



Background

The **Health Care Consumers' Association (HCCA) of the ACT** was formed over 30 years ago to provide a voice for consumers on local health issues and now provides opportunities for health care consumers in the ACT to participate in all levels of health service planning, policy development and decision making.

The HCCA involves consumers through:

- consumer representation
- consultations
- training in health rights and navigating the health system
- community forums
- information sessions about health services
- advocating for issues of concern to consumers

The HCCA is dedicated to the promotion of consumer-centred health care, which we believe can be successfully achieved through the application of five key principles, as endorsed by the International Association of Patient Organisations¹:

1. **Respect**
2. **Choice and empowerment**
3. **Consumer involvement in health policy**
4. **Access and support**
5. **Information**

It is with reference to these principles that the HCCA has developed its submission.

¹ IAPO, Declaration on Patient-Centred Healthcare. <http://www.patientsorganizations.org/pchreview>

The HCCA Submission on Enhancing Patient Experience through the Implementation of a Patient and Family Centred Care Model

The HCCA welcomes the opportunity to provide input to the consultation on 'Enhancing Patient Experience through the Implementation of a Patient and Family Centred Care Model'. Our members have had a long-standing interest in the concept of consumer centred care for more than a decade.

We support the establishment of the Patient and family Centred Care (PFCC) team and agree that it is appropriate for its role to be based within the Quality and Safety Unit. The quality and safety of services for consumers needs to be the focus of any family and patient centred care model. As a consumer organisation, HCCA is well placed to work with the ACT Health Directorate in further defining and developing the role of the PFCC team.

To date HCCA has had limited involvement in the development of the model to improve Consumer Centred Care within the Health Directorate and are looking forward to more constructive engagement.

The organisational context:

Consumer centred care is increasingly playing a role in the development of policies and procedures and in the culture of health services. We have been very impressed with the clear statements and demonstration of commitment to consumer centred care by the senior leaders within the Health Directorate. We note that the Health Directorate has entered into Agreements with the Commonwealth government that provide for an increased focus on consumer centred care². The Directorate's Corporate Plan 2010 – 2012 also includes references to progressing consumer centred care, and consumer experience is included in the list of the priorities and the seven key performance areas. Also we note that the ACT Quality and Safety Framework 2010–2015³ gives commitments to the ATC public health system being consumer-centred in addition to being driven by information and organised for safety.

This Framework refers to the key issues that were identified as needing to be progressed (from the 2004-2008 ACT Health Quality Action Plan) and we are very keen to see these appear on the work program of the PFCC Team.

The Framework identifies the need to improve the streamlining of referral and assessment procedures and while the Directorate has made some headway in this, we still think this is an area requiring more work and the PFCC team can contribute to making a difference in this area.

² ACT Health Corporate Plan 2010 – 2012 p. 3

<http://health.act.gov.au/c/health?a=dlpubpoldoc&document=2144> accessed 22 October 2012 at

³ ACT Quality and Safety Framework 2010 – 2015 accessed 20 October 2012 at

<http://www.health.act.gov.au/c/health?a=dlpubpoldoc&document=2202>

The Framework also makes reference to the need for research and evidence regarding consumer centred care and using this evidence to inform the development of health service policies and procedures, leading to improved focus in the consumer. We support more research into patient experience.

We understand that the Quality and Safety Framework is currently being reviewed in light of the governance changes in 2011. We look forward to providing comment on this.

Broader context

Principles of consumer centred care are increasingly reflected in a range of other documents, including the Australian Medical Council *Code of Good Medical Practice* and medical education curricula. The Royal Australian College of Physicians curricula for advanced trainees on professional qualities is consistent with the principles of consumer centred care, emphasising the need for good communication, clear and accurate information and building respectful relationships. The College of General Practice has also developed material on open communication. Nursing and allied health competencies are also being revised or developed to promote consumer centred care.

And, of course '*Partnering with Consumers*' is Standard 2 of the 10 NSQHSS. It is a particularly important Standard because it provides the framework for active partnership with consumers by health service organisations.

Defining the term

<p><i>Consumer Centred Care? Patient Centred Care? Patient and Family Centred Care? Person Centred Care? Relationship Centred Care?</i></p>

A clear, shared understanding of consumer centred care is likely to lead to huge improvements in service delivery areas, including more satisfied staff and higher staff retention rates, decreased costs, fewer medication errors and adverse events, and improved patient experience.

The HCCA proposes that the Health Directorate partner with consumer organisations and consumers to define consumer centred care. If consumers are not part of the process then we hold concerns that this will become more about compliance in terms of achievements against standards rather than a true redesign and making improvements. We want the emphasis to remain on the care rather than staffing and administrative issues relating to the model of service and service delivery.

In July last year we posted to the HCCA blog⁴ on the concept of consumer centred care. We included a summary of the key points from a range of sources defining consumer centred care.

- Providing care that is easy for patients to get when they need it. Making sure that healthcare staff respect and respond to patient choices, needs and values. Forming partnerships between patients, their family, carers and healthcare providers. ([ACSQHC](#))
- providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions ([The Kings Fund](#))
- consumer centred care is one aspect of health care quality, as important as care being safe, clinically effective, timely and equitable ([The Kings Fund](#))
- the essence of patient-centred healthcare is that the healthcare system is designed and delivered to address the healthcare needs and preferences of patients so that healthcare is appropriate and cost-effective (International Alliance of Patients' Organizations)
- the essential theme is the importance of delivering healthcare in a manner that works best for patients. In a patient-centered approach to health care, providers partner with patients and their family members to identify and satisfy the full range of patient needs and preferences. ([Planetree](#))
- The Seven Attributes of Patient-Centred Care: Superb access to care, patient engagement in care, clinical information systems that support high-quality care, practice-based learning, and quality improvement, care coordination, integrated and comprehensive team care, routine patient feedback to doctors, publicly available information ([The Commonwealth Fund](#))
- Five Principles of patient centred care: Respect, choice and empowerment, patient involvement in health policy, access and support, information. ([IAPO](#))

In 2007 the World Health Organisation⁵ released a paper on *People-centred health care. A policy framework* . This document states that:

People-centred health care is rooted in universally held values and principles which are enshrined in international law, such as human rights and dignity, non-discrimination, participation and empowerment, access and equity, and a partnership of equals. It aims to achieve better outcomes for individuals, families, communities, health practitioners, health care organizations and health systems by promoting the following:

⁴ <http://hcca-act.blogspot.com.au/2011/07/reflections-on-patient-centred-care.html>

⁵ WHO, Western Pacific Region. *People-centred health care. A policy framework*. Geneva: World Health Organisation, 2007, p. 7.

1. Culture of care and communication. Health care users being informed and involved in decision-making and having choices; providers showing respect for their privacy and dignity, and responding to their needs in a holistic manner.
2. Responsible, responsive and accountable services and institutions, providing affordable, accessible, safe, ethical, effective, evidence-based and holistic health care.
3. Supportive health care environments. Putting in place appropriate policies and interventions, positive care and work environments, strong primary care workforce, and mechanisms for stakeholders' involvement in health services planning, policy development and feedback for quality improvement

In the US, the Affordable Care Act has established the Patient-Centered Outcomes Research Institute (PCORI). This was created by US Congress through the 2010 Patient Protection and Affordable Care Act as an independent, non-profit research organization to help patients and those who care for them make informed health decisions. PCORI will commission research that is responsive to the values and interests of patients and will provide patients and their caregivers with reliable, evidence-based information for the health care choices they face. PCORI followed a consultative process to develop a definition of patient centred care in terms of research so that there is shared understanding. In February this year they released their definition of Patient-Centered Outcomes Research⁶. We have included the link in our references. One of the things that appeals to the HCCA is that they have framed it on terms of questions that are patient centred. We see that these questions are an improvement on the *Ask Me 3*⁷ questions that have also been in use in the US to improve patient centred care and health literacy. PCORI has four questions:

1. *"Given my personal characteristics, conditions and preferences, what should I expect will happen to me?"*
2. *"What are my options and what are the potential benefits and harms of those options?"*
3. *"What can I do to improve the outcomes that are most important to me?"*
4. *"How can clinicians and the care delivery systems they work in help me make the best decisions about my health and healthcare?"*

In 2010 the Kings Fund⁸ worked with social care organisations to build a shared understanding of how to deliver high-quality, patient-centred, cost-effective care. They

⁶ <http://www.pcori.org/assets/PCOR-Definition-Revised-Draft-and-Responses-to-Input.pdf>

⁷ National Patient Safety Foundation, Ask Me 3, <http://www.npsf.org/for-healthcare-professionals/programs/ask-me-3/>

⁸ How to deliver high-quality, patient-centred, cost-effective care: Consensus solutions from the voluntary sector <http://www.kingsfund.org.uk/sites/files/kf/how-to-deliver-high-quality-patient-centred-cost-effective-care-16-september-2010-kings-fund.pdf>

identified five key themes that the health and social care system must embrace to be sustainable and to ensure quality. These themes are also closely aligned to the discussions we have had with consumers about consumer centred care. The themes are:

- co-ordinated care
- patients engaged in decisions about their care
- supported self-management
- prevention, early diagnosis and intervention and
- emotional, psychological and practical support

We see the following are the building blocks of consumer centred care:

- health rights
- health literacy; and
- the social determinants of health. That is, identifying and considering the characteristics of the consumers and community they are there to serve, e.g., our social and economic situation, cultural background, preferences, practices, beliefs, needs and capacity.

We think there is value in defining the term consumer centered care collaboratively, with consumers, carers and Health Directorate staff.

The model:

To date the development of the model has been piecemeal. We are unsure of the evaluation process that is planned (or has been undertaken) to evaluate the effectiveness of work to date.

Improving consumer experience involves changing minds but this takes time, and by creating a structured approach, the Directorate should be able to monitor success. The HCCA has been very supportive of the efforts of the Health Directorate in moving towards consumer centred care, but has, been concerned that there has not been a structure and coordinated approach to this. That is not to say excellent work has not taken place, but that we think a structured approach will mean the changes are more sustainable. The development of the Patient Experience Leader role within the Quality and Safety Unit is a good move, as it firmly places patient experience and consumer issues in the context of quality and safety of services

The structures

We are unconvinced that the proposed structures are the appropriate ones. The document appears to have been written with a structure that does not necessarily reflect the need.

We would like to contribute to the discussion of mapping potential structures once the definition has been agreed.

There are already many committees on which consumers are involved and consumer feedback is received and consumers are interviewed and their patient journey recorded. We are unclear as to how the proposed structures will fit with the existing arrangements. We are also of the view that evaluation of the effectiveness of the work to date needs to be undertaken so that it can be used to inform future work.

Consumers and our family and friends see things that busy health-care workers often do not. It follows that safety will be improved if patients are included as full partners in reform initiatives, and learning can be used to inform systemic quality and safety improvements. Consumer stories are invaluable tools for motivating and contextualising the need to change services to deliver quality consumer-centred care.

Consumer representatives play a vital role in contributing to quality improvement processes and it is important that they are respected and valued in health committee work, otherwise the engagement is tokenistic. It is important to involve consumers who have had direct experience with the health service. Consumer representatives must be comfortable and briefed so they can speak up with confidence at health committees. Consumer peak organisations, such as the HCCA, play an important role in providing consumer support and training.

We strongly suggest that the model of PFCC be mapped against the Consumer and Carer Participation and the Quality and Safety Frameworks. We see that these, in addition to the Charter of Healthcare Rights, set the parameters. The qualities of patient centred care are encapsulated in the *Australian Charter of Health Care Rights*, which promotes respectful relationships and trust between consumers and people who work in health services. This Charter is the cornerstone of our responses and submissions to local and federal government on draft health policies; it is also the foundation on which we base our advice and information to consumers and community organisations about our health system.

A number of states in the US have enacted law that requires all hospitals to create and maintain Patient and Family Advisory Councils. These Councils are groups of current and former patients and family members who collaborate with hospital staff to improve the care experience. There appears to be some similarity with the groups in the model proposed by the Directorate. Consumer organisations (equivalent to the HCCA) have been involved in the development of these Councils and in developing the plans and reports. One particular example we have considered is in Massachusetts⁹. The review of their annual reports suggests that the purpose and effectiveness of the Councils is not yet clear and they are unsure the degree to which they have influence the quality improvement projects.

⁹ Patient Family Advisory Councils: A Review of 2011 Activity Reports 2012. Accessed on 18 October at <http://www.ipfcc.org/advance/topics/Review-of-PFAC-2011-Reports.pdf>

The bottom line is that there are lots of models and we need to work together to build one that is appropriate to our community and accommodates the strength of the existing arrangements and relationships.

The process

There are many ways to look at what patient centred care is and how to change the values, culture and practice in health services. At the core the HCCA is of the view that consumers and consumer organisations must be engaged in a partnership to develop this model. Changing health services to be built and delivered around the consumers will only occur when we, the consumers, are partners in the planning of services and active in our treatment.

To date the HCCA has had limited involvement in the development of the model to improve Consumer Centred Care within the Health Directorate and are looking forward to more constructive engagement.

There is no shortage of peer reviewed material relating to how to improve the systems within health care, and there is a growing volume of works relating to consumer experience and engagement. These need to be considered in developing the model.

SA Health has been working closely with our colleagues at Health Consumers' Alliance of South Australia on progressing their model of patient centred care. This has involved adaptation of the Planetree model. We are very excited about the potential to hold similar workshops in the ACT and welcome the opportunity to discuss this with the Patient Experience Leader.

Our colleagues in South Australia have undertaken similar work with very positive results. In October they convened a workshop between SA Health, consumers and representatives of consumer organisations which looked to

- Increase understanding of CCC using principles underlying the Planetree Model
- Develop an understanding of the business case of consumer centred care
- Determine ways in which stories of great care can be identified and promoted
- Explore how consumers can be involved in culture change and how HCCA can support consumer advocates and representatives

We propose that HCCA and ACTHD hold a joint workshop to explore how we can collaborate for consumer centred care and culture change in our health services and work together to build on this vision.

Within our membership there has been much discussion about the need for the Health Directorate staff to get to know our community and the people they serve, our social and cultural backgrounds. This could be seen as a measure of the Directorate's commitment to consumer centred care. For example, having Community Development Workers at the Community Health Centred and public hospitals could advance this.

Building an understanding of the community requires consumer and carer participation. We think that the Consumer and Carer Participation Framework needs to be considered more closely in the development of the model of Consumer Centred Care.

The Directorate has made a good start in moving towards consumer centred care and the HCCA has been very supportive of these efforts. We are excited about the opportunities to work in an inclusive and collaborative way with the Directorate to develop the model in a structured and coordinated way. We look forward working with you to develop the model

Darlene Cox
Executive Director
2 November 2012

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