and broader health matters. The Toolkit was tested for usability through a series of small group activities with consumers, HCQ Committee members and other community and health-related stakeholders. HCQ believes the toolkit will be a useful and understandable resource for health consumers, their families and carers to assist them in advocating around health matters.

- **Doing systems advocacy**  
HCQ continued to undertake systems advocacy in regards to key state and national health reform initiatives as outlined in terms of reference one and two, through formal submissions and participation in forums and workshops, and meetings and deputations with state and national ministers, members of parliament, government and non-government agencies, health practitioner bodies and other consumer organisations. Current health reform agendas create an environment where advocacy acts as a mechanism towards achieving more person-centred, accessible, safe healthcare and a responsive health system.
- **Responding to systemic issues**  
Queensland health consumers have identified a number of key systemic issues, which HCQ raised with the Office of the Deputy Premier, relevant areas of Queensland Health and other health bodies and statutory agencies. The issues include open disclosure; clinical handover; patient travel assistance; and advance care planning. HCQ has also advocated around a range of national health matters including the Quality Use of Pathology; the Medicare Benefits Schedule Quality Framework; the Australian Health Technology Assessment Review; the Quality HealthCare Conversation; the National Women's Health Policy Consultation; a Benzodiazepines Workshop; and Good Medical Practice consultation.

### **Australian Charter of Healthcare Rights**

The Deputy Premier and Minister for Health, The Hon. Paul Lucas officially launched Queensland's adoption of the Australian Charter of Healthcare Rights and Queensland Health's Charter Implementation Standard in the presence of 90 health consumers, health professionals, Queensland health staff and representatives of health and community organisations in March 2010. The Charter marks the culmination of individual and systemic advocacy undertaken over significant time by committed health consumers and consumer organisations and moves the focus to consumer and patient rights as recipients of healthcare services across the Australian health sector. The Charter provides health consumers with information about their rights in accessing health services, and empowers them to work together in partnership with health professionals and service providers to achieve safe, quality healthcare and a better health system. HCQ believes the Charter is an important document which supports individual and systems advocacy and is a valuable tool for consumers, their carers and supporters, health professionals and organisations to understand the rights of health consumers and ensure the delivery of accessible, safe and quality healthcare and open communication of any concerns they may have in relation to that healthcare.



*At the Queensland Launch of the Australian Charter of Healthcare Rights*



Knowing my health rights

*“Thank you for including me in the HCQ workshop on advocacy...it was a knowledge workshop”*

(Chair Mt Isa Health Community Council)

## Australian Charter of Healthcare Rights

Supported by Queensland Health

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

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

### Guiding principles

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

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

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

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



For further information please visit [www.safeyourquality.gov.au](http://www.safeyourquality.gov.au)

AUSTRALIAN COMMISSION ON SAFETY AND QUALITY IN HEALTHCARE



### What can I expect from the Australian health system?

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

## Term of reference five – reporting and advising on future governance priorities

### Annual Report to the Deputy Premier

HCQ's published Annual Report 2008-09 provided the Deputy Premier and Minister for Health, Queensland health consumers and our other stakeholders with an overview of our key achievements during HCQ's first 10 months of operation and detailed the body's future priorities.

HCQ's Annual Report 2009-10 further details the body's ongoing achievements over the past 12 months in line with our five terms of reference and future priorities.

### Quarterly Reports to the Deputy Premier

During 2009-10, HCQ provided four Quarterly Reports (July-September 2009; October-December 2009; January-March 2010; and April-June 2010) to the Deputy Premier and Minister for Health. The Reports identified the strategies and activities HCQ employed to meet its five terms of reference.

### Formal Committee meetings

HCQ's committee had a number of formal meetings throughout the year, including

- 10 formal committee meetings and teleconferences
- 12 Committee working group sessions to support the work of the overall Committee with a focus on health reform, consumer engagement and advocacy development initiatives.

## Forums and workshops

During the year, HCQ Committee members and Secretariat staff attended a variety of forums, workshops and conferences. The purpose was to network with key stakeholders who have the ability to influence health policy and service delivery and to build Committee and staff knowledge, capacity and skills to engage with and advocate on behalf of Queensland health consumers.

During 2009-10 over 30 different forums, workshops and conferences were attended. These included:

- Australian Patients for Patient Safety Workshop, Western Australia
- National Registration and Accreditation Scheme for Health Professionals Workshop, Brisbane
- Consumers Health Forum of Australia (CHF):
  - » Members Forum on Medicines Policy, Melbourne
  - » Quality Use of Pathology Workshops, Brisbane and Melbourne
  - » Quality Healthcare Conversations National Workshop, Sydney
  - » Review of Health Technology Assessment in Australia, Sydney
  - » Quality Use of Diagnostic Imaging Project National Workshop
  - » Deciding About New Medicines Consultation Workshop, Sydney
- General Practice Queensland: Workforce Summit, Brisbane and Queensland Divisional Forum
- National Strategic Framework for Rural and Remote Health Consultation Workshop, Brisbane
- Health Issues Centre Victoria Conference, Melbourne
- International Association of Public Participation: IAP2 Method and Communication, Brisbane
- Integrated Primary Health Care Conference, Melbourne

## Future governance and priorities

When establishing HCQ, the Queensland Government also committed to review the body at the end of our initial two-year term. HCQ's term of reference five includes the provision of advice to the Deputy Premier and Minister for Health from HCQ's Ministerial Consumer Advisory Committee around future governance options and priorities. To this end, HCQ's Committee participated in a Futures Planning Workshop with Professor Lesley Chenoweth in January 2010. HCQ's Committee provided a report of the workshop outcomes and recommendations to the Deputy Premier about their preferred future governance model for a peak health consumer body in Queensland.

Queensland Health will also conduct a review of HCQ in the second half of 2010, with recommendations being made to the Deputy Premier and Director-General, Queensland Health about the preferred governance arrangements and future priorities of a peak statewide health consumer body in Queensland beyond the current term of HCQ's Committee.



*HCQ Committee and Secretariat in action*



*Carolyn, Elizabeth, Paige, Kym and Margaret*

## **Our Secretariat staff**

HCQ acknowledges the Secretariat's contribution and commitment to progressing our work during 2009-10. Staff during the year were:

**Paige Armstrong**  
Director

**Carolyn McDiarmid**  
Senior Policy Officer

**Olivia Spadina**  
Senior Policy Officer

**Russell Flynn**  
Senior Policy Officer  
(on leave from December 2009)

**Nadine Eckert**  
Senior Policy Officer  
(from December 2009 until April 2010)

**Elizabeth Chenoweth**  
Senior Policy Officer  
(from May 2010)

**Bronwen Morris**  
A/Executive Support Officer  
(until November 2009)

**Margaret Micale**  
Executive Support Officer  
(from December 2009)

## **Our contractors**

HCQ also acknowledges the valuable contribution made by a range of contractors towards HCQ delivering on our terms of reference during 2009-10. We would especially like to mention the ongoing support of:

Kym McCabe

Michelle Moss

Penny Neller

## Our future directions

Following almost two years of operation, HCQ's future priorities include:

- continuing to act as Queensland consumers' voice in health
- continuing to provide strategic advice on state and national health initiatives with a focus on current reform implementation in line with HCQ's strategic priority areas of quality and safety; equitable access and targeted responses; and participation and engagement
- consolidating HCQ's Consumer Network and Consumer Representatives Program based on the external review of the programs
- publishing and promoting HCQ's Consumer Engagement Framework
- launching HCQ's Health Advocacy Framework and Advocacy Toolkit to strengthen individual and systems health advocacy
- continuing to work collaboratively with consumers, government and non-government organisations, state and national consumer bodies, and state and commonwealth governments, to ensure the consumer perspective is represented and influences the implementation of national health reforms and other initiatives
- providing systemic advocacy in the areas of dental care; Queensland's implementation of the Council of Australian Government agreed reforms; patient transport assistance; health workforce issues; and consumer engagement in health policy development and service and program development, implementation and evaluation

- furthering our work around advance care planning and ehealth matters
- continuing to work with the Australian Commission on Safety and Quality in Health Care, the Health Quality and Complaints Commission; Queensland Health's Centre for Healthcare Improvement; and professional health bodies and networks around quality and safety issues impacting on consumers' satisfaction with their healthcare and the quality and safety of service delivery
- sustaining consumer capacity through increased awareness of HCQ and its role and function and the development of local consumer leaders and networks
- providing statewide consumers with training around the Australian Charter of Healthcare Rights and raising awareness around those rights with the health workforce
- collaborating with the Deputy Premier and Queensland Health around implementing the approved model for a future peak health consumer body in Queensland following HCQ's review.

## Our Committee

HCQ's Committee was appointed in August 2008 and commenced activities on 1 September 2008 for a two-year term. Photos of each Committee Member during 2009-10 follow:



*Mark Tucker-Evans,  
Brisbane (Chairperson)*



*Jeff Cheverton, Brisbane  
(until November 2009)*



*Janelle Colquhoun,  
Brisbane*



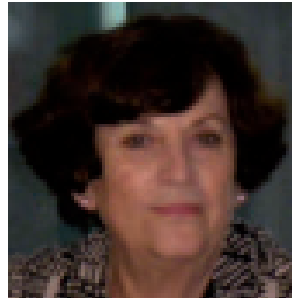
*Beryl Crosby, Bundaberg*



*Melissa Fox, Brisbane*



*Brendan Horne, Brisbane*



*Sherry Kaurila, Ingham*



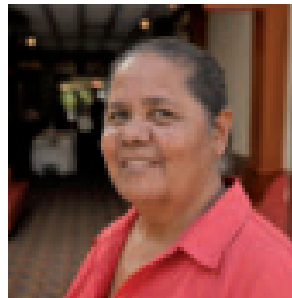
*Mary Martin, Brisbane*



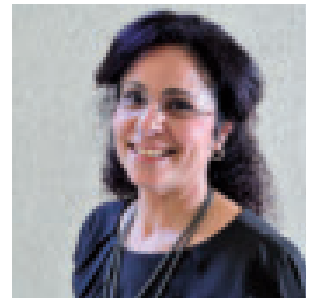
*Alan Neilan, Mount Isa*



*Myra Pincott AO,  
Emu Park*



*Gwen Schrieber, Cairns*



*Odette Tewfik, Brisbane*



*Agnes Whiten OAM,  
Brisbane*

## Our Committee Working Groups to 30 June 2010

In addition to HCQ's formal committee meetings, a number of strategic Committee working groups were developed to inform the work of the Secretariat. The working groups were:

### Consumer Engagement Reference Group

This group guided HCQ's development of our Consumer Engagement Framework and Plan.

It was intended that the Framework would assist health consumers to better engage with their healthcare and the health system to achieve better health outcomes at an individual, service and broader agency level. The Framework was developed to support and influence health practitioners and agencies to achieve meaningful and responsive consumer engagement that becomes a catalyst for change.

#### Members:

Mark Tucker-Evans, Beryl Crosby, Janelle Colquhoun, Melissa Fox, Myra Pincott and Odette Tewfik.

### E-Bulletin and Website Working Group

This group provides advice on the content and layout of HCQ's e-bulletin and website.

#### Members:

Mark Tucker-Evans, Janelle Colquhoun, Beryl Crosby and Odette Tewfik.

### Advocacy Development Working Group

This group guided HCQ's health advocacy initiatives to inform the development of the Health Advocacy Framework and Toolkit which would provide structure and support to individual health consumers, their families and carers, and organisations to advocate for better health outcomes.

#### Members:

Mark Tucker-Evans, Beryl Crosby, Melissa Fox, Sherry Kaurila, Mary Martin, Odette Tewfik and Agnes Whiten.

### eHealth Working Group

This group was formed to focus on the complex issues involved in the implementation of eHealth mechanisms and to provide advice, from the consumer perspective, to Queensland Health's eHealth Stakeholder Reference Group.

#### Members:

Mark Tucker-Evans, Sherry Kaurila, Mary Martin, Alan Neilan, Myra Pincott and Odette Tewfik.

## Attachment 1

Specific initiatives where HCQ assisted statewide Queensland health consumers to actively provide input into activities as requested by health-related agencies and other professional bodies and tertiary institutions.

- Selection/interview panel members for Queensland Health's statewide clinical networks:
  - » Stroke and dementia
  - » Child and youth
  - » Respiratory
  - » General Medicine
  - » Anaesthesia and perioperative care.
- Queensland Health's activities:
  - » Patient Safety and Quality Committee
  - » Patient Safety Symposium Judging Panel
  - » Multicultural Steering Committee
  - » Review of the Variable Life Adjusted Displays
  - » Sub-acute demand and supply analysis study on consumer and carer perspectives
  - » Healthcare Improvement Symposium and Awards
  - » Clinical Policy Unit Acute resuscitation planning and End-of-Life Focus Group
  - » E-health Stakeholder Reference Group
  - » Queensland Maternal and Perinatal Quality Council
  - » Statewide Anaesthesia and Perioperative Care Clinical Network Steering Committee
  - » Research Project on 'Understand the perspective of a victim of crime in Queensland'
  - » Informed Consent Reference Group
  - » Patient Safety and Quality Improvement Service Internet Group.
- Selection/interview panels for other professional bodies and tertiary institutions:
  - » Queensland Self-management Alliance Executive Officer Position
  - » Griffith University School of Nursing and Midwifery Advisory Group
  - » Sexual Assault Service System Improvement Expert Advisory Group.
- Other health-related engagement activities:
  - » The Australian Patients for Patient Safety Workshop in Western Australia
  - » Health Quality and Complaints Commission Health Services Improvement Network Meetings
  - » National Strategic Framework for Rural and Remote Health Consultation Workshop
  - » Final consultation on the Draft Indicators of Effective Open Disclosure
  - » Clinical Education and Training Queensland Forums – Townsville and Brisbane
  - » Integrated Primary Healthcare Conference: Accessible and comprehensive community-based healthcare for all
  - » Australian Council on Healthcare Standards: Medication safety workshop
  - » Department of Health and Ageing: National women's health policy workshop
  - » QUT School of Medicine Consultative Committee
  - » The Power of Apology Symposium
  - » Multicultural Summit
  - » General Practice Workforce Summit
  - » General Practice Queensland Primary Healthcare Stakeholder Roundtable

- » Sunshine Coast Primary Healthcare Forum
- » Health Issues Centre: Participate in Health Conference – My Story Matters
- » The Queensland Compact Intersectional Forum
- » Lesbian, Gay, Bisexual and Transgender Health Stakeholder’s Workshop
- » Victim Support Services Research Project
- » Walk This Way: Recognising Third Sector Value Luncheon Launch
- » Australian Transgender Support Association of Queensland
- » Public Panel of Assessors: For Selection to a Professional Conduct Review Panel
- » Griffith University, School of Nursing and Midwifery Advisory Committee
- » Sexual Assault Service System Improvement
- » Queensland Maternal and Perinatal Quality Council
- » General Practice Advisory Council.

# Australian Charter of Healthcare Rights

Supported by Queensland Health

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

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

## Guiding principles

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

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

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

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



For further information please visit [www.safetyandquality.gov.au](http://www.safetyandquality.gov.au)

AUSTRALIAN COMMISSION ON  
SAFETY AND QUALITY IN HEALTHCARE



Queensland Government

## What can I expect from the Australian health system?

### My rights

### What this means

#### Access

I have a right to health care.

I can access services to address my healthcare needs.

#### Safety

I have a right to receive safe and high quality care.

I receive safe and high quality health services, provided with professional care, skill and competence.

#### Respect

I have a right to be shown respect, dignity and consideration.

The care provided shows respect to me and my culture, beliefs, values and personal characteristics.

#### Communication

I have a right to be informed about services, treatment, options and costs in a clear and open way.

I receive open, timely and appropriate communication about my health care in a way I can understand.

#### Participation

I have a right to be included in decisions and choices about my care.

I may join in making decisions and choices about my care and about health service planning.

#### Privacy

I have a right to privacy and confidentiality of my personal information.

My personal privacy is maintained and proper handling of my personal health and other information is assured.

#### Comment

I have a right to comment on my care and to have my concerns addressed.

I can comment on or complain about my care and have my concerns dealt with properly and promptly.



### Mission statement

Health Consumers Queensland (HCQ) supports the voices of Queensland consumers to achieve better health outcomes.

### Guiding principle

HCQ is committed to the consumer perspective in the development and delivery of health services.

### Aspirations

- To engage, to empower and to give a voice to consumers through individual and systems advocacy.
- To work collaboratively with government, Health Community Councils, the community, consumer organisations and other stakeholders to achieve this end.
- To provide relevant and timely advice to the Minister for Health reflecting the voice of consumers.

### Key priority areas

- Quality and safety
- Equitable access and targeted responses
- Participation and engagement

HCQ identifies **health consumers** as people who use, or are potential users, of health services including their family and carers. Consumers may participate as individuals, groups, organizations of consumers, consumer representatives or communities.

The Carers (Recognition) Amendment Act 2010 identifies a **carer** as an individual who provides, in a non-contractual and unpaid capacity, ongoing care or assistance to another person who, because of disability, frailty, chronic illness or pain, requires assistance with everyday tasks. Also, a grandparent can be a carer of his or her grandchild if the child lives with the grandparent; and the grandparent is the primary care-giver and decision-maker for the child. However, if a child's parent or parents remain the primary care-givers and decision-makers for the child, the child's grandparent is not the child's carer only because the grandparent cares for the child while the child's parent or parents are working or the child, together with the child's parent or parents, lives with the grandparent.

*...your voice in health*

## Health Consumers Queensland Annual Report 2009-10

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