

Submission to the Australian Commission on Safety and Quality in Health Care Draft National Patient Charter of Rights

March 2008

Introduction

*'A charter of rights and standards for health care consumers is what's needed to ensure that the entire system benefits by becoming more accountable to the citizens who pay for it and more responsive to the consumers who need to use it.'*¹

The Consumers Health Forum of Australia (CHF) is the national voice for health consumers. As an independent non-government organisation, CHF helps shape Australia's health system by representing and involving consumers in health policy and program development (see Appendix 1).

Safety and quality in health care is one of three priority areas for advocacy for CHF. The CHF Safety and Quality Project 2007-08: 'It's all about communication' is a specially funded project CHF is conducting with the Australian Commission for Safety and Quality in Health Care (the Safety and Quality Commission). It is part of the ongoing CHF vision to ensure consumers shape safety and quality in health care in Australia. The project aims to engage and involve health consumers across Australia in improving the safety and quality in health care services. For further information about the project please see the project page on the CHF website at <http://www.chf.org.au>.

The Safety and Quality Commission is developing a draft National Patient Charter of Rights (the Charter), including a statement of patient rights, and supporting principles document. CHF is working closely with the Safety and Quality Commission to involve consumers in the consultation. In this submission, CHF considers:

- Whether the Charter is what consumers want
- What the key opportunities and risks of a health rights charter are to consumers
- Whether the Principles help consumer to understand how the charter will work, and
- The role of consumers in developing and implementing the Charter.

This submission is based on ongoing consultation with CHF members and consumer representatives including CHF workshops on health rights in 2007 in MacKay, Perth and Broome, the 2007 CHF Safety and Quality Project Consumer Representatives Workshop, and responses to the CHF information paper *The role of health rights charters in improving safety and quality in healthcare*.²

What we mean by health rights

The United Nations Universal Declaration of Human Rights (1948)³ is the universal standard for the rights and freedoms of all people. It states that everyone is born equal in dignity and rights, and that they have the right to a standard of living adequate for their good health and well being. In 2006 the United Nations released a report about standards of physical and

¹ Kate Moore, A Health Consumers' Charter, Health Forum, August 1993.

² CHF Information paper: The role of health rights charters in improving safety and quality in healthcare http://www.chf.org.au/Docs/Downloads/463_Health_Rights_Charter.pdf

³ United Nations, Universal Declaration of Human Rights, Articles 1 and 25, 1948. <http://www.unhchr.ch/udhr/lang/eng.htm>

mental health. It stated that ‘The right to health can be understood as the right to an effective and integrated health system encompassing health care which is accessible to all.’⁴

The Constitution of the World Health Organisation also states that ‘The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being’.⁵

CHF and health rights charters

Over the past 20 years, CHF has done considerable work in the area of health rights, including the development or adoption of three different statements of consumer health rights. The CHF position on health rights has shifted over this time.

In 1989, CHF released a draft statement of consumer health rights and responsibilities.⁶ Its focus was on consumers’ rights to appropriate good quality health care, to determine what happens in their care, to information and privacy and to equitable access to services. The 1989 document also set out a number of consumers’ responsibilities around providing information and making decisions about their own care.

In 1993, CHF reviewed its statement of consumer health rights and released a revised *Charter of Consumer Health Rights*. This document reflected two key shifts in the position of CHF in regards to health rights. The section on consumer responsibilities was withdrawn from the Charter. After all, there are times when consumers are unable to provide all the information asked of them by a provider or make a decision not to do so. Consumers trust health professionals to give the best health care possible with the information available to them. The 1993 Charter also strongly emphasised that when a health service upholds consumer health rights the quality of the health care provided also improves. At this time it was considered essential that a health rights charter be used as an educational tool for both consumers and providers and that, ‘It must be used in a broader process of setting standards for health care’.⁷

By 1999, CHF had adopted the United Nations Guidelines for Consumer Protection in its *Eight Consumer Rights* fact sheet in the *Guidelines for Consumer Representatives*.⁸ These include the right to safety, the right to be informed, the right to choose and the right to be heard.

In 2007, at the CHF Safety and Quality Project Consumer Representatives Workshop, health rights and communication issues were considered the two highest priority safety and quality issues for consumers. A national health rights charter has the potential to become a valuable tool for helping consumers and health care providers ensure good quality care is achieved. However, there is also a risk that it would become a symbolic document of little value that duplicates existing health rights charters.

This history has helped some consumers understand why others had lost confidence in the value of health charters, and shifted the focus of this submission towards how effective implementation of a health rights charter might be achieved.

⁴ The United Nations Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, 2006.

http://www.who.int/hhr/Right_to_health-factsheet.pdf

⁵ Constitution of the World Health Organisation, 2006

http://www.who.int/governance/eb/who_constitution_en.pdf

⁶ Consumers Health Forum of Australia, Consumer Health Rights – A summary of your health rights and responsibilities, 1989.

⁷ Consumers Health Forum of Australia, Charter of Rights for Health Consumers, Health Forum No. 26, August 1993.

⁸ Consumers Health Forum of Australia, Charter of Health Consumer Rights, 1999.

http://www.chf.org.au/Docs/Downloads/Charter_of_Health_Rights.pdf

The current proposal

The draft Charter sets out eight key rights (see Appendix 2) for health care consumers and describes these rights in the context of what ‘patients’ are entitled to expect from the health system.

CHF does not support the use of the term ‘patient’ because it can be disempowering and its use is often limited to hospital and medical care. For example, one consumers’ response to the information paper was: *‘I do not like “patient”. It has the perception of “bed” and “hospital” and not as a patient of allied health, dentists etc’*.⁹ As the draft Charter is targeted at consumers of all health services, not just hospitals, CHF recommends that the term ‘patients’ is replaced with ‘consumers’ in the Charter.

CHF also received strong support from CHF members and consumer representatives that the Draft National Patients Charter of Rights is called a Health Rights Charter and recommends that this change is made.

The Safety and Quality Commission developed a Charter Principles guidance document (see Appendix 3) to explain in more detail the principles underpinning each of the rights and what they could mean in practice. Its purpose is to clarify some of the expectations that consumers, carers and providers may have about each of these rights and what they mean for all those involved.

CHF supports the Principles in their flexibility to provide guidance on a range of situations. CHF, however, is concerned that the lack of practical examples and specific information on how consumer health rights can be applied or protected in individual situations or health care settings may lead to further confusion for health consumers, carers and healthcare providers.

‘The charter is not specific on how health rights can be applied in individual cases. E.g. disabled people, elderly persons, migrants with limited speaking abilities’.
*‘Perhaps some practice examples to illustrate good workable applications of the principles’*⁹

As a result, CHF recommends that the Charter and guiding principles are supported by a series of information sheets that provide practical examples of how the health rights can be applied in a variety of situations. The information sheets could be similar to the information sheets and frequently asked questions developed by the Office of the Privacy Commissioner to support their National Privacy Principles.¹⁰

Opportunities and risks of the draft Charter

Involving consumers in their own health care

The draft Charter provides an opportunity to strengthen the role of consumers in their own health care. Clarifying the role of consumers in making decisions about their care, their rights to equitable access to services and their right to information about their care and treatment options should result in better health outcomes for consumers.

Currently, the draft Charter is quite individually focused and CHF maintains that it should include consumer groups involved in service improvement and consumers’ support networks and their carers.

⁹ Consumer response.

¹⁰ For further information see www.privacy.gov.au

Consumers are partners in decision making

*'The key opportunity is that it is a 'pivotal' opportunity for consumers and healthcare providers to work together on improving the system.'*¹¹

The draft Charter also has the potential for facilitating more collaborative relationships between consumers and health care providers by clarifying what consumers expect from their health care and what health care services are expected to provide. As health consumers expect that they will be active partners in their own health, CHF welcomes the supportive statements of strong consumer participation in the draft Charter.

The draft Charter Principles includes two statements of what the health care provider can expect from consumers. CHF does not support the inclusion of consumer obligations or responsibilities in health rights charters. Health rights should not be conditional or impose obligations on consumers. The Charter must also ensure that no-one's behaviour infringes on the rights of others, such as when one consumer's rights impinge on another consumers rights.

CHF notes that there is a risk that some health care providers will feel threatened by the draft Charter. This could create barriers to communication between consumers and health care providers. For example, one consumer response about the draft Charter was that: *'There is the risk that consumers will expect too much and healthcare providers will feel threatened and not cooperate'*.¹¹ As a result, CHF maintains that the Charter will only work if all stakeholders work together and support and take ownership of the Charter.

The consumer rights, as defined by the draft Charter, must be consistent with all pre-existing legislation and documents that protect the rights of health consumers in Australia. There is the risk that the draft Charter will simply duplicate the role of other rights documents without adding any additional value. It may also create expectations for consumers that a health service cannot deliver.

Accountability for safety and quality

CHF commends the development of the draft charter as the health rights, if maintained, have the potential to improve the safety and quality of health services through supporting active participation of consumers in their care and by clarifying expectations of health service providers.

There is an opportunity for this draft Charter to further reinforce standards of safety and quality in health care. It could link to the minimum safety standards being outlined in the Safety and Quality Commission Alternative Model for the Accreditation of Health Care Services.

The Safety and Quality Commission is also coordinating a number of other national health care reforms focusing on safety and quality processes such as open disclosure, patient handover and patient identification. These initiatives have implications for consumer health rights and must be consistent with and linked to the principles outlined in a draft Charter.

There is a risk that the Charter may become a token symbol of a health care provider's commitment to consumer health rights. If this is to be avoided, the implementation of the draft Charter must also include methods of measuring and reporting on whether consumer health rights are being maintained.

¹¹ Consumer response.

Education and awareness as part of further consultations

The draft Charter offers unique opportunities for improving levels of safety and quality in health care for consumers. For these opportunities to be maximised there needs to be a comprehensive professional development, education and awareness strategy for consumers and providers.

Currently none of the existing health rights charters in Australia have any legal standing and they vary in their focus and structure. Consumers need to know what their health rights are and what they can do if they are not supported and the information and education must also include information on how to take action if consumers' rights have been compromised.

Consumer and health service provider education should result in improvements in communication and understanding of health rights that lead to stronger partnerships between consumers and providers. All key stakeholders need to be involved in a comprehensive consultation process to develop a strategy that supports greater collaboration between consumers and providers. Changing the name to Health Rights Charter will underpin this collaboration.

Consumer involvement in the development of the draft Charter was limited. Consumers offer a unique perspective on health care and need to be at the forefront of these discussions, explaining the changes that are needed and having a central role in implementing outcomes. CHF strongly supports increasing the participation of consumers in the further development of the Charter, and its implementation.

*'No charter can be implemented without adequate education of both the providers and consumers. Such education programs are a wonderful opportunity to assist both groups to understand the needs and problems of the other and to develop new procedures, approaches, and perhaps most importantly, attitudes.'*¹²

Key issues for consumers

- Consumers need to know what their health rights are and what they can do if they are not supported.
- A health rights document should protect and not undermine consumer's rights.
- Consumers should be involved in the development of a health rights document.
- A health rights document needs the support of both consumers and providers if it is to be effective.
- The draft Charter must be consistent with all national and international human rights and consumer rights documents and must not undermine any consumer health rights that currently exist.
- The draft Charter must have a substantial role in improving safety and quality in health care though being directly linked to existing safety and quality initiatives.
- The implementation of the draft Charter must be accompanied by a comprehensive education strategy for both consumers and health care providers.
- Consumers must have a central and ongoing role in the development of the draft Charter and its implementation.

¹² Response to the CHF Information Paper: The role of health rights charters in improving safety and quality in healthcare.

Conclusion

*'The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being...Promoting and protecting health and respecting, protecting and fulfilling human rights are inextricably linked.'*¹³

As users of health care services, consumers have a strong interest in ensuring that the health system delivers the safest and highest quality health care possible. When the rights of consumers to participate and make choices about their own care are upheld, better health care, better health outcomes and a safer and higher quality health system should follow.

CHF believes that the development of a draft National Charter of Patient Rights may provide a pivotal opportunity for both consumers and health care providers to work together to improve the health system in Australia. CHF also believes that the Charter will provide consumers with the opportunity to be active partners in their own health, and this has the potential to improve health outcomes.

¹³ World Health Organisation, Linkages between health and human rights, Health and Human Rights Web page <http://www.who.int/hhr/en/>

Appendix 1 – Background



The Consumers Health Forum of Australia Inc (CHF) is the national voice for health consumers. As an independent non-government organisation, CHF helps shape Australia's health system by representing and involving consumers in health policy and program development.

Health consumers have a unique and important perspective on health as the users and beneficiaries of health care and, ultimately, those who pay for it. CHF takes consumers' views to government and policy makers, providing an important balance to the views of health care professionals, service providers and industry to achieve a health system that reflects the needs of all stakeholders.

CHF member organisations reach millions of Australian health consumers across a wide range of health interests and health system experiences. Health policy is developed through wide consultation with members, ensuring a broad, representative, health consumer perspective.

Current priorities include safety and quality in health care, safe and appropriate use of medicines and health care for people with chronic conditions. CHF also facilitates the appointment of consumer representatives on over 200 national health-related committees. CHF believes all consumers should receive affordable, safe, good quality health care at the time they need it. The best outcomes are achieved when consumers are involved in decisions about and management of their own health care. Consumers should receive health care information when they need it in a form they can understand, particularly about using medicines.

Established in 1987, CHF receives funding from the Australian Government Department of Health and Ageing and membership fees. It seeks external funding for priority projects. With its ability to access a variety of health consumer networks and extensive knowledge of consumer issues, CHF is a respected and influential contributor to the Australian health debate.

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Appendix 2 - Summary of the draft Charter

The eight health rights stated in the draft Charter are:

1. **Access:** I am entitled access to public health care.
2. **Respect:** I am entitled to respect, dignity and consideration.
3. **Safety:** I am entitled to safe and competent care.
4. **Communication:** I am entitled to clear communication throughout the period of care.
5. **Information:** I am entitled to be informed about services, treatment and care.
6. **Participation:** I am entitled to be included in making decisions and choices about care.
7. **Privacy:** I am entitled to confidentiality of my personal information.
8. **Redress:** I am entitled to comment about my care and have my concerns addressed.¹⁴

¹⁴ Australian Commission on Safety and Quality In Health Care, Draft National Patient Charter of Rights – Consultation Paper, 22 January, 2008.

<http://www.safetyandquality.org/internet/safety/publishing.nsf/Content/PriorityProgram-01>

Appendix 3 - Summary of the draft Charter Principles

Below is a summary of the draft Charter Principles.

1. **Access:** All patients are entitled to equitable access to appropriate and timely health care based on need and transparent decision making by the provider.
2. **Respect:** There must be mutual respect at all times between patients and health care providers. Patients are entitled to care that is sensitive to cultural and personal needs.
3. **Safety:** A patient is entitled to care that is professional and clinically appropriate, in an environment that is working to ensure patient safety.
4. **Communication:** A patient is entitled to communication that is open, detailed and understandable, including the use of an interpreter (where available). They are entitled to ask questions and to receive appropriate responses.
5. **Information:** A patient is entitled to information about their care, who is providing it, treatment options, risks involved, costs, follow-up care required and differences between being a public or private patient.

Patients are expected to provide detailed information about their health history, including any changes in their condition. They are also expected to follow plans agreed with the provider.

6. **Participation:** A patient and their carers are entitled to question and be involved in decisions about their treatment and care, to give fully informed consent prior to any procedure, seek a second opinion and withdraw consent or refuse treatment.
7. **Privacy:** A patient is entitled to expect that their personal information will remain confidential and will be collected, disclosed and stored in accordance with relevant privacy legislation.
8. **Redress:** A patient is entitled to have access to processes to comment and make complaints about the care they receive and to have their concerns dealt with properly and promptly.