

**AUSTRALIAN COMMISSION  
ON SAFETY AND QUALITY IN HEALTH CARE**

August 2018

# **Review of the Australian Charter of Healthcare Rights**

**Consultation Report (Phase 1)**

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## Acknowledgements

The Australian Commission on Safety and Quality in Health Care (the Commission) would like to formally thank all those who spent their time and effort writing submissions to the review of the Australian Charter of Healthcare Rights (the Charter). A special thank you to the Aboriginal and Torres Strait Islander consumers from the Torres and Cape Hospital and Health Service Queensland who welcomed Commission staff to discuss the review of the Charter and its application in their communities. The volume of information provided was substantial, and the Commission is optimistic that this unique resource can be drawn upon in the future.

All submissions received were considered by the Commission and have contributed to the development of the second edition of the Charter.

# Introduction

The Australian Charter of Healthcare Rights (the Charter) describes the rights of consumers accessing healthcare, and is intended to provide consumers, their families, carers, and health service organisations with a shared understanding of healthcare rights.

The Charter applies to all healthcare settings, including public and private hospitals, general practice, dental services and other community settings. Since its release in 2008, the Charter has been consistently one of the Commission's most frequently downloaded resources however; there is limited information available on how well it is used, and how it might be improved.

Implementation of the Charter is embedded in both the first and second edition of the National Safety and Quality and Health Service Standards (NSQHS Standards), and supported by several targeted guides for consumers, clinicians and health service organisations. There are also translated, Braille and audio versions of the Charter available.

The review of the Charter is being undertaken in two phases.

- **Phase One:**  
Reviewing the content of the current Charter, specifically its understandability, acceptability, utility and appropriateness for the current Australian context, and developing a draft second edition of the Charter.
- **Phase Two:**  
Consulting on the draft second edition of the Charter and finalising the changes, and exploring how the health sector is implementing the Charter. This includes identifying opportunities for the Commission to support improved implementation and developing resources where appropriate.

This consultation report describes the findings of a consultation process for Phase One of the review of the Charter. The information gathered as part of this process is being used to inform modification of the content of the Charter.

## The consultation process

This consultation report includes analysis of the collated feedback from two sources:

- A focus group held with Aboriginal and Torres Strait Islander consumers and consumer representatives in Weipa, Queensland
- An online survey open to the public

### Focus group with Aboriginal and Torres Strait Islander consumers

Eight consumers and consumer representatives, from the Torres and Cape Health and Hospital Service Consumer Advisory Committee, participated in a focus group held by the Commission in Weipa, Queensland. The members were from different communities and regions across Torres Strait and Cape York, with a diverse range of experiences and backgrounds.

Prior to the focus group, the participants were provided with a copy of the Charter and the guide for patients, consumers, families and carers, and were asked to reflect on a series of questions about the Charter.

At the focus group meeting the group were asked whether the rights in the Charter were clear and useful, if there was information that was not relevant, gaps in the rights as expressed, and whether there was anything additional that could be provided to ensure the Charter was meaningful for Aboriginal and Torres Strait Islander people from their communities.

The comments from the participants of the focus group are included in the key findings section of this report.

### Online survey open to the public

The Commission also sought feedback on the Charter from the general public via an online survey released in May 2018. The survey was open for five weeks and distributed to a wide range of stakeholders inviting them to participate in the online survey. Some respondents made submissions via email. Stakeholders invited to participate included:

- Consumers and consumer organisations
- Clinicians and health service organisations' workforce
- Primary health networks
- Complaints commissioners
- Australian, state and territory health departments
- Registration boards and specialist medical colleges
- Condition specific groups
- Other organisations that use the Charter including community and primary care services.

### Content of the survey

The online survey asked respondents 22 qualitative questions. In addition, some demographic data was collected about the survey respondent's location and their role or organisation type for example were they a consumer, carer, health service staff, practice manager. The online survey intended to support our understanding of:

- Health sector awareness and understanding of the Charter and its content
- The types of organisations and people working with the Charter
- How the Charter is being implemented in the health sector
- Whether the information in the Charter continues to be meaningful and relevant or whether it requires updating to address any gaps
- How the Commission can target resources to continue supporting its implementation.

## Process for analysing survey submissions

Standard analysis techniques for analysing qualitative (narrative) information were used for both the survey data and the submissions received via email.

A small team undertook the first stage of analysis, exporting the data to excel then the coding of data into themes. Coding was then aided by the use of NVivo, a software programme which allows the user to categorise and group textual information for later interpretation. The phases of analysis undertaken are given in [Table 1](#).

**Table 1: Phases of qualitative data analysis**

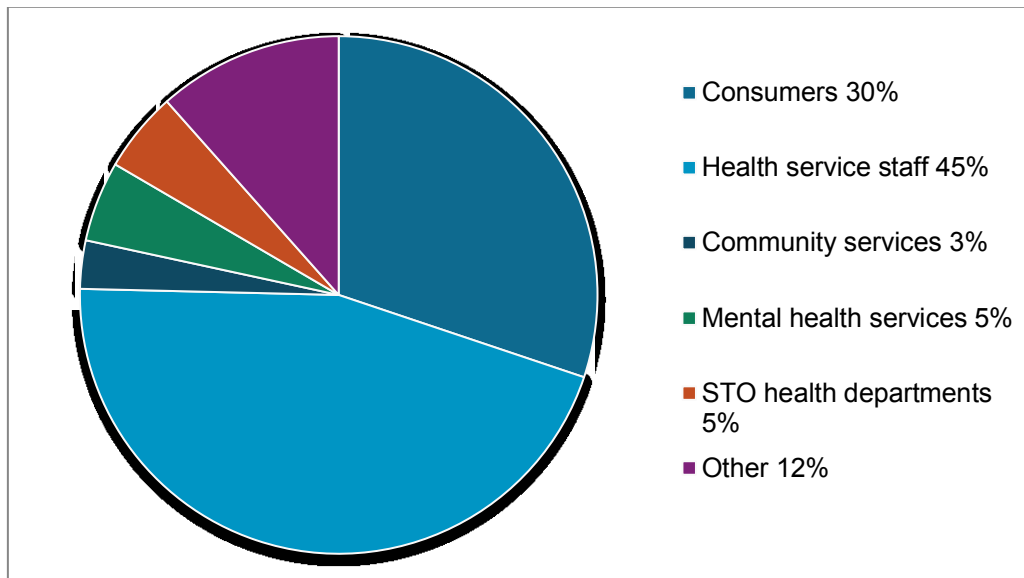
Phase	Task
<b>1. Preparation</b>	Collection of survey responses via online survey Export of survey data to Excel Development of initial codes or themes based on principle outputs to be reported on Export of data into NVivo
<b>2. Coding</b>	Coders begin coding in Nvivo Descriptive coding of responses applying and modifying coding scheme as appropriate
<b>3. Thematic analysis</b>	Interpreting patterns or themes in the coded content Sub-coding continues within each group of responses until saturation point is reached (no new themes are emerging).
<b>4. Write up</b>	Write-up of thematic findings guided by principle outputs to be reported on.

## About the respondents

There were 908 submissions received by the Commission to the public consultation process. Of those 904 submissions were received via the online survey and four submissions were received via email.

The majority of submissions were provided by staff working in health services (45%) followed by consumers, carers and consumer representatives (30%). [Figure 1](#) provides the proportion of respondents by category.

**Figure 1: Demographics of respondents**



A smaller proportion of submissions were received by staff from community services, state and territory health departments, mental health services, and other sectors such as aged care, primary health networks, medical colleges and universities. [Table 2](#) includes numbers of respondents by type of respondent.



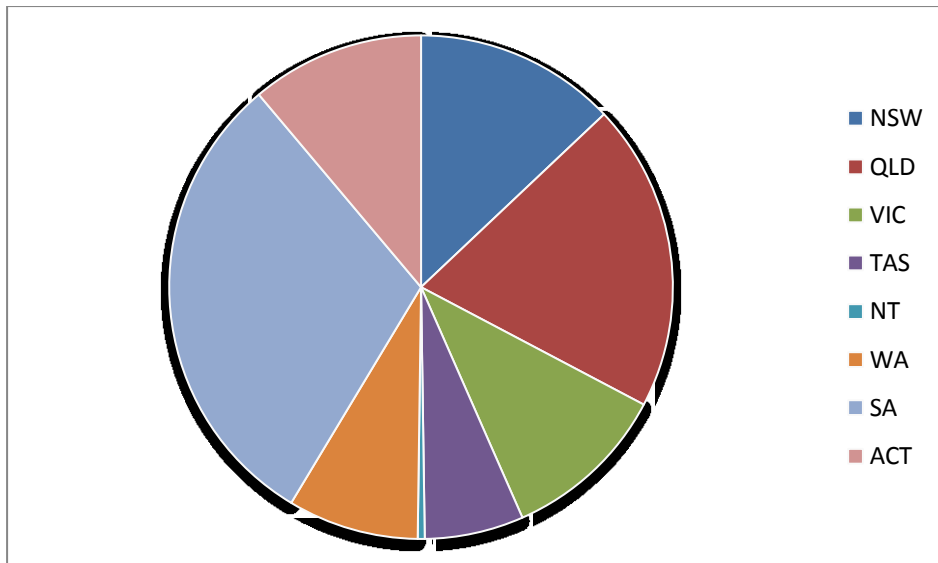
**Table 2: Numbers of online responses, by type of respondent**

Type	Number
Consumer	126
Consumer representative/advocate	112
Carer	31
Hospital employee - clinician, nurse, doctor, specialist, allied health, administration	323
Health service manager	51
Day procedure service	8
Private allied health practice	8
Pharmacy	9
General Practitioners and primary care staff	8
Aboriginal Medical Service	6
State and Territory Health Departments	32
Complaints Commissioner and complaints management	9
Community services	27
Migrant and refugee services	3
Mental Health services	43
Disability services	4
other	104
<b>Total</b>	<b>904</b>

Demographic data on location was requested, but was not compulsory to complete. Of the 440 people who indicated their location most submissions were from South Australia (30%), followed by Queensland (20%), New South Wales (13%), ACT (11%), Victoria (11%), WA

(8%), Tasmania (6%) and NT (1%). [Figure 2](#) shows the proportion of respondents who completed this item by state.

**Figure 2: Location of respondent, by state (%)**



## Key findings of the consultation process

It is important to note that not all questions in the survey were compulsory to answer. Respondents were able to choose which questions they wanted to skip and those they wanted to provide feedback on. Therefore the data reported in this section only reflects the views of respondents that chose to answer the question.

### Awareness of the Charter

#### **64% of respondents had used and/or read the Charter**

Most of these respondents had seen the Charter in a hospital and hospital waiting room (45%), followed by GP practices (16%) and day procedure services (10%).

The two most commonly identified uses of the Charter were to help communicate information to consumers about healthcare rights; and to understand the kind of care the respondent should receive and how they should be treated.

### Usefulness and clarity of the content

#### **93% of survey respondents found the information in the Charter useful**

The analysis of the free-text survey responses identified several themes about the usefulness of the Charter. There were positive comments about how the Charter helps make the role of the consumer, their rights when interacting with the healthcare systems, and what they can expect from the healthcare system explicit.

This was supported by some respondents reporting that having a clear understanding of their rights made them feel more empowered and confident about engaging with the healthcare system, and speaking up or raising a concern.

#### **7% of respondents reported that the Charter is not useful.**

The main reasons reported by these respondents was with a lack of prior awareness of the Charter, including lack of promotion within their health service and staff awareness and engagement with the Charter. It was also noted that there was no legal requirement to implement the Charter.

#### **86% thought the rights were clearly explained**

The majority of respondents indicated that they thought the rights were clearly written and easy to understand. However, others thought that the rights would benefit from translation into plain language, as well as simple infographics and messages to support understanding.

For example, some respondents indicated that there is not necessarily a shared understanding about some of the terms within the Charter, such as 'access', 'safe and high quality care' and 'personal characteristics'. In addition, several new terms were suggested for inclusion such as 'listen', 'compassion', 'dignity' and 'choice'.

There were also calls for the content of the Charter resources to be redeveloped using health literacy design principles, including increasing use of graphics and imagery, providing alternate models of resources, and using culturally appropriate and inclusive messaging.

Participants from the focus group suggested that for their communities and health services some of the terms within the Charter were easily misinterpreted. For example, the term charter in the Torres Strait usually referred to a transport service. In addition, they commented that the introductory contextual information for the Charter was framed in an

overly bureaucratic way that had little meaning for their communities. Participants suggested a range of ways of writing the information so that the intent was more easily and simply described, and therefore could be more useful for their communities.

### Suggested changes to the rights

**99% of the respondents thought that none of the existing rights should be removed.**

There was significant agreement with the relevance, applicability and meaningfulness of the rights described in the current Charter. Both survey respondents and participants in the focus groups thought that the rights described in the Charter are all important. However, a range of comments were provided about changes that could be made to improve the existing rights in the Charter.

### Suggestions for enhancing existing rights

There were a range of comments and suggestions for enhancing the existing seven rights to overtly include a number of areas. These are identified in [Table 3](#).

**Table 3: Suggestions for enhancing existing rights**

Existing right	Suggested expansion to include:
<b>Access</b>	<ul style="list-style-type: none"> <li>• Timeliness, prioritisation, waiting periods</li> <li>• The impact of location on access (differences in access between people in metropolitan and rural/remote areas)</li> <li>• Cost, affordability of private services</li> <li>• Equity of access to services for all people</li> <li>• Quality, appropriate care</li> </ul>
<b>Safety</b>	<ul style="list-style-type: none"> <li>• Personal safety, staff safety</li> <li>• Quality of information, evidence-based information</li> <li>• Culturally safe care</li> <li>• Clinically safe care</li> <li>• Well-being, psychological safety</li> </ul>
<b>Respect</b>	<ul style="list-style-type: none"> <li>• Inclusion of responsibilities, mutual respect, respect for staff</li> <li>• Respect for culture, cultural safety</li> <li>• Individualised care, respect for decision-making/choices</li> <li>• Open disclosure</li> </ul>
<b>Communication</b>	<ul style="list-style-type: none"> <li>• Individualised, person-centred communication and care</li> <li>• Informed consent</li> <li>• Information about costs</li> <li>• Health literacy principles</li> </ul>

	<ul style="list-style-type: none"> <li>• Access to quality, evidence-based information</li> <li>• Carer/family involvement in decision-making and/or information sharing</li> <li>• Access to written translations, interpreters and communication aids</li> <li>• Open disclosure</li> </ul>
<b>Participation</b>	<ul style="list-style-type: none"> <li>• Decision-making, choice/control</li> <li>• Carer/family involvement in decision-making and information sharing</li> <li>• Informed consent</li> <li>• Individualised care, person-centred care</li> </ul>
<b>Privacy</b>	<ul style="list-style-type: none"> <li>• Health information – access by consumers, privacy, security, information sharing</li> <li>• Environmental privacy e.g. gender specific wards</li> <li>• Privacy legislation</li> </ul>
<b>Comment</b>	<ul style="list-style-type: none"> <li>• Complaints, making a complaint without fear of retribution, being advised when things goes wrong (open disclosure)</li> <li>• Declining treatment</li> <li>• Culturally appropriate care</li> <li>• Inclusion of responsibilities, including respect for staff</li> <li>• Staff being aware of rights, providing respectful practice</li> </ul>

### Suggestions for issues for new rights

In addition to the suggestions to modify and enhance the existing seven rights, there were a range of specific issues suggested as potential new rights. Some of the suggestions related to rights:

- of dying patients including access to end-of-life care, euthanasia and Advance Care Directives
- to medication access including access to essential medicines, complementary medicines and/or alternative therapies
- to coordinated care including coordination of care between different systems (such as healthcare system, the National Disability Insurance Scheme, aged care system)
- to a second opinion, or referral to an alternative service
- to care planning and communication about care planning, including written discharge plans
- to access new and emerging treatments and medicines including participation in clinical trials, genetic testing and telehealth.

## **Other comments about rights**

There were also comments received in the survey that talked about being more explicit about the rights of healthcare workers in the healthcare system, which may reflect the greater participation of healthcare staff than consumers in the survey.

Some respondents also referred to the legislative framework for the Charter in the context of governance, accountability and responsibility for implementing and upholding the Charter within health service organisations. There also were calls for greater reference and links to be made to the international framework for human rights.

## **Tailored resources**

Some respondents to the survey requested the Commission either develop a range of different tailored Charter resources, or collaborate with other organisations to support the adaptation of Charter resources for a specific groups or populations.

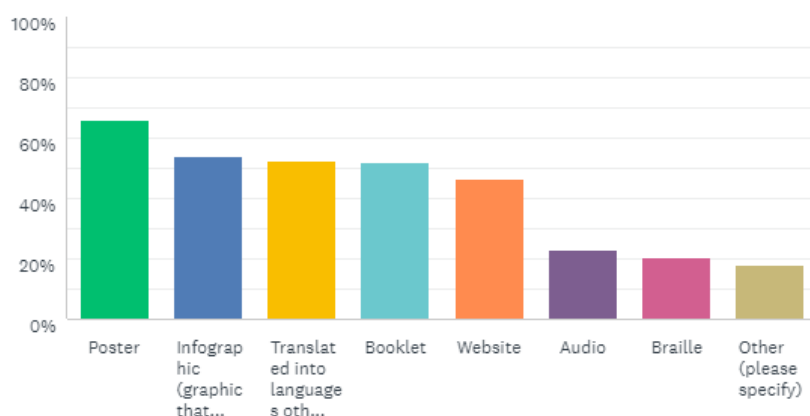
Some of those specific groups identified include for Aboriginal and Torres Strait Islander communities; carers and other support people; consumer and community volunteers or representatives; substitute decision makers; people from culturally and linguistically diverse backgrounds; people with disabilities; people with hearing loss; consumers with a lived mental health experience; people living in residential aged care facilities; pregnant women and new parents; children and young people; people who are lesbian, gay, bisexual, transgender, intersex, questioning or asexual; people with dementia and other cognitive impairment; and people in correctional facilities.

## **Improvements to the format**

Diversity of format and presentation, and the capacity to adapt information to meet local needs was a key theme of discussion with the focus group participants. The group were interested in being able to adapt the language and look of the second edition of the Charter to develop local versions that had a look and feel that was meaningful to community members. Participants requested multimedia resources including simple posters, infographics, audio materials such as talking posters, and short videos for use in waiting rooms.

From the survey, most respondents were interested in the Commission developing a poster (66%) and in an infographic (54%). Respondents also indicated that translated versions of the Charter were important (52%), as well as having a booklet version available (52%) and information available on a website (47%). [Figure 3](#) provides a graph of the preferred information formats.

**Figure 3: Preference for format of information about the Charter\***



*\*Respondents could choose multiple options.*

## Conclusion

The majority of respondents in this initial consultation believed that the rights described in the Charter are all important, relevant and needed. Respondents have provided a range of suggestions for building on the existing rights, as well as some suggestions for areas where additional rights could be included. Respondents have also provided advice on the need to reframe the rights, using more accessible and easy to understand language when communicating the rights and the underlying intent.

The Commission has taken this feedback and is developing a draft of a second edition of the Charter, incorporating many of the suggestions.

## Next steps

This report and the draft second edition of the Charter will be provided to the Commission's Partnering with Consumers Committee for discussion; following which a revised version will be provided to the Commission's standing committees for comment.

The Commission will then undertake a broad public consultation process on the draft second edition of the Charter, in parallel to further consultation and exploration of type of resources that are needed to support improved implementation of the Charter.

This second phase of the project will involve convening a small number of workshops in different states and territories, as well as conducting a range of interviews with consumers, clinicians, managers, policy makers and complaints commissioners on their views on how to better support implementation of the Charter.

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