

# **NATIONAL PATIENT CHARTER OF RIGHTS**

## **Consultation Report**

**June 2008**

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# 1. Introduction

The Australian Commission on Safety and Quality in Health Care (the Commission) was formed in 2006 to lead and coordinate improvements in safety and quality. For its work in 2007-2008, the Commission adopted a number of Priority Programs, one of which was to develop a National Patient Charter of Rights.

The aim of the program is to develop a National Patient Charter of Rights that sets out the key rights of people receiving care within the Australian health care system. The purpose of the Charter is to provide information about patients' rights to underpin the provision of safe and high quality care, and to support a shared understanding of the rights of people receiving care. The Charter has been developed to be applicable in all settings in which health care is delivered, including public hospitals, private hospitals, general practice and other ambulatory care environments.

This program was initiated because the Commission considers that a uniform statement of patient rights is a basic requirement for a safe and high quality health system. Patient charters of rights have existed in Australia for some time, however their impact on safety and quality has been limited. The Commission's role as a national leader in safety and quality will help to ensure that the National Patient Charter of Rights has a key role in driving safety and quality improvements and supporting the role of patients and consumers in this process.

The development of the Charter has involved the following steps:

- ▶ review of existing Australian and international charters and development of an initial working draft
- ▶ initial consultation with a multi-disciplinary Reference Group established for the program
- ▶ revision of the initial working draft charter based on feedback from the Reference Group
- ▶ preparation of a consultation paper that contained a draft National Patient Charter of Rights, and a set of National Patient Charter Principles that expanded on the rights
- ▶ wide consultation with stakeholders about the Charter
- ▶ review of consultation feedback and revised documents by the Reference Group, internal Commission committees and Commissioners.

The final draft of the Charter will be presented to Health Ministers for endorsement in July 2008.

This document is a report of the consultation process conducted as part of this program. The report contains summaries of the processes used for the consultation, the feedback received and the Commission's response to this feedback.

## 2. Consultation process

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The primary aim of the consultation was to obtain the views of consumers, community groups, health service providers, clinical professional bodies, governments and other organisations and individuals about the Charter.

To facilitate the consultation process a consultation paper was prepared that contained information about the purpose and rationale for the program, a draft National Patient Charter of Rights and set of National Patient Charter Principles, options for implementation of the Charter and a series of questions about which the Commission sought feedback.<sup>1</sup> The broad areas covered by these consultation questions included:

1. The existence, structure and presentation of the National Patient Charter of Rights and National Patient Charter Principles
2. The coverage of the rights included in the Charter
3. The details of the points included in the Principles
4. The balance between rights and responsibilities
5. The relationship between the Charter and other existing charters
6. Possible uses of the Charter
7. How the Charter might apply in different sectors and settings.

The main methods used for gaining input about the Charter were as follows:

- ▶ wide distribution of the consultation paper to over 500 organisations with an invitation to provide a written submission
- ▶ attendance at two workshops conducted by the Western Australian Health Consumers' Council and Consumers' Health Forum about health rights
- ▶ holding two round table workshops with consumers and health service providers about the Charter.

In addition, some face to face meetings with selected consumer and community organisations were held to discuss the Charter, and the issues concerning health rights that affected their members or constituents. As only a small number of these meetings were held, and the issues that arose in them were also reflected in the written submissions and workshops, they will not be discussed separately in this report.

### 2.1 Written submissions

The consultation paper was sent to 515 organisations and individuals with an invitation to provide a written submission. The distribution included:

- ▶ national consumer organisations
- ▶ State and Territory consumer peak bodies, where they exist

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<sup>1</sup> The consultation paper is available on the Commission's website ([www.safetyandquality.org](http://www.safetyandquality.org)).

- ▶ State and Territory governments
- ▶ State and Territory health services
- ▶ private hospital representative organisations
- ▶ national clinical industrial, professional and peak bodies
- ▶ State and Territory safety and quality councils
- ▶ State and Territory complaints commissioners
- ▶ medical indemnity organisations
- ▶ clinical standards setting and accreditation organisations
- ▶ university medical schools.

In addition, in some jurisdictions the consultation paper was sent to individual hospitals or consumer and community organisations where it was considered necessary to obtain appropriate feedback.

The consultation paper was also available on the Commission’s website, with information about the consultation process, and an invitation to make a submission. Some organisations also distributed the consultation paper within their own networks.

The Commission received 96 written submissions regarding the Charter. A list of organisations and individuals making submissions is included in the Appendix, and their submissions are available on the Commission’s website. Eight individuals and organisations did not want their submission to be made public. The details of these submissions are not included in the Appendix or on the Commission’s website, however their comments have been taken into account in this report. Table 1 provides a summary of the origin of the submissions received.

**Table 1: Written submissions received for National Patient Charter of Rights consultation by type of organisation**

Type of organisation	Number of written responses
Individuals not representing an organisation	11
Consumer or community organisation	22
Government department	13
Health service, hospital or community health facility	16
Professional or clinical peak body	24
Other	10

## 2.2 Workshops

Feedback from four workshops also contributed to the consultation.

Two workshops were organised by the Western Australia Health Consumers' Council and the Consumers' Health Forum and attended by Commission staff. These workshops were held on:

- ▶ Monday 11 February 2008, Perth
- ▶ Tuesday 12 February 2008, Broome.

These workshops were focussed on health rights broadly, but also included specific discussion of the Charter. Participants in both workshops were mainly consumer representatives and members of the local communities. In Broome some representatives from the local hospital and population health service also attended.

Two workshops were organised by the Commission and the Consumers' Health Forum. These workshops were held on:

- ▶ Wednesday 27 February, Sydney
- ▶ Friday 29 February, Melbourne.

These workshops were focussed specifically on the Charter, and included both consumer and health service provider representatives.

### 3. Consultation feedback

This section summarises the feedback received during the consultation. The written submissions and workshops provided a very rich source of information about the Charter, how it could be used, and issues associated with health rights generally.

The consultation feedback in this section is structured largely according to the seven key areas about which the Commission sought comment in the consultation paper. An additional section has been added in presenting this feedback that considers all of the comments about each of the rights in the same section. This is because many comments about the details of the rights and principles overlapped, and they are combined in this report to prevent repetition. The eight sections summarising the feedback from the consultation process are:

1. The National Patient Charter of Rights and National Patient Charter Principles
2. General comments about the nature of the rights included in the Charter
3. General comments about the Principles
4. Specific comments about each of the rights
5. The balance between rights and responsibilities
6. The relationship between the Charter and other existing charters
7. Possible uses of the Charter
8. How the Charter might apply in different sectors and settings

The discussion of each of these areas of consultation feedback includes the following components:

- ▶ summary of the relevant aspect of the Charter or Principles
- ▶ the key focus questions for the Commission (where applicable)
- ▶ summary of the feedback and comments obtained
- ▶ the proposed response to the consultation feedback, incorporating the suggestions from the program Reference Group.

Before describing the feedback from the consultation in detail there are three general points that need to be made.

Firstly, there was a wide range of views present in the feedback received about the Charter. This means that it is not possible to act on all of the comments and suggestions provided. The aim of the Charter and the role of the Commission in leading and coordinating safety and quality nationally were considered when determining how to deal with the consultation feedback.

Secondly, in some cases the comments provided were outside the scope of this program and potential current action by the Commission. Generally such comments have not been included in this report, but can be seen in the submissions on the Commission's website.

Finally, the views and comments summarised in this document come from both the written submissions received by the Commission, and the workshops that were held to discuss the Charter. In some cases the text notes whether the comments were from the workshops or the written submissions. However as a general point, throughout the text the term “respondent” is used to describe both the organisations and individuals who provided written submissions, and the workshops where comments were provided.

## 3.1 National Patient Charter of Rights and National Patient Charter Principles

### Introduction

Two documents were presented for comment, the National Patient Charter of Rights and National Patient Charter Principles. The Charter was a concise statement of patient rights that was targeted specifically at patients. The Principles contained more detail about these rights, and it was considered that it could be used by health services and providers as well as patients.

The specific points the Commission sought feedback on in the consultation paper were:

- ▶ Whether the existence of both the Charter and Principles is useful
- ▶ Suitability of the Charter and Principles for use by patients and providers
- ▶ Whether the language used in the Charter and the Principles is appropriate
- ▶ Preferred options (including structure, style and presentation) for articulating patient rights and entitlements for patients and providers.

### Major issues

Fifty four respondents commented on the nature or structure of the Charter and the Principles. There was strong support for the Commission's initiative to develop a National Patient Charter of Rights and the approach taken.

Two respondents were not supportive of the Commission's program to develop the Charter. One submission considered that without reform of the health system as a whole the Charter would not be effective or useful.

Thirty three respondents commented on the structure, presentation and format of the Charter and Principles. Most respondents considered that it was useful to have additional information such as that included in the Principles to support and explain the rights included in the Charter.

There were different views about the way the information in the Charter and the Principles should be structured. Twenty two respondents considered that having one short summary document and one separate, longer, explanatory document was more useful. One of the main reasons for this view was that the two documents had different purposes and could be used in different ways. Eleven respondents thought that having all information in one document was preferable, particularly as separating the rights and the principles may be confusing and repetitive.

*"Health Issues Centre believes that it is useful to have both documents/statements. Our experience working with both consumers and community members and health care service providers is that a broad statement of rights is made meaningful when it is more clearly defined in terms of direct practice service delivery implications."  
(Submission 38, Health Issues Centre)*

*“While the intention of the Commission is clear in delineating the Rights from the Principles in the consultation paper, it does look confusing and repetitive to the casual observer.” (Submission 46, Allied Health Professions Australia)*

Respondents also considered that the way the Charter was presented was important to assist both patients and providers to clearly understand their rights. Suggestions included use of illustrations, large print, small brochures, audio-visual material and internet sites.

The tone and level of the language used in the Charter was thought to be essential in supporting the use of the Charter among the general public. Thirty respondents mentioned the language used in the Charter and the Principles. Seventeen respondents considered that the language was appropriate for both providers and consumers, while 15 thought that the language used was too complex and needed to be simpler.

Another issue raised by 22 respondents was the use of the term “patient” in the Charter and the Principles. Comments suggested that the term “patient” had connotations related specifically to hospitals, and was not applicable to people seeking care in other environments, such as community-based primary health care or allied health. It was suggested that the term “consumer” or “client” could be used instead.

*“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 consumer’s 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’. 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.” (Consumers’ Health Forum, Submission 86)*

Linked to this point were 10 respondents who suggested that an alternative title for the Charter should be used so that it encompasses all health settings and providers. Suggestions included *National Health Consumer’s Charter of Rights*, *National Health Charter*, *Health Care Charter of Rights*.

Three respondents suggested that it would be useful to include definitions of some of the terms used in the Charter. This was considered to be important to prevent misinterpretation, particularly for terms that were critical or terms that were interchangeable and had different meanings in different contexts.

Five respondents made comments suggesting that the Charter could be used for purposes in addition to providing information about patient rights. Purposes that were suggested were most commonly associated with advocating for particular groups or the establishment of particular rights.

*“The Charter and the Principles be extended to identify ways through which trust can be created between service providers and the [culturally and linguistically diverse] communities to break the barriers that many [culturally and linguistically diverse] people have in acting on their right to redress.” (Federation of Ethnic Communities’ Council of Australia, Submission 40)*

## Response

Regarding the use of the term “patient”, “consumer” or “client”, it was considered that the phrase “patients and consumers” will be used in the Charter. While this may appear cumbersome, it is likely to be less alienating for the different parts of the health care sector than any one of the terms alone, and could be adapted to specific settings as required.

Following on from this point, with the focus of the Charter on both patients and consumers, the title of the document needs to change to reflect this broader focus. It has been retitled *Australian Charter of Healthcare Rights* for future versions of the document. However, to ensure consistency with the consultation paper, the title *National Patient Charter of Rights* will continue to be used in this report.

The two separate documents included in the consultation paper, the National Patient Charter of Rights and National Patient Charter Principles, were developed because they were considered to have different purposes. While there were some comments to the contrary in the consultation, the Commission considers that there are still advantages in this approach, and that information about patient rights should continue to be presented in two forms: as a short one page summary document, and a longer explanatory or background document.

Nonetheless, the issue of information in the Charter and Principles being overlapping and potentially confusing is valid and needs to be addressed. To do this a new document has been developed to support the Charter and replace the existing National Patient Charter Principles. This document is titled *Achieving Healthcare Rights* and is designed to be useful to patients, health care professionals and health services. The focus of this document is to provide a simple explanation of each right included in the Charter, and information about how patients, health care professionals and health service organisations can contribute to the realisation of patients’ rights. As well as reducing the existing duplication between the Charter and the Principles, this new document will address concerns about the need to include more information about patient responsibilities in the Charter and Principles (see Section 3.3 and 3.5).

In terms of presenting the Charter in various ways to meet the needs of specific audiences, the Commission is not likely to be in a position to undertake this work. However, the Charter will be made freely available for other organisations who may wish to adapt it in ways that best meet their needs (see Section 3.8 below and the draft Implementation Strategy).

The comments of some respondents suggested that the Charter should be more than a statement of the rights of patients, and possibly have an advocacy role. The Commission’s purpose in developing the Charter was as a tool to provide information about the rights of patients, and thereby promote safety and quality across the whole health system. It was considered that the Charter should not be an instrument for putting forward the interests of particular groups, or include information in it that is specific to the needs of particular groups. However the existence of the Charter as a nationally agreed statement of patient and consumer rights could be used by advocacy or other interest groups to promote issues reflected in the Charter.

Other actions that will be taken as a result of feedback from the consultation include:

- ▶ engaging an expert to review the Charter for plain English use
- ▶ obtaining advice about ways to maximise the visual impact and readability of the Charter
- ▶ exploring the need and feasibility of including a glossary into the Charter or any supporting documents.

## 3.2 Rights: General comments

### Introduction

The consultation paper presented a draft National Patient Charter of Rights for comment. The Charter was a short document that provided brief information about eight key patient rights: Access, Respect, Safety, Communication, Information, Participation, Privacy and Redress. The Charter was specifically targeted at patients and was framed in the context of the question: “What can I expect from the health system?”.

The specific points the Commission sought feedback on in the consultation paper were:

- ▶ Whether the rights included in the Charter are sufficient to cover the range of patient and human rights
- ▶ The extent to which the rights represent patient concerns when receiving health care.

### Main issues

This section includes general comments about the rights included in the Charter and whether they are adequate and appropriate. Specific comments about suggested changes or additions to each right are included in Section 3.4.

Of the 37 respondents who made general comments on the rights included in the Charter, 27 considered that the eight proposed rights sufficiently covered the spectrum of patient rights and broader human rights and also reflected the predominant expectations and concerns of patients seeking health care.

Two respondents considered that some of the rights could overlap and did not need to be included in the Charter. In particular, it was suggested that the Communication, Information and Participation rights could be collapsed, and that the Access right was not needed given that access to medical services was built into the Medicare legislation.

Eleven respondents suggested additional rights they considered should be included in the Charter (as distinct from changes to existing rights discussed in Section 3.4). The suggested additions included rights covering:

- ▶ good quality services
- ▶ access to medical records or other records created by a health service provider
- ▶ seeking amendments, additions or comments to medical records
- ▶ access to services without discrimination
- ▶ prompt service
- ▶ information in a format and language readily understood
- ▶ seeking a second opinion
- ▶ adequate pain relief

- ▶ efficiency of health services
- ▶ health services that are proven to be effective
- ▶ continuity of care
- ▶ compensation in the event of injury
- ▶ care that is culturally appropriate
- ▶ support from families and carers
- ▶ wellbeing and satisfaction of basic needs
- ▶ healthy environment
- ▶ an efficient, effective, safe and high quality health system.

Seven respondents considered that the eight rights were too general, vague, aspirational or difficult to measure. One of these considered that the rights needed to be strengthened in terms of substance and enforceability.

Six respondents raised concerns about the use of the phrase “I am entitled to...” in the Charter. They suggested that this term needed to be strengthened, and that the phrase “I have a right to...” more directly expressed the meaning of the Charter.

Four respondents made comments about the order of the rights in the Charter. One suggested that Respect should be the first right, while three others suggested Safety should be the first right.

An issue raised by three respondents was the nature and purpose of the rights included in the Charter. This included the view that there were differences between some of the rights. For example, the right to safe and competent care could be considered as a minimum standard in all health care organisations, whereas the right to access to services was affected by issues such as geographical location. It was also considered that some of the rights interlinked and contributed to the achievement of other rights.

*“The current set of the 8 rights is a combination of desired outcomes, such as Access and Safety, and tools to achieve such outcomes, such as Communication, Information and Participation. In other words, Safety can be achieved using clear communication, current information and facilitated participation. It might be useful, therefore, for the Commission reconsider if the purpose of the patient rights is about seeking specific outcomes (high level) or to provide patients and health care providers with the tools to do so (low level).” (Submission 30, Australian Psychological Society)*

## Response

Most respondents were supportive of the eight rights included in the Charter. Some suggestions were made about rights that could be added or omitted. Some of these suggestions were outside the scope of the Charter. The Commission did not consider that additional rights should be added to the

Charter; however, the right to Information has been dropped as it overlapped with the rights to Communication and Participation.

Regarding the nature of the rights included in the Charter, it is reasonable to note that the emphasis of some of the rights included in the Charter may be more towards the outcomes of care, and some towards the processes of care. However all are basic rights that all people should have when receiving health care services. The Charter is a statement summarising these rights, rather than making distinctions between different types of rights.

However the issue of the rights being realised in different ways is important, so that, for example, individual health care providers are not seen to be responsible for upholding the right to access to health services when they may have no control over what services are offered. Where relevant, information about this issue will be included in any documents supporting the Charter.

Other changes and actions undertaken as a result of the consultation include:

- ▶ using the phrase “I have a right to...” rather than “I am entitled to...” in the Charter
- ▶ changing the order of the rights so that Safety is first, and Access is last as it underpins all of the other rights.

## 3.3 Principles: General comments

### Introduction

The National Patient Charter Principles were developed to provide more detail about the meaning and application of the rights included in the Charter. The Principles included examples of the way in which specific rights could be manifested, as well as a small number of patient responsibilities. It was considered that the Principles could be used by health services and health care providers, as well as by patients.

The specific points the Commission sought feedback on in the consultation paper were:

- ▶ Whether the explanations included in the Principles assist in understanding the rights and responsibilities of patients and providers
- ▶ Whether there are additional points that should be included in the Principles to adequately explain the meaning and application of the rights.

### Main issues

This section includes general comments about the National Patient Charter Principles. A large number of specific comments about suggested changes to the Principles were made, and are discussed in Section 3.4.

Eighteen respondents considered that the Principles assisted in understanding the rights in the Charter. One submission thought that the Principles were too hospital specific, and another that each health setting may need to adapt the wording of the Principles to ensure they were applicable. Several submissions considered that more details were needed for the Principles to applications in particular health care settings.

Many submissions noted the need to include more detail on patient responsibilities in the Principles. These comments are discussed in more detail in Section 3.5.

Some of Principles are linked to existing legislation and law. Five submissions suggested that relevant legislation should be referenced in the Principles.

### Response

The response from the consultation indicated support for a document that provides additional information about the rights included in the Charter. However there were concerns about the Principles.

Based on the feedback received from the consultation, it appears that the Principles were at times interpreted as if they should be an exhaustive list of the ways in which the rights in the Charter could be manifested, and hence the suggestions for considerable details to be added. It was not the intention that the Principles would have this role, and it is misleading to consider that they comprehensively describe each right. In addition, the title, National Patient

Charter Principles, is ambiguous, and it is not clear how the document should be used.

Therefore, as noted in Section 3.1, a new document has been developed to replace the Principles and support the Charter, *Achieving Healthcare Rights*.

With the change in the focus of the new background document from the existing Principles, some of the comments regarding the Principles are not relevant, while others continue to apply.

Regarding the issue of the specificity of the Principles, we would intend that *Achieving Healthcare Rights* is intended to be applicable across all health care settings. It will be developed so that there is not too much emphasis on any particular health care setting. The Commission will not be adapting *Achieving Healthcare Rights* to specific contexts and environments (see Section 3.8). However the material in it could be adapted by others as required to best meet the needs of specific communities, health care settings or people with specific conditions and diseases.

## 3.4 Rights and Principles: Specific comments

### Introduction

The consultation paper presented the National Patient Charter of Rights and National Patient Charter Principles for comment. The eight rights included in the Charter and the Principles were:

- ▶ **Access:** Equity of access to public health care
- ▶ **Respect:** Respect, dignity and consideration
- ▶ **Safety:** Promoting safe and competent care
- ▶ **Communication:** Communicating clearly throughout the period of care
- ▶ **Information:** Being informed about services, treatment and care
- ▶ **Participation:** Informed decision making and informed choices
- ▶ **Privacy:** Ensuring personal information is secure
- ▶ **Redress:** Commenting on care and having concerns addressed.

Information about these rights was presented in brief in the Charter. The Principles contained additional points that expanded on the meaning of these rights.

A number of general questions were asked in the consultation paper about the utility of the Charter and the Principles and the coverage of these rights. In addition the written submissions and the participants in the workshops made a large number of comments with suggested changes to the rights and points included in the Principles. Because the comments about the Charter and the comments about the Principles largely overlapped, they have been combined together in this section.

### Main issues

General comments about the rights included in the Charter and the Principles are included in Sections 3.2 and 3.3. This section contains specific comments that were made about each of the rights, whether those comments were made in response to questions about the Charter, or questions about the Principles. A number of specific comments that apply to all of the rights are included at the end of the summary of the eight rights.

#### **Access**

Forty four respondents raised issues about the right to access. Seventeen comments were made specifically about the nature of this right in Australia, particularly in terms of:

- ▶ whether there is a right to access to health care generally, or whether the right is limited to public hospital services and access to Medicare benefits

- ▶ the need to include a reference to ability to pay for services that are not covered by Medicare
- ▶ the nature of the right in the context of services delivered by private hospitals
- ▶ the limitations of accessing services for people living in rural and remote areas
- ▶ that access should not be limited to clinical need or the ability to pay, but should also include issues such as religion, race, sexuality, culture, gender, language, or disability.

Other issues that were mentioned concerning the right of access included:

- ▶ that care should be able to be accessed in a timely way
- ▶ that it was important that patients are aware of their right to be treated in a public hospital as a public or private patient
- ▶ that it would be useful to state that patients may need to be transferred to a service better equipped to meet their needs
- ▶ the need to address discrimination under the right to access
- ▶ the need to include access to environmental and preventive health care.

Responsibilities of patients that were mentioned under the right to access included:

- ▶ that patients should keep appointments and notify the health care provider or facility if they are unable to attend
- ▶ that patients should be prepared to attend another facility for treatment if necessary.

### ***Respect***

Forty four respondents raised issues concerning the right to respect. Issues that were mentioned included:

- ▶ that the right to respect should include the right to emotional, psychological and social support throughout the encounter with the health system
- ▶ that the right to respect should include respect for a person's gender, culture, beliefs, values, sexuality, religion, psychological needs, personal privacy, diagnosis and socioeconomic background
- ▶ that the interpretation of the word "consideration" is unclear, and that "compassion" would be preferable
- ▶ that advance planning and advance care directives should be included under the right to respect
- ▶ that there should be a more explicit reference to Indigenous Australians and culturally diverse communities
- ▶ that the reference to palliative care be removed in terms of relief from suffering that is dignified, comforting and supportive, as this should be the case in all situations.

There were different views about the reference to the need for “mutual respect” in the Principles. Some respondents considered that this was inappropriate in a patient charter of rights, while others were supportive of including this requirement.

### **Safety**

Thirty three respondents raised issues concerning the right to safety. Issues that were mentioned included:

- ▶ the need to include a stronger reference to quality care within this right
- ▶ the emphasis should be on providing safe care, not only promoting it as is currently stated in the Charter
- ▶ that there should be a stronger emphasis on evidence based practice
- ▶ that there was a right to care provided by health professionals with appropriate qualifications, who are registered with the appropriate regulatory body, assessed as competent to provide care, and who undertake continuing professional development
- ▶ that obligations under the open disclosure standard should be included under this right
- ▶ that patients have a right to feel safe when they are accessing health services
- ▶ that the principle regarding “care that is informed and clinically appropriate” is unclear and that the two concepts should be separated
- ▶ a right to an environment that is safe and clean should be included
- ▶ that issues concerning the care of children should be addressed under the right to safety.

Responsibilities that were mentioned under this right included:

- ▶ to follow agreed instructions from health care professionals regarding treatment provided
- ▶ to participate in treatment in a safe manner
- ▶ to follow the policies and procedures of the health care facility where treatment is provided.

### **Communication**

Forty two respondents raised issues concerning communication. Fifteen comments were specifically about access to interpreters, including:

- ▶ that there should be access to a qualified health interpreter (and translator) in all circumstances where necessary, and throughout the period of care
- ▶ that it is important to outline what is meant by a “qualified” health interpreter
- ▶ that housekeeping staff do not meet the criterion of a qualified health interpreter
- ▶ that family members should not be used as interpreters.

Other issues that were raised regarding the right to communication included:

- ▶ the need for communication to be open, honest, appropriate, effective, timely and provided in a respectful manner
- ▶ the need for communication to be in a language and medium appropriate to the individual
- ▶ that a patient has a right to have a person of their choosing present to ensure clear communication
- ▶ that there is a right to full and frank disclosure as specified in the open disclosure standard
- ▶ that some patients may need support to ask questions and communicate fully with health care staff, for example people with limited literacy and language skills
- ▶ that communication is two-way process, and patients have a right and responsibility to give and receive clear communication with health professionals involved in their care.

The main responsibility mentioned under this right included the need to communicate and ask questions if anything is uncertain.

### ***Information***

Forty eight respondents raised issues concerning information. Some of these issues concerned the nature or type of information that patients have a right to receive. Information that it was thought to be important to provide included:

- ▶ details regarding open disclosure
- ▶ all treatment options including medications, risks, benefits, consequences and possible side effects
- ▶ how to make a complaint
- ▶ support for advocates
- ▶ health records during and after treatment, with opportunities to correct any discrepancies
- ▶ continuing health care arrangements in the community
- ▶ health promotion and appropriate prevention information
- ▶ evidence based information
- ▶ services, treatment and care options
- ▶ any additional costs associated with services and treatment
- ▶ health care arrangements when about to leave hospital, including referrals to support services
- ▶ information about relevant clinical trials
- ▶ copies of test results
- ▶ safety and quality information about health care providers.

Other comments concerned the way in which information should be provided. Points included:

- ▶ information should be provided in a timely manner
- ▶ information should be provided in a language and medium appropriate to the individual
- ▶ the right to information should include an entitlement to ask questions and be provided with comprehensible and comprehensive answers
- ▶ the need to recognise the capacity of the person receiving information, and that some patients may need support to understand the information provided
- ▶ where possible information provided should be supported by printed fact sheets

Responsibilities mentioned under this right included:

- ▶ providing complete and honest information about medical history and current treatment
- ▶ informing health care providers when conditions change
- ▶ providing information about private health insurance status.

### ***Participation***

Fifty one respondents raised issues about participation. Issues that were mentioned included:

- ▶ that patients should be equally involved in decision making
- ▶ the need to involve patients and consumers in decisions about health service policies and planning
- ▶ the right to a second opinion should be extended to the right to a “further” opinion
- ▶ participation of the patient in decision making should be done at the most appropriate point in their treatment and recovery where they can fully understand the implications
- ▶ high quality information needs to be provided to support patients to participate in their health care
- ▶ consent to participate in teaching and research activities needs to be given without duress
- ▶ additional resources may be needed to support participation by children, young people, people with a mental illness and marginalised groups
- ▶ health care professionals need to respect the right of patients to refuse treatment.

The main responsibility mentioned under this right was the need to accept the consequences of decisions not to proceed with treatment.

### ***Privacy***

Twenty one respondents raised issues about privacy. Issues that were mentioned included:

- ▶ that privacy and confidentiality were different concepts and were not interchangeable
- ▶ that further information was needed about the links between privacy, electronic health records and the sharing of information electronically
- ▶ that there should be a right for a patient to be informed of and make decisions about the use of the personal health information
- ▶ that more detail is needed about what people can expect regarding the privacy of their personal health information
- ▶ the need for balance between privacy and the need to share information between health care providers
- ▶ the role of carers and substitute decision makers should be acknowledged with regard to the privacy of information
- ▶ that good privacy involves issues such as the right to access, the requirement that information be accurate and kept up to date
- ▶ that this right needs to correspond with Commonwealth and jurisdictional privacy legislation.

The main responsibility mentioned under this right was to respect the privacy and confidentiality of others.

### ***Redress***

Thirty three written submissions raised issues about redress. One of the main issues that emerged was dissatisfaction regarding use of the term “redress”. Respondents considered that this term was confusing and was not commonly used in the health sector. Suggestions to replace this term included “feedback”, “be heard”, “have a say” and “complain”.

Other issues that were mentioned included:

- ▶ the need to include more information about actions that can be taken for individuals who believe their rights have been breached and the process of making a complaint
- ▶ the need to include the right to make a complaint without fear of retribution
- ▶ that there should be information about how health services address issues when consumers make a complaint
- ▶ that information should be included about the need to deal with complaints promptly, properly, transparently and with empathy
- ▶ the right to redress should be expanded to include the right to compensation
- ▶ there should be the right to a response about a complaint.

### ***Additional comments***

Some comments about the content of the rights that were applicable across a number of rights. These included:

- ▶ that there needs to be more emphasis on quality of care
- ▶ that there needs to be more emphasis on the role of carers

- ▶ that it is important to recognise that some aspects of the rights might have to be restricted in emergency situations
- ▶ need to recognise the capacity of individuals receiving care in terms of their ability to understand their rights
- ▶ subjective terms such as “appropriate”, “adequate”, “satisfactory” may have to be defined in the Charter

## Response

As is clear from the comments in this section, a large number of suggestions were made regarding the details of the rights included in the Charter and the Principles. Because the wide range of these comments and the development of *Achieving Healthcare Rights* to replace the Principles, a detailed response to each of these points has not been provided. All of the comments about specific changes to wording and suggestions for additional points were taken into account in revising the Charter. However given that the comments sometimes reflect different points of view, it is not possible to accept all of them. The Commission’s purpose to develop a Charter that provides information about the core rights of all people seeking health care in all settings was the guiding principle regarding what changes were made to the Charter.

Although a detailed response is not provided in this report, there was one issue raised consistently during the workshops and written submissions that is discussed here. This concerns the right to access health care services. Based on the feedback from the consultation it appears that there was some uncertainty in the Charter and the Principles about the nature and extent of this right.

There are a number of core international statements to which Australia is a signatory that include statements about the right to health, including the *Universal Declaration of Human Rights* and the *International Covenant on Economic, Social and Cultural Rights*.<sup>2 3</sup> The *International Covenant on Economic, Social and Cultural Rights* contains the most comprehensive statement regarding the right to health and states that parties to the Covenant recognise “*the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*” (Article 12.1). The application of this statement is wide ranging, but includes obligations regarding the right of access to, and equitable distribution of, health facilities, goods and services.<sup>4</sup>

In Australia, Medicare is the mechanism by which universal access to health care is provided. For those who are eligible, Medicare provides:<sup>5</sup>

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<sup>2</sup> United Nations, *Universal Declaration of Human Rights*, <http://www.un.org/Overview/rights.html>, accessed 31 March 2008.

<sup>3</sup> Office of the High Commissioner for Human Rights, *International Covenant on Economic, Social and Cultural Rights*, [http://www.unhchr.ch/html/menu3/b/a\\_cescr.htm](http://www.unhchr.ch/html/menu3/b/a_cescr.htm), accessed 31 March 2008.

<sup>4</sup> United Nations Economic and Social Council, *The right to the highest attainable standard of health*, [http://www.unhchr.ch/tbs/doc.nsf/\(symbol\)/E.C.12.2000.4.En?OpenDocument](http://www.unhchr.ch/tbs/doc.nsf/(symbol)/E.C.12.2000.4.En?OpenDocument), accessed 31 March 2008.

<sup>5</sup> People who reside in Australia (other than Norfolk Island) are eligible for Medicare if they hold Australian citizenship, have been issued with a permanent visa, hold New Zealand citizenship, or have applied for a permanent visa (with some additional conditions).

- ▶ free treatment as public patient in a public hospital
- ▶ universal access to the Medicare rebate for out of hospital services.<sup>6</sup>

This means that Medicare does not guarantee the right to access bulk-billed out of hospital services such as general practice; the right is to access the Medicare rebate.<sup>7</sup> This is reflected in what is known about access to health services in Australia, particularly in rural and remote areas, where there is a shortage of medical practitioners, limited public health services available and long waiting lists for services that exist. In addition, in both urban and rural areas access to some health care services is dependent on the ability to pay (examples include, among other things, private hospital services, private allied health services and some medications).

Despite these limitations to the way in which the right to access is realised, many of which were noted by respondents in the consultation process, there does exist in Australia a right to health care, and this is reflected in the Charter. However the restrictions that exist regarding this right also need to be noted so that individuals seeking care do not have expectations about their ability to access services that cannot be met. This is noted in *Achieving Healthcare Rights*.

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<sup>6</sup> Medicare Australia, <http://www.medicareaustralia.gov.au>, accessed 31 March 2008.

<sup>7</sup> Elliot, A. *Is Medicare universal?* Research Note no 37 2002-03, Parliament of Australia Parliamentary Library, 2003, <http://www.aph.gov.au/library/pubs/RN/2002-03/03rn37.htm>, accessed 17 March 2008.

## 3.5 Rights and responsibilities

### Introduction

The balance between patient and provider rights and responsibilities in the Charter and the Principles is important as it reflects the purpose of the documents and the way in which they can be used. The Charter was specifically designed to express the rights of patients, and includes only statements of patient rights. The focus of the Principles was to explain and support the Charter, and it mainly included statements of patient entitlements. However the Principles also included a small number of points that referred to the responsibilities of patients. Despite this predominant focus on patient rights, the introduction to both the Charter and the Principles included a statement regarding the need to recognise that there are different roles and responsibilities for both patients and providers in the health care system.

The specific points the Commission sought feedback on in the consultation paper were:

- ▶ Whether the balance between the roles, rights and responsibilities of patients and providers is appropriate in the Principles
- ▶ Whether the Charter could have more of an emphasis on patient responsibilities as well as rights
- ▶ Whether there are other rights, roles and responsibilities that impact on patients and providers that should be included in either the Charter or the Principles

### Major issues

From the 96 written submissions and four workshops, 58 respondents made some comments about the balance between rights and responsibilities in the Charter and the Principles.

Thirty seven respondents considered that there should be more emphasis in the Charter, and particularly the Principles, on patient responsibilities. Reasons given for this view were associated with issues such as the need for a partnership between providers and patients in the delivery of care, the importance of recognising the rights of providers and the inclusion of responsibilities as a way of encouraging patient participation in the health care process.

*“A Patient Charter of Rights must include patient responsibilities as well and these are notably absent in any detail. Patients (and their families, carers and other nominated support people, where appropriate) have responsibilities when accessing the health care system in order to ensure that they receive the best individual care and that we maintain a safe, fair, high quality health care system for everyone.” (Submission 60, Australian Medical Association)*

Fourteen respondents considered that patient responsibilities should not be included in a patient charter of rights. Generally these respondents were not of

the view that patients did not have responsibilities in their health care. Rather, they considered that these responsibilities should not be in a charter of rights, but in a separate document. Reasons for this view included that patients rights are fundamental, and exist without regard to the responsibility of the individual, and that inclusion of responsibilities would detract from the Charter's primary purpose.

*"Rights are not conditional or qualified on the basis of responsibilities, all the more so as substantial amounts of health care are provided to people when they are not capable of meeting responsibilities due to cognitive impairment, acute illness, special needs or other factors."*

*Submission 12, Health and Community Services Complaints  
Commissioner, South Australia)*

Only six respondents considered that the Charter and Principles had an appropriate balance between rights and responsibilities.

Other issues that were mentioned by respondents included the need for the Charter and the Principles to include a discussion of the rights and responsibilities of providers.

## Response

The majority of respondents who commented on this issue wanted more information about patient responsibilities included in the Charter. Rather than include details of specific patient responsibilities in the Charter or any supporting documents, a new document has been developed, *Achieving Healthcare Rights*. *Achieving Healthcare Rights* is targeted at patients, health care professionals and health service organisations. It is focused on the contributions that patients, health care professionals and health service organisations can make to the achievement of patient rights. The information about contributions that patients can make incorporates many of the suggestions about patient responsibilities made by respondents (see Figure 1).

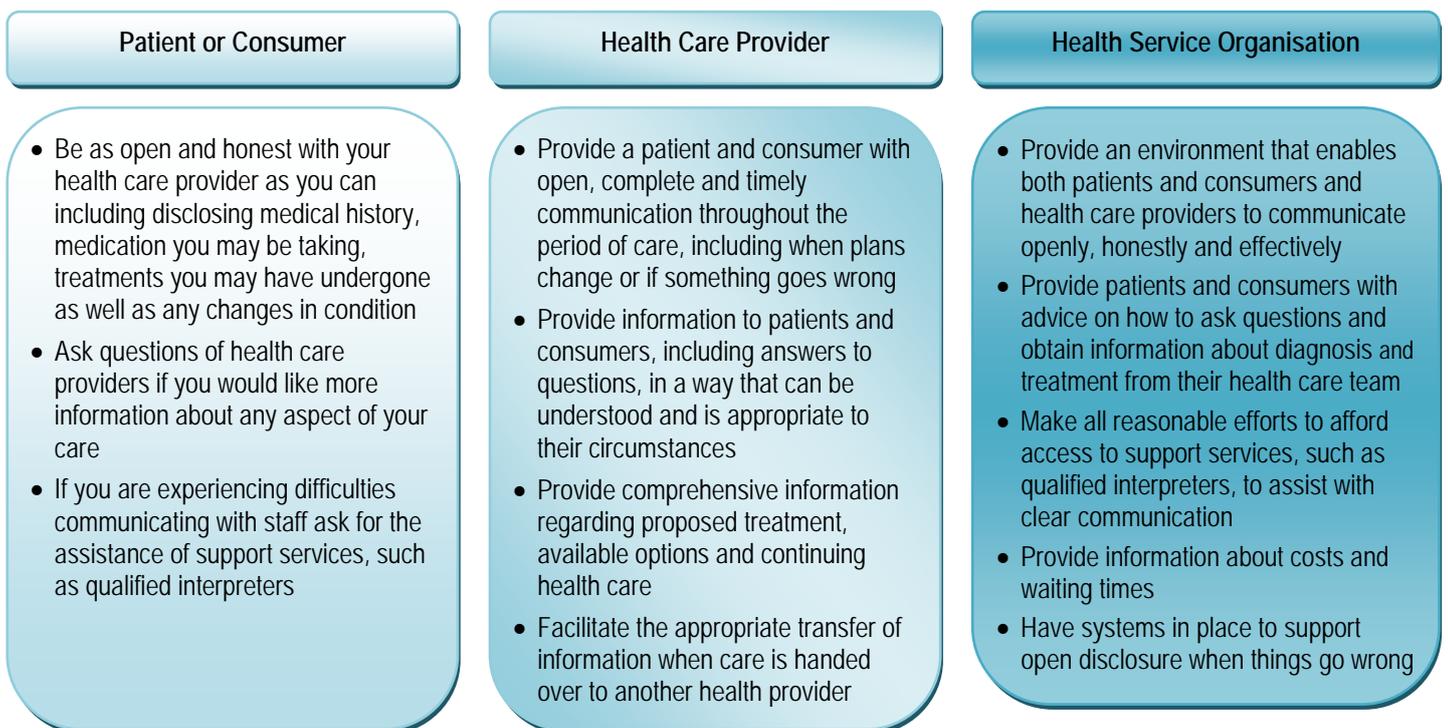
**Figure 1: Extract from *Achieving Healthcare Rights* illustrating how the document provides information about the contribution patients, consumers, health care providers and health service organisations can contribute to the achievements of the rights in the Charter**

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

The full and open exchange of information between patients, consumers and health care providers is necessary to obtain the best possible health outcomes. This can be facilitated by clear, timely and effective two-way communication, in a language and format that is understandable by the recipient.

Patients and consumers have a right to be fully informed about all aspects of their health care including what options are available, where the services would be provided and what are the costs of the service.

Some of the ways you can contribute to achieving effective communication and sharing of information are listed below.



## 3.6 Existing charters

### Introduction

As noted earlier, there are already a range of patient charters in Australia, most of which are applicable in specific contexts or environments. The content of some of these charters were used in the development of the National Patient Charter of Rights and National Patient Charter Principles. When the Charter is finalised it may be used to inform the other charters, exist along side them, or in some cases replace them.

The specific points the Commission sought feedback on in the consultation paper were:

- ▶ The relationship between existing charters, the new Charter and Principles
- ▶ The extent to which the National Charter and Principles creates gaps or overlap with other charters
- ▶ The potential value added by having a National Patient Charter of Rights
- ▶ How the Charter and Principles could be used to support existing charters.

### Main issues

The main issue that emerged in the feedback on this topic was the nature of the relationship between the National Patient Charter of Rights and existing charters, particularly the public patients' charters that States and Territories are required to develop under the Australian Health Care Agreements. While 24 respondents thought that the adoption of a single set of rights applying to all patients nationally was valuable, six also thought it was important that the relationship between the different charters be clearly articulated to avoid confusion and duplication.

Five respondents considered that the existence of a number of different charters within the one jurisdiction (such as the National Charter, public patients charters, health care complaints charter) could be confusing for patients, and not provide them with any added benefit.

*"...the Charter significantly overlaps with the Draft Code of Health Rights and Responsibilities (Qld), recently released by the Queensland Health Quality and Complaints Commission, and the Queensland Health Public Patients' Charter. This needs to be simplified for patients – a patient admitted to a Queensland hospital theoretically will receive three documents that all significantly overlap." (Submission 21, Gold Coast Health Community Council)*

There were two main themes of regarding the way in which the Charter could interact with existing codes and charters. Of the 29 respondents who commented specifically on this issue, eight suggested that that the Charter could replace existing jurisdictional, hospital or other charters. The other respondents considered that the Charter should be the principal national

document and act as the basis or minimum standard for other charters and codes. In some cases it was suggested that existing charters may need to be changed to be consistent with the Charter. Some jurisdictions and complaints commissions mentioned that they were already using the Charter to guide the review of their charters.

*“We would prefer to see a national charter that covers the core, basic rights that apply across all healthcare settings – allowing existing or new charters to adapt these rights and add other rights as applicable to individual settings.” (Submission 47, Sydney Adventist Hospital)*

*“There is no need for specific statements of rights for each locality as they are an expression of fundamental rights that apply across the population and not a reflection of locality. ... If there is a national statement of rights expressed in the Charter there will not be a need for specific hospital charters.” (Submission 11, National Health Call Centre Network)*

## Response

The Commission’s purpose in developing the National Patient Charter of Rights was to have a document that specified the key rights for everyone receiving health care services in Australia. Because of the potential for confusion and duplication with multiple charters at a national, jurisdictional and health service level, the Commission’s view is that the Charter becomes the single statement of healthcare rights for Australia replacing all other existing charters. This approach was strongly recommended by the Commission’s Inter Jurisdictional Committee, made up of representatives from each of the States and Territories.

Although the Commission believes that there should be only one statement of health rights in Australia, States, Territories and other health providers will be able to develop their own supplementary documents to support use of the Charter in practice. These may include guidelines for staff or explanatory information for patients and consumers. In addition, *Achieving Healthcare Rights* has been developed by the Commission to provide guidance about how all participants in the health care process can contribute to achieving the rights in the Charter. The Commission will make *Achieving Healthcare Rights* widely available.

## 3.7 Possible uses of the Charter and Principles

### Introduction

The way the National Patient Charter of Rights and the National Patient Charter Principles are used is equally as important as the content of these documents. A number of options were proposed in the consultation paper about how the Charter and the Principles could be used at national, jurisdictional and organisational levels.

The specific points the Commission sought feedback on included:

- ▶ The potential role for the Charter and Principles in standard setting, accreditation, education and training
- ▶ The potential for the Charter and Principles to be used to inform, develop or review public hospital charters
- ▶ The potential for the Charter and Principles to inform the review of private hospital charters
- ▶ The use of the Charter and Principles to support any requirements included in the next round of discussions about the Australian Health Care Agreements
- ▶ Other preferred options for implementing and enacting the Charter and Principles.

### Main issues

Forty six respondents made comments about the use of the Charter. All of the options mentioned in the consultation paper were supported by respondents.

Regarding education and training, it was thought that the Charter should be incorporated into both undergraduate and graduate education curricula and ongoing professional development training for health care providers. Education about specific areas of the Charter such as communication, cultural competency and informed consent was also thought to be important for health professionals. In addition, the importance of educating patients and consumers about the Charter and their rights was mentioned. One respondent also suggested that the Charter would be useful for educating members of parliament, advisers and government officers.

*“...we have undertaken a curriculum mapping exercise of the Social and Professional Responsibilities curriculum standard and the Charter to ensure that each of the eight rights and their associated principles are already incorporated in the Social and Professional Responsibilities curriculum. ... we undertake to include the Charter as a reference in our standard to ensure that trainees can incorporate the content of the document in its entirety into their professional practice.” (Submission 1, The Royal Australian and New Zealand College of Ophthalmologists.)*

Including the Charter in accreditation and quality standards and processes was strongly supported. It was thought that the accreditation process provided a useful mechanism to monitor the use of the Charter. Linked to this was the suggestion that the Charter should be used as the basis for performance reporting of health services.

*“...ACHS believes that there is a role for the Charter and Principles to both inform future reviews of the existing standards/criteria and as a means of facilitating analysis of national performance.” (Submission 35, Australian Council on Healthcare Standards)*

There was strong support for using the Charter to provide guidance for jurisdictional charters, those used in public and private hospitals, local health services and complaints commissions. It was thought that the Charter would provide a useful basis for standardising the variety of charters that exist nationally.

*“The potential value added by having a National Patient Charter of Rights would be the provision of a national standard upon which to review and amend pre-existing patients charters against. The existence of a National Patient Charter of Rights would also be beneficial as a reference in the creation and development of new patient charters.” (Submission 83, Office of Safety and Quality in Healthcare, Department of Health, Government of Western Australia)*

As well as including the Charter into the requirements for the Australian Health Care Agreements, some submissions thought that compliance with the charter should be linked directly to government funding.

*“The national charter should not be a voluntary code but rather a requirement for funding and covered under legislation. There also need to be consequences attached to non-compliance with the charter. (Submission 43, Children, Youth and Women’s Health Service, Government of South Australia)*

Other options that were suggested regarding the use of the Charter included:

- ▶ providing the Charter with a legislative basis
- ▶ conducting a public media campaign to raise awareness of the Charter
- ▶ use of the Charter by complaints commissions as the basis for receiving and resolving complaints
- ▶ using the Charter as the basis for more detailed guidelines, education packages or other documentation supporting the use of the Charter for both patients and providers
- ▶ inclusion of appropriate sections of the Charter into health practitioners’ codes of ethics or codes of practice
- ▶ making the Charter publicly available such as through websites like HealthInsite
- ▶ use for benchmarking and performance reporting
- ▶ evaluation, research and patient surveys

- ▶ use in credentialing of health care providers by institutions and employers.

Three respondents noted that there would be a cost associated with implementation of the Charter.

Two respondents mentioned the need to trial the Charter within different community groups, patient groups and settings before it is implemented.

## Response

The responses received in the consultation supported the options already identified by the Commission in the consultation paper, and provided a number of other suggestions about how the Charter should be used. Many of these suggestions have been incorporated into the draft Implementation Strategy.

The draft Implementation Strategy discusses the options for implementation in more detail. The role and capacity of the Commission is limited, and accordingly it is not able to act on all of the suggestions or options for implementing the Charter. Therefore, the draft Implementation Strategy has two sections: the ways in which the Commission can implement the Charter; and the ways in which other organisations can implement the Charter. The options discussed in the draft Implementation Strategy include:

- ▶ Options for implementation by the Commission:
  - ▶ publish and disseminate the Charter
  - ▶ promote the Charter through the general and health media
  - ▶ translate the Charter into key community languages
  - ▶ use the Charter to guide Commission work
- ▶ Options for implementation by other organisations:
  - ▶ use the Charter to inform patients of their rights
  - ▶ adapt the Charter to specific contexts
  - ▶ link the Charter to existing or new accreditation processes
  - ▶ incorporate the Charter into education and training curricula
  - ▶ make reference to the Charter in the Australian Health Care Agreements
  - ▶ make reference to the Charter in health professional codes
  - ▶ use the Charter to review complaints
  - ▶ consider the Charter in policy and planning.

One of the issues raised in the consultation process was the need for the Charter to be regulated by legislation. Some respondents expressed concern that without legislative force the Charter would be ineffective.

This option of making the Charter a legislative instrument was not included in the draft Implementation Strategy as it was considered that policy, rather than legal, mechanisms would provide a more effective basis for implementation of the Charter. The reasons for this approach are associated with the purpose of the Charter and the role of the Commission.

The overall purpose of the Charter is to provide information about patients rights in order to support safe and high quality care. The rights included in the Charter are not new. The Charter is a vehicle for summarising already existing rights in a coordinated way, rather than an expression of new rights that need some form of legitimation.

Also, the Commission is not a regulatory body with enforcement powers: various courts, tribunals and administrative bodies already have enforcement power over the rights set out in the Charter. For example, responsibility for acting on complaints about health services and health service providers rests with health care complaints commissions. Using the Charter to inform the work of complaints commissions, rather than having separate legislation associated with the Charter, would also ensure that the Charter was integrated into existing mechanisms. The Commission has information from one jurisdiction that it will be using the Charter as a framework for its code of rights and responsibilities that will be used in the monitoring and reviewing complaints.

Furthermore, the Commission considers that linking the Charter to accreditation processes that focus on implementation at an organisational and systems level will provide a more appropriate, sustainable and successful enforcement approach than embodying it in legislation. A recent review of the introduction of open disclosure in countries including the United States, Australia and the United Kingdom suggests that this type of approach may be more a more promising method of regulating disclosure of errors than legislation.<sup>8</sup>

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<sup>8</sup> Gallagher TA, Studdert D, Levinson W. Disclosing harmful medical errors to patients, *New England Journal of Medicine* 2007, 356: 2713-2719.

## 3.8 How the Charter applies in different sectors and settings

### Introduction

The Charter and Principles have been developed as broad documents that apply to all patients receiving care regardless of where the patient may be, the reason for seeking care or the type of health service involved. The Charter was not designed to be applicable to the needs of specific communities, health care settings or people with specific conditions or diseases.

The specific points the Commission sought feedback on included:

- ▶ Whether more detail is needed to make the Charter and Principles applicable in practice
- ▶ Whether the Charter and Principles will be able to be adapted to meeting the needs of specific health care settings or patient or community groups.

### Main issues

Twenty one respondents made comments about this issue, and there was strong support for the Charter as a broad-based document applicable to all communities and individuals. Twenty respondents thought that the Charter was sufficiently flexible to allow it to be adapted as required, although one respondent thought that it may be difficult to adapt the Charter to different health care settings such as psychiatric units.

*“The level of detail provided in the Charter and accompanying Principles achieves its aim of being relevant across all health care settings. There is an opportunity for specific health care settings or patient groups to develop tailored examples relevant to their context based on the guiding patient rights and principles set out in the national Charter.” (Submission 25, National Breast and Ovarian Cancer Centre)*

Contexts for which it was suggested that the Charter may need to be adapted included:

- ▶ local health services
- ▶ specific health care settings, such as private pharmacies
- ▶ community services and child protection services
- ▶ the private sector
- ▶ Indigenous health care settings
- ▶ rural and remote communities
- ▶ culturally and linguistically diverse communities
- ▶ correctional facilities
- ▶ refugee detention centres

- ▶ children and young people
- ▶ individuals with impaired decision making capability such as those with mental illness, intellectual disability, acquired brain injury or dementia
- ▶ individuals with rare diseases.

The involvement of people from these particular contexts was thought to be particularly important in ensuring that the any specific details added to the Charter were appropriate.

One strategy that was suggested for making the Charter applicable more widely was to make it available in other languages.

## Response

It was considered that the Charter should be targeted at the whole population and the health sector as a whole, and not contain specific information that is only relevant in certain environments or for certain groups of people. The nature of the Charter is that it provides information about health rights that are applicable widely. The details of how these rights are realised can then be modified according to particular contexts.

Because of the specialised knowledge and expertise required to adapt the Charter for different contexts, and the resources required to do so, the Commission is not likely to be in a position to undertake the task of adapting the Charter for the range of specific groups or circumstances in which it could be used. However the Commission will allow organisations to freely adapt the Charter as required for their specific needs.

In terms of meeting the needs of specific language groups within the community, the Charter will be translated into a number of major community languages.

## 4. Summary

As part of its program to develop a national patient charter of rights the Commission undertook a consultation process in January and February 2008. Four workshops were held during the consultation, and 96 written submissions were received about the Charter. This report contains a summary of the feedback from the consultation, and the responses to the consultation.

These actions and changes are listed below.

1. The term “patient” in the Charter and associated documents is replaced with “patient or consumer”.
2. The title of the Charter is changed from *National Patient Charter of Rights to Australian Charter of Healthcare Rights*.
3. Information about the rights of patients and consumers is provided in two linked documents: a brief one page summary of rights targeted at patients and consumers, and a longer background or explanatory document targeted at patients, consumers, health care providers and health service organisations.
4. The longer explanatory document is titled *Achieving Healthcare Rights* and contains information about how patients and consumers, health care professionals and health service organisations can all contribute to the realisation of patient rights.
5. The language and look of the Charter is reviewed by an expert in terms of readability and visual appeal.
6. The need and feasibility of including a glossary in the longer background document is explored.
7. The Commission does not adapt the Charter to meet the needs of specific audiences.
8. The Charter is not presented by the Commission as a tool to promote the needs of specific groups.
9. The number of rights included in the Charter is kept small.
10. The number of rights in the Charter is reduced by dropping Information.
11. The phrase “I am entitled to...” is replaced with “I have a right to...”.
12. The order of the rights in the Charter is changed, with Safety becoming the first right.
13. Inclusion of specific suggestions regarding wording of the rights in the Charter is guided by the Commission’s purpose in developing the Charter and the role of the Commission.
14. The suggestion of including more information about patient responsibilities in the Charter and Principles is addressed by developing a new supporting document titled *Achieving Healthcare Rights* that includes information about

the contribution that patients and consumers, health care professionals and health service organisations can make to realising the rights in the Charter.

15. Recommend that the Charter becomes the single patient charter in Australia, replacing other patient charters.
16. Options for implementation of the Charter by the Commission include:  
publishing and dissemination, promotion through general and health media.  
translation into key community languages, as a guide for Commission work,  
as the basis for reviewing other Charters.
17. Options for implementation of the Charter by other organisations include:  
informing patients of their rights, adapting to specific contexts, linking to  
existing or new accreditation processes, incorporating into education and  
training curricula, linking to the Australian Health care Agreements, being  
referred to in health professional codes, as a basis for reviewing complaints,  
to be considered in policy and planning.
18. The Charter is flexible enough to be modified for the needs of specific  
groups.
19. The Charter is translated into a number of community languages.

## Appendix

The following written submissions were provided in the consultation.

1. The Royal Australian and New Zealand College of Ophthalmologists
2. Medical Indemnity Industry Association of Australia
3. Cochrane Consumers Network
4. Country Health, South Australia
5. Department of Human Services, Victoria
6. Rural Doctors Association of Australia
7. Office of the Dean, School of Medicine, The University of Notre Dame
8. Darebin Community Health
9. The Royal Australasian College of Medical Administrators
10. President, ACT Branch, Heart Support Australia,
11. National Health Call Centre Network Ltd
12. Health and Community Services Complaints Commissioner, South Australia
13. Medical Consumers Association Inc
14. Dr Madeline Turnbull
15. Australian Podiatry Council
16. Victorian Mental Illness Awareness Council
17. Australian General Practice Limited / Quality in Practice Pty Ltd
18. Individual, not for publication
19. Individual, not for publication
20. Peter MacCallum Cancer Centre
21. Gold Coast Health Community Council
22. Dr Julie Synman
23. Peak Consumer and Community Advisory Group, Children, Youth and Women's Health Service, Women's & Children's Hospital Campus
24. Australian and New Zealand College of Anaesthetists
25. National Breast and Ovarian Cancer Centre
26. Mercy Health and Aged Care
27. Australian Physiotherapy Association
28. Deafness Forum of Australia
29. Organisation, not for publication

30. Australian Psychological Society, Victoria
31. Hopewell Centre, Hopewell Hospice Services
32. La Trobe Community Health Service
33. NSW Consumer Advisory Group - Mental Health Inc
34. Princess Alexandra Hospital Health Service District
35. Australian Council on Healthcare Standards
36. Council of Social Service of New South Wales
37. Pharmaceutical Society of Australia
38. Health Issues Centre
39. Australian Institute of Radiography
40. Federation of Ethnic Communities' Councils of Australia
41. Australian Dental Association
42. Health Community Councils within the Southside Health Service District
43. Children, Youth and Women's Health Service, South Australia
44. Private Mental Health Consumer Carer Network
45. OT Australia, Australian Association of Occupational Therapists
46. Allied Health Professions Australia
47. Sydney Adventist Hospital
48. Public Interest Advocacy Centre
49. Department of Health and Ageing
50. Australian Healthcare and Hospitals Association, Canberra
51. Individual, not for publication
52. Australian Injecting and Illicit Drug Users League
53. Alzheimer's Australia
54. Ms Beatrice Pullar
55. Palliative Care Australia
56. Ms Robyn Rourke
57. The Royal Australian and New Zealand College of Radiologists
58. CHOICE
59. The Victorian Quality Council
60. Australian Medical Association
61. Queensland Health
62. The Royal College of Physicians
63. Bayside Health
64. Australian Private Hospitals Association

65. Southern Health
66. Carers Australia
67. Faculty of Health Sciences and Medicine, Bond University
68. Ms Ann Revell
69. The Pharmacy Guild of Australia
70. Little Company of Mary Health Care
71. South Eastern Sydney Illawarra Area Health Service
72. Sydney South West Area Health Service
73. Australian Greek Welfare Society
74. Health Rights and Community Action Inc
75. NSW Health
76. Royal College of Nursing Australia
77. Breast Cancer Network Australia
78. Australian College of Rural and Remote Medicine
79. Office of the Public Advocate
80. Office of the Privacy Commissioner
81. Australian Nursing and Midwifery Council
82. Australian Nursing Federation
83. Office of Safety and Quality, WA Department of Health
84. Individual, not for publication
85. South Australia Department of Health
86. Consumers Health Forum of Australia
87. ACT Health
88. Department of Health and Human Services Tasmania
89. NSW Commission for Children and Young People
90. The Royal Australian College of General Practitioners
91. Individual, not for publication
92. Individual, not for publication
93. Royal Australian College of Surgeons
94. Alice Springs Hospital Management Board
95. Hunter New England Area Health Service
96. Greater Southern Area Health Service