AUSTRALIAN COMMISSION
ON SAFETY AND QUALITY IN HEALTH CARE

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Review of the Australian Charter of Healthcare Rights

Consultation Report (Phase 2)

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The Commission would like to thank the consumer organisations, health departments and health services who assisted the Commission to organise the workshops. These organisations are:

- Health Consumers Council Western Australia
- Health Consumers Alliance South Australia
- Health Consumers New South Wales
- Health Consumers Queensland
- People with Disabilities Western Australia
- Torres and Cape Hospital and Health Service Queensland
- Perth Children's Hospital, Western Australia
- Port Lincoln Health Service, South Australia
- Liverpool Hospital, New South Wales
- South Australia Health
- Department of Health, Western Australia.

A special thank you to all of the consumers, advocates, health service staff and policy makers who gave their time to participate in workshops and surveys, providing valuable feedback on the draft Charter and its use.

Introduction

The Australian Charter of Healthcare Rights (the Charter) describes the rights of consumers accessing health care, 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 was limited information available on how effectively 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 (NSQHS) Standards, and is supported by several targeted guides for consumers, clinicians and health service organisations. Translated, Braille and audio versions of the Charter were also developed to support the first edition of the Charter.

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

- **Phase 1** (completed) - reviewing the content of the Charter focusing on its understandability, acceptability, utility and appropriateness for the Australian context, and modifying the Charter content where appropriate

- **Phase 2** (current phase) - consultation on the content and design of the draft second edition of the Charter and identifying opportunities for the Commission to develop resources to support improved implementation.

During Phase 1 of the project, public consultation via an online survey was undertaken between May and July 2018. Submissions were received from 908 individuals including consumers, clinicians, managers, academics and policy makers. In addition, a focus group with Aboriginal and Torres Strait Islander consumers was held in Weipa, Queensland.

A consultation report on the key findings was published which identified key issues for inclusion in the draft second edition of the Charter. The report can be found at: https://www.safetyandquality.gov.au/wp-content/uploads/2019/02/Consultation-Report-Phase-1-Review-of-the-Australian-Charter-of-Healthcare-Rights-August-2018.pdf

Based on this consultation process and feedback from the states and territories, Complaints Commissioners and expert committees, the second edition of the Charter was drafted.

This report provides information from Phase 1 of the project on the kinds of resources and strategies that could be used to improve the awareness and implementation of the Charter, as well as information from Phase 2 of the consultation process.

The consultation process

This consultation report analyses feedback received from:

- Seven workshops were held across Australia in Western Australia, South Australia and New South Wales. Workshops were attended by consumers, managers, policy makers and health service staff
- An online survey on the draft second edition of the Charter which was open to the public between in February and March 2019 (the 2019 survey)
- Phase 1 online survey responses on suggested resources and strategies for implementation (the 2018 survey).

Workshops with consumers and health service staff

Four workshops were facilitated by Commission staff with consumers and consumer advocates across three states. The workshop participants were recruited by state-based consumer organisations on behalf of the Commission. The workshops were organised by:

- Health Consumers Council WA
- Health Consumers Alliance SA
- Health Consumers NSW.

Health Consumers Council WA organised an additional workshop on behalf of the Commission with a group of consumers from People with Disabilities WA.

Three workshops were facilitated by Commission staff with health service staff and health policy makers across three states. These workshops were held at the following locations:

- Perth Children's Hospital (WA)
- Port Lincoln Health Service (SA)
- Liverpool Hospital (NSW).

The health service staff who attended the workshops were primarily from public health services from a range of specialities, backgrounds and with varying levels of experience with implementing the Charter.

Prior to the workshops, the participants were provided with a copy of the draft second edition of the Charter (**Appendix 1**), the Phase 1 Consultation Report and were asked to complete a pre-workshop survey about the Charter.

At the workshops, participants were provided with information about the review of the Charter and were asked to comment on the content, language and design in the second edition. Participants were also asked to provide feedback on what types of resources would help them to use the Charter. Feedback provided at the workshops is detailed in the key findings section of this report.

Online survey – February - March 2019

The Commission undertook public consultation on the draft second edition of the Charter via an online survey during February and March 2019. The survey was open for four weeks and was distributed to a wide range of stakeholders. Additionally, some respondents provided written submissions to the survey via email. Stakeholders invited to participate in the survey included:

- Consumers and consumer organisations
- Health service staff

- Health departments (Commonwealth and state and territory)
- Primary health networks
- Complaints Commissioners
- 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 survey asked respondents four questions about the second edition of the Charter:

- Are the rights clearly explained? If not, please explain which rights should be improved
- Is the language easy to understand? If not, please explain how the language could be improved
- Do you have any comments on the design of the Charter?
- Do you have any other comments on the Charter?

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 undertaken using Excel. The phases of analysis undertaken are provided in Table 1.

Table 1: Phases of qualitative data analysis

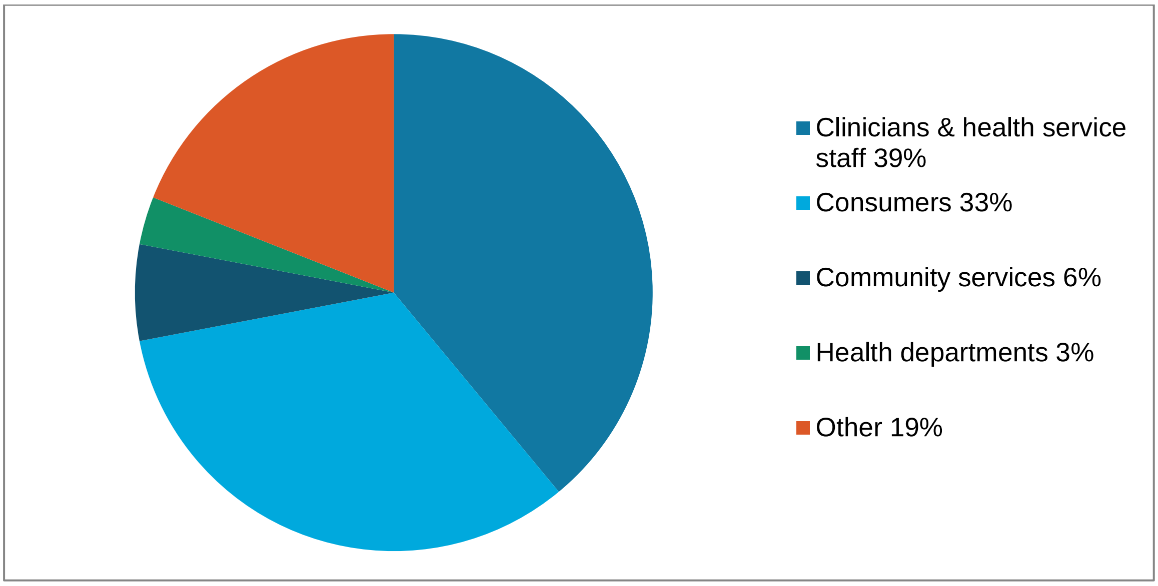
Phase	Task
1. Preparation	• Collection of survey responses via online survey • Export of survey data to Excel • Development of initial codes or themes based on principle outputs to be reported on.
2. Coding	• Coding undertaken in Excel • Descriptive coding of responses • Applying and modifying coding scheme.
3. Thematic analysis	• Interpreting patterns or themes in the coded content • Sub-coding continued within each group of responses.
4. Write up	• Write-up of thematic findings guided by principle outputs to be reported on.

About the respondents

602 submissions were received by the Commission to the online public consultation process. Of those, 596 submissions were received via the online survey and six submissions were received via email.

The majority of submissions were provided by staff working in health services (39%) followed by consumers, carers and consumer representatives (33%). Figure 1 provides the proportion of respondents by category.

Figure 1: Demographics of respondents



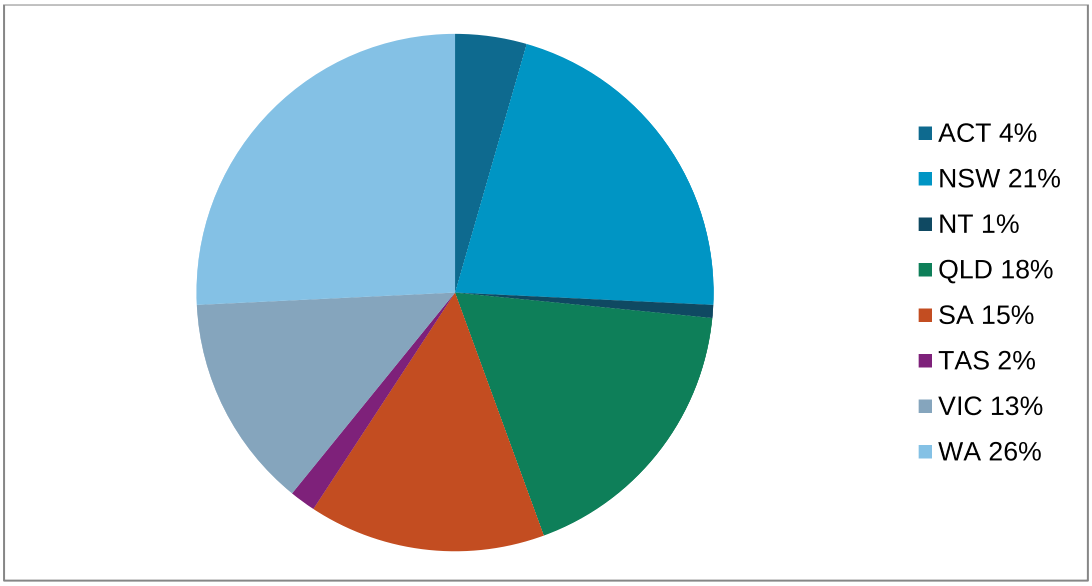
A smaller proportion of submissions were received by staff from community services, state and territory health departments, mental health services, university/education providers and professional organisations. Table 2 provides numbers of respondents by type of respondent.

Table 2: Number of online responses, by type of respondent

Role or workplace	Responses
Health service staff e.g. nurse, doctor, allied health, administration	170
Consumer	95
Consumer representative/advocate	83
Health service manager	57
Other	57
Community services	34
Carer	18
State and Territory Health Departments	18
Mental health services	14
University or education provider	12
Professional organisation or association	10
General Practitioner or primary care staff	8
Complaints Commissioner or complaints management areas	7
Aboriginal Medical Service or Aboriginal health workers	5
Day procedure services	3
Private allied health providers	2
Migrant and refugee services	2
Pharmacy	1
Clinical college	0
Total	**596**

Demographic data on respondent location was requested, but was not compulsory to complete. Of the 493 people who indicated their location the most submissions were from Western Australia (26%), followed by New South Wales (21%), Queensland (18%), South Australia (15%), Victoria (13%), Australian Capital Territory (4%), Tasmania (2%) and Northern Territory (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

This section explores the key themes identified during the 2019 consultation on the second edition of the Charter. The analysis draws on feedback from the 2019 public survey, workshops with consumers and health service staff, and data from the 2018 survey about resources that the Commission could develop to support implementation. As the Charter is a document for consumers, further analysis of themes raised by consumers has also been undertaken.

The key areas of feedback are:

- Content in the second edition
- Design of the second edition
- Summary of themes identified by consumers
- Resources to support the use of the second edition.

1. Content in the second edition

Feedback from both the survey and the workshops indicated that the content in the second edition of the Charter has been improved, making it clearer, more user-friendly and engaging.

88% of survey respondents thought the rights were clearly explained

The majority of survey respondents (88%) identified that the rights in the second edition were clearly written, easy to understand and were an improvement on the original version of the Charter. This positive feedback was also echoed by workshop participants.

However, feedback also identified that some of the concepts in the Charter may be too complex for some people to understand. For example, concepts such as ‘access’, ‘respect’, ‘partnership’ and ‘informed consent’ may not be easily understood by people with low health literacy and require further clarification. Terms such as ‘be engaged’ were considered to be jargon by some respondents. Additionally, it was noted that terms used in the headings of some of the rights were repeated in the explanatory statements which did not enhance an understanding of the terms. Some respondents were concerned that the ‘Guiding Principles’ included in the first edition of the Charter had been removed, but others preferred the simpler introduction to the rights.

Some consumer workshop participants also agreed that some of the statements in the Charter were too high-level and lacking in the specifics needed for people to be able to exercise their rights. It was suggested that a statement such as ‘ask a staff member about your rights’ be included to direct consumers to who they could speak about their rights.

A number of changes to the rights were suggested by survey respondents and workshop participants, as summarised in Table 3.

91% of survey respondents found the language easy to understand

Positively, the majority of survey respondents (91%) reported that the language in the second edition of the Charter was easy to understand. Comments included that the language is clear, simple and more person-centred.

However, some respondents felt that the Charter was too long and too complex for people with low health literacy and that plainer language should be used. Respondents suggested that the Charter be translated into community languages and simpler formats, such as ‘Easy

English’, infographics, large text, audio and video versions to support understanding (see section on ‘Resources to support the Charter’).

Feedback on suggested changes to the rights

Table 3 summarises the main changes or enhancements to the rights that were suggested by survey respondents and workshop participants.

Table 3: Themes suggested by respondents

Right	Suggested themes
Access	• Clarify the meaning of access • The right to physical access for those with a disability • Timely access to care • Cost, affordability of specialist services • Appropriate care
Safety	• Personal safety, staff safety • Quality of care • Culturally safe care • Well-being, psychological safety • Trust
Respect	• Include responsibilities, mutual respect, respect for staff • Developmental age and competence • Respect for an individual’s choices
Partnership	• Informed consent • Shared decision making • Honesty in communication • Open and meaningful communication • Acknowledgement of capacity and capability in decision-making • Carer/family involvement in decision-making and/or information sharing • Right to refuse or decline treatment • Right to a second opinion • Communicate my wishes • Ask questions
Information	• Informed consent and explanation of what informed consent is

	- Individualised care, person-centred care - Access to written translations, interpreters and communication aids - Open disclosure, including the impact on the consumer - Access to quality, evidence-based information - Alternative options and treatments - Costs and financial consent
Privacy	- Explain what 'privacy respected' means - Health information – access by consumers, privacy, security, information sharing - Reference to privacy legislation
Give feedback	- Complaints, making a complaint without fear of retribution, being advised when things goes wrong (open disclosure) - Staff being aware of rights, providing respectful practice - Sharing experiences and participating in improving the quality of health services - Have concerns listened to and considered - Positive and negative feedback - Complaints being responded to in a transparent and timely way

Given the necessity to retain a succinct version of the Charter, some of the clarification identified and issues raised will be considered for inclusion in supporting materials and resources.

Other comments about rights

Survey respondents provided a number of additional comments about issues to be considered during the review of the Charter. Similar to feedback received during the first survey in 2018, many respondents (mostly from those who identified as health service staff) requested that the Charter include a section on 'responsibilities' to promote the rights of staff to be respected and work in a safe work environment.

Feedback was received about the need to include an explanation of the legal context that the Charter sits within including state legislation, NSQHS Standards and other levers for change including governance and responsibility within health service organisations.

It was also suggested that the Charter include the contact details of external complaints organisations for consumers to contact to escalate concerns about their rights not being met.

2. Design of the second edition

Feedback received during the consultation indicated that the new Charter design was simple, engaging and easy to read.

Much of the feedback on the design of the Charter was in relation to the graphic (see Appendix 1). Many people responded positively to the graphic however some thought that the image did not reflect the diversity in the Australian population. To improve the diversity depicted in the graphic it was suggested that additional groups be included, such as an Aboriginal and Torres Strait Islander person, an older person, a person with a physical disability, a Caucasian male and a child/young person.

The use of a graphic rather than a photo was also an issue which divided survey respondents and workshop participants. While some people thought that the graphic gave the Charter a friendly and an accessible tone, others said that the graphic detracted from the gravity of the Charter. Some people reported a preference for the use of a photo instead of a graphic.

The colour scheme used in the Charter also received a mixed response. Some people found the orange colour used in the heading to be warm and engaging. Other people highlighted that orange (or amber) may be perceived as a warning colour and suggested changing the colour to green or blue.

To improve the readability of the Charter it was suggested removing the capitalised text. Other suggestions included providing space for health services to include their own local contact details and logo, providing alternative graphics to enable health services to tailor the Charter to local populations and adding a QR (machine readable) code which links to further information.

In addition to feedback on the Charter, workshop participants were asked to review two posters developed to support the release of the Charter (see Appendix 2). Participants liked the diversity shown in the graphic of the poster and the call to action in the poster heading, ‘Do you know your healthcare rights?’.

3. Summary of key themes identified by consumers

Further analysis of the data was undertaken to examine themes that were particularly important to consumers. Overall, the majority of consumer survey respondents reported that the rights in the second edition of the Charter were clearly explained (68%) and easy to understand (70%), though these percentages are lower than for survey respondents overall (88% and 91% respectively).

Similar to other feedback received, consumers reported that the language in the second edition was too complex and that some of the terms and phrases could be more simply explained. Consumers also requested more explanation about how they could use the Charter, including information about who they could speak to if their rights were not being met.

Consumer views on the graphic used in the second edition were divided, with some people reporting preference for a cartoon, while others preferring the use of a photograph. These comments were consistent with the views of respondents overall. Consumers also provided suggestions for improving the representativeness of the graphic and particular groups that should be included.

Consumers also emphasised the need for increased awareness of the Charter by health service staff, consumers and by the general population. To support this, consumers suggested various types of resources be developed to reach people from different groups and levels of health literacy. Suggestions for resources included posters, translations into community languages, videos that could be shown in waiting rooms and shared on social media and resources to support the education of staff about healthcare rights.

4. Resources to support the second edition

Data gathered during the Phase 1 survey in 2018 included feedback on the types of resources that the Commission could develop to support the implementation of the second edition of the Charter. During Phase 2, workshop participants were also asked for their views on the types of supportive resources that would be useful for their context. The analysis of feedback from both of these sources indicated:

> **36% of respondents from 2018 survey had not seen or used the Charter before**

This is an important statistic as it demonstrates that, even amongst individuals and organisations familiar with the Commission, there are many who are not aware of the Charter. This means that there is a need to undertake awareness raising activities to actively promote the second edition of the Charter.

> **72% of 2018 survey respondents had not used any supporting guides for the Charter**

The survey responses demonstrated the limited visibility of the existing Charter resources.

Survey respondents and workshop participants provided a range of suggestions on resources that would be useful to support awareness and use of the Charter. These included:

- Posters
- Guide for consumers
- Guide to support health service staff
- Translated versions in community languages
- Audio and video resources
- Tailored resources for Aboriginal and Torres Strait Islander people
- Accessible documents including, ‘Easy English’, braille and large text versions
- Infographics
- PowerPoint presentation and learning resources for health service staff.

Workshop participants discussed strategies to increase awareness and engagement with the Charter by clinicians and the general public. Four main themes emerged from these discussions.

Promotion in health services

Workshop participants agreed that promotion of the Charter could be improved in health services and suggested ways in which this could be implemented, such as:

- Including the Charter and supporting information in patient’s admission or discharge packs
- Utilising video screens/scrolling screens on patient entertainment systems and in waiting rooms
- Referencing the Charter on health service feedback forms
- Increasing staff awareness about the Charter to encourage discussions with patients about their healthcare rights
- Including the Charter in staff induction packs and education sessions
- Making the Charter visible across health services such as, in waiting areas and in lifts
- Engaging community advisory committees to champion the Charter, highlighting good practise and creating networks.

Education

Health service staff provided feedback that they would like tools to support them when discussing the Charter with consumers. Many participants felt that there should be a greater awareness within health service organisations of the rights and what they look like in practise. As such, staff education was considered a key aspect of increasing awareness of the Charter by:

- Integrating the Charter into local learning modules and mandatory training for health service staff, providing staff with additional training about how to use it, and linking to policy, guidelines and NSQHS Standards
- Providing the Charter and resources to clinical colleges and peak professional bodies for inclusion in professional development and training
- Liaising with universities and other education providers to have the Charter included in relevant curricula.

Online and Social media

Consumers, in particular, suggested utilising social media and other online resources to promote the Charter to reach a wider audience and to raise awareness and understanding of healthcare rights by the general public. Suggestions included:

- Sharing videos, animation and graphics online via YouTube and through twitter and Facebook platforms
- Developing an engaging website or page for the Charter with a short web address link that is easy to remember and share
- Working with consumer organisations to raise online awareness of the Charter.

Wider awareness

Many workshop groups discussed strategies for elevating the understanding of healthcare rights to the level of ‘general knowledge’ in the community. Suggestions included sharing the Charter in public areas like Centrelink, Medicare, local councils and distributing through community groups.

Conclusion

Feedback received during the consultation on the second edition of the Charter was positive, with the majority of respondents reporting that the rights were clearly explained and easy to understand. Issues identified mainly related to terms that some people considered complex, or the need to describe some rights in more detail. Some divergent views were reported on the design of the Charter, particularly in regards to the graphic. A range of suggestions on the types of resources that the Commission could develop to support the use of the Charter were also provided.

Next steps

The Commission is grateful for the feedback received during this consultation and will use this to develop the final version of the second edition of the Charter. While it may not be possible to incorporate all of the suggestions received, the Commission will endeavour to include as many as possible within the resources that are developed to support the implementation of the Charter.

This report, and the revised second edition of the Charter, will be provided to the Commission’s standing committees and Board for approval. The Commission anticipates releasing the second edition of the Charter in mid-2019.

Following the release of the Charter, the Commission will develop a suite of resources to support the implementation of the Charter. This will be undertaken in stages, and further targeted consultation on individual supporting resources will also be undertaken as the work progresses.

Appendix 1

Figure 3 – Draft second edition of the Charter that was subject to the phase 2 consultation

My healthcare rights

THE AUSTRALIAN CHARTER OF HEALTHCARE RIGHTS describes the rights you, your family or someone you care for has when they access health care.

These rights apply to all people in all healthcare settings in Australia.

I HAVE A RIGHT TO:

ACCESS

- Access services and treatment to meet my healthcare needs

SAFETY

- Safe and high quality health care
- Receive care in a safe environment

RESPECT

- Be cared for as an individual and treated with dignity and respect
- Have my culture, identity, beliefs, and choices acknowledged and respected

PARTNERSHIP

- Engage in open communication and make decisions about my health care
- Include the people that I want in planning and decision-making
- Share my experience and participate in improving the quality of health services

INFORMATION

- Be engaged in informed consent, be told about my condition and the possible benefits and risks of tests and treatments
- Clear and timely information about services, waiting times and costs
- Be given assistance to help me to understand health information
- Access my health information
- Be told if something has gone wrong during my health care, how it happened and what is being done to make care safer

PRIVACY

- Have my privacy respected
- Have my personal and health information kept secure and confidential

GIVE FEEDBACK

- Provide feedback or make a complaint without it affecting the way that I am treated
- Have my concerns dealt with in a fair and timely way

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For more information visit
www.safetyandquality.gov.au/rights

Appendix 2

Figure 4 – Draft poster to support the second edition of the Charter that was subject to the phase 2 workshop consultation

Do you know your healthcare rights?

- ✓ ACCESS
- ✓ SAFETY
- ✓ RESPECT
- ✓ PARTNERSHIP
- ✓ INFORMATION
- ✓ PRIVACY
- ✓ GIVE FEEDBACK

The **Australian Charter of Healthcare Rights** applies to people in all healthcare settings. It describes the rights you, your family or someone you care for has when they access health care.

AUSTRALIAN COMMISSION ON SAFETY AND QUALITY IN HEALTH CARE

For more information about the Australian Charter of Healthcare Rights visit **www.safetyandquality.gov.au/rights**

Figure 5 – Draft poster to support the second edition of the Charter that was subject to the phase 2 workshop consultation

Do you know your healthcare rights?

The **Australian Charter of Healthcare Rights** applies to people in all healthcare settings.

It describes the rights you, your family or someone you care for has when they access health care.

- ✓ **Access**
- ✓ **Safety**
- ✓ **Respect**
- ✓ **Partnership**
- ✓ **Information**
- ✓ **Privacy**
- ✓ **Give Feedback**

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