



# Partnering with Consumers

A guide for consumers

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# Contents

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<b>Introduction</b>	<b>2</b>	<b>Chapter 3: Partnering with consumers</b>	<b>20</b>
Who is this Guide for?	3	What does partnering with consumers mean?	21
The purpose of this Guide	3	Types of partnerships	22
How to use this Guide	3	What does partnership look like in practice?	24
		Roles in supporting effective partnerships	26
<b>Chapter 1: Person-centred care</b>	<b>4</b>	Reflective questions for consumers	30
Principles of person-centred care	5	Reflective questions about health service organisations	30
The evidence for person-centred care	6	Further reading	31
How consumers can get involved	6		
Reflective questions for consumers	8	<b>Chapter 4: Building skills and consumer leadership</b>	<b>32</b>
Reflective questions about health service organisations	8	Consumer leadership and roles for leaders	33
Further reading	9	Partnering challenges	36
		Building skills and capabilities	37
<b>Chapter 2: The Standards and accreditation</b>	<b>10</b>	Reflective questions for consumers	38
What are the Standards?	11	Reflective questions about health service organisations	38
What is the Partnering with Consumers Standard?	12	Further reading	39
How can consumers use the Partnering with Consumers Standard?	13		
What is accreditation?	16	<b>Glossary</b>	<b>40</b>
Where to find an organisation's accreditation result	16		
How consumers are involved in accreditation	17	<b>Important websites</b>	<b>42</b>
Reflective questions for consumers	18		
Reflective questions about health service organisations	18	<b>Acknowledgments</b>	<b>43</b>
Further reading	19		
		<b>Appendix</b>	<b>44</b>

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# Introduction

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The consumer voice is important to enable health service organisations to improve delivery of safe and high-quality care. By working together, consumers and health service organisations can help improve:

- The delivery of health services
- The experience for patients, their carers and family members
- Health outcomes.

The National Safety and Quality Health Service Standards (the Standards) – developed by the Australian Commission for Safety and Quality in Health Care (the Commission) require health service organisations to form partnerships with consumers. This is detailed in the Partnering with Consumers Standard, which recognises that consumers (patients, families and carers) and health service organisations must partner to deliver person-centred care.

The Commission is the Australian Government agency responsible for setting standards for health service organisations to follow. These standards aim to protect the public from harm and improve the quality of health care in Australia.

This Guide has been developed by consumers for consumers. It is hoped that it will help both consumers and health service organisations understand how to get the most from their partnerships so that there are better health outcomes for all consumers.

**You have the right to access healthcare services and treatment that meets your needs**



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## Who is this Guide for?

This Guide has been developed for consumers who:

- Would like to know how to better communicate and partner with clinicians and health service organisations to improve their own care, as well as health services more broadly
- Would like to understand how they can become consumer advocates or consumer representatives, and what they can do to influence change
- Are already consumer representatives, advocates, advisors, members of consumer networks or organisations and would like to understand how the Partnering with Consumers Standard can support them.

## The purpose of this Guide

This Guide aims to:

- Help consumers understand how the Standards can make health services safer and more responsive
- Help consumers understand how they can work with health service organisations to create a better health system
- Provide a reference point for health service organisations to understand how important it is to get the consumer perspective to improve their services.

## How to use this Guide

This Guide has four chapters:

- 1 Person-centred care**
- 2 The Standards and accreditation**
- 3 Partnering with consumers**
- 4 Building skills and consumer leadership**

Each chapter has a section with reflective questions for consumers and health service organisations and a further reading section, with links to resources and extra information. More information for health service organisations is available on the Commission's website at [safetyandquality.gov.au/standards/nsqhs-standards/resources-nsqhs-standards](https://www.safetyandquality.gov.au/standards/nsqhs-standards/resources-nsqhs-standards).

A glossary and a list of some key websites are available at the end of this Guide.

# Chapter ①

## Person-centred care

This chapter looks at the importance of person-centred care to consumer experience and health outcomes. It explains:

- Principles of person-centred care
- The evidence for person-centred care
- How consumers can get involved.



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## Principles of person-centred care

Person-centred care is health care that respects the patient, their family and carers, and responds to the person's preferences, needs and values.

Person-centred care offers respect, emotional support, physical comfort, information, communication, continuity and transition of care. It recognises that the way you are treated as a person and the way you are treated for your condition affects your experience when receiving care.

There are key principles that consumers should expect to see in a health service organisation that is delivering person-centred care.

### Consumer involvement

Consumer partnerships are needed at all levels of the health service organisation. Consumers, including patients, carers and community members, are meaningfully involved in decision-making about health policy, planning, care and treatment, their wellbeing and the wellbeing of the community.

***'Nothing about us without us.'***

***'Consumer experience is really important.'***

When healthcare providers partner with consumers, they are recognising the value of the consumer voice in achieving person-centred care and the need for consumers' experience and expertise to help shape decisions about health care.

## Support for healthcare rights

Consumers need to understand and act on their healthcare rights. Everyone who is seeking or receiving care in Australia has certain rights regarding their care. These rights are described in the *Australian Charter of Healthcare Rights* (the Charter). You have a right to clear information about your condition, risks and benefits of treatment options, and the option to decline treatment, so you can give your informed consent. A clinician must ask for your informed consent before giving any treatment. The Charter is available on the Commission's website at [safetyandquality.gov.au/our-work/partnering-consumers/australian-charter-healthcare-rights](https://www.safetyandquality.gov.au/our-work/partnering-consumers/australian-charter-healthcare-rights).

***'I have the right to receive safe and high-quality health care that meets the national Standards, and to share my experience to improve the service.'***

***'Many consumers have no idea they have the right to say no, ask questions.'***

### Shared information

Consumers should have access to all the information they need to make decisions and choices about their own care, and about the design and delivery of services more broadly. Consumers have the right to ask for information to be given to them in a way that meets their needs. It should be easy to understand, accessible and keep them informed about their care.

***'How can I make a decision when I only have the information the doctor chooses to tell me.'***

***'Sharing information is sharing power.'***

### Shared decision making

Shared decision making is when a clinician and a consumer discuss the benefits and risks of treatment options, along with the consumer's choices and goals for their health. The clinician and consumer will work together to reach a decision.

***'Consumers have important knowledge and experience needed for making good decisions.'***

## The evidence for person-centred care

Research conducted over the last 40 years has proven that effective partnerships with consumers:

- Improve health outcomes, including reduced hospitalisations
- Reduce healthcare-acquired infections
- Reduce length of stay in hospital
- Improve use of preventive care
- Improve safe medicine use.

## How consumers can get involved

Person-centred care can only happen when there are strong partnerships between consumers and health service organisations.

The Partnering with Consumer Standard is in place to help health service organisations deliver person-centred care. Consumer representatives can help clinicians, health service organisations

and the healthcare system to think more about the needs and preferences of patients, carers and their communities. They do this by making sure information and services meet people's needs. Always remember that person-centred care is central to the relationship between health service organisations and consumers – and to the Partnering with Consumers Standard.

Several types of partnerships exist. Consumers are needed at all levels of a health service organisation including:

- **As individual** patients, family members or carers of people using health services
- **In a service, program or department** as advocates, representatives or members of a project advisory committee
- **In health service organisations** in governance, planning and policy; this could be as a board member, member of a consumer advisory committee or consultative committee
- **Across systems** as advocates, expert advisors, committee members or board members within the health system.

Figure 1: Benefits of person-centred care\*



\* Australian Commission on Safety and Quality in Health Care. Review of the key attributes of high-performing person-centred healthcare organisations. Sydney: ACSQHC; 2018.

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**Consumers are experts** because they have lived experiences of health conditions and services that they, their families and communities have used.

While everyone might be a patient at some time in their lives, not everyone can represent consumers. For example, healthcare professionals or clinicians can be patients, but may not be suitable consumer representatives as they bring knowledge and experiences beyond their patient experience.

### Individual engagement

This level of engagement relates to when care is being provided, such as during a medical appointment. A consumer can advocate for themselves, a family member, or someone else they care for by:

- Asking questions to support understanding and making decisions about their own care
- Using their own experiences to help improve health services
- Completing a survey or giving feedback after using a health service.

### Service, program or department engagement

Most health service organisations have policies in place to work with consumers. This involves participation of consumers in the overall design of a service, department or program. Consumers may be full members of quality improvement and redesign teams. Engagement at this level may include:

- Giving feedback on policies, information products and other documents
- Participating in workshops to discuss an issue or topic
- Joining a project advisory committee to set up or improve a service
- Sharing experiences and a consumer view to educate or train health professionals.

### Health service organisation engagement

Engagement at this level involves consumers participating in a health service organisation's governance, policy and planning. This may include:

- Participating in the governance structure, such as a consumer advisory group or the board of a hospital or health service
- Being involved in committees addressing patient safety, clinical governance, facility design, quality improvement, ethics, and research and evaluation/measurement
- Being involved in partnerships between the health service organisation and local community groups and forums; for example, a partnership between a mainstream hospital and the local Aboriginal Community Controlled Health Organisation to create culturally safe environments.

**‘Consumers are the renewable energy and the secret ingredient to transformational change within the health and care system.’**

Alison Trimble (King's Fund 2018)



## Health system engagement

Many regional, state/territory and national organisations work with consumers when considering policy changes and making decisions. These organisations understand how important it is for consumers to be involved at all levels, including on their boards, so that they can deliver safe, high-quality and person-centred health care. Engagement at this level may include:

- Membership of consumer organisations, such as the Consumers Health Forum
- Invitations to share consumer experiences in high level governance or decision-making committees and boards
- Contributing to national and statewide policy discussions involving multiple stakeholders.

*'I want to contribute where I think I can make a difference.'*

*'I expect to be valued for my skills, experience and perspectives.'*

*'I bring a consumer perspective that focuses the board on safety and quality during our discussions and decisions.'*

## Reflective questions for consumers

- How do you engage with health service organisations as a consumer?
- If you are a consumer representative or advocate with a health service organisation, have you asked for the organisation's consumer engagement framework, and found out how your work fits?
- How well does the health service organisation you work with understand and deliver person-centred care?
- How could the health service organisation you work with improve how it works with you?
- How could the health service organisation you work with offer more person-centred care?
- If you are not involved in health care as a consumer representative or advocate, would you like to take up this role and at what level would you like to be involved?

## Reflective questions about health service organisations

- How well does the organisation deliver person-centred care?
- What are the organisation's areas of strength in person-centred care, and where can the organisation improve?
- Have you read the organisation's consumer engagement framework?
- At what levels of the organisation do consumers have a voice?
- Is there opportunity and support available to engage a diverse range of consumers?
- Does the organisation seek and value contributions from consumers?
- Are consumers trained and supported to make meaningful contributions?

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## Further reading

### From the Commission

**Understanding My Healthcare Rights: A guide for consumers** (2020). A comprehensive guide to the *Australian Charter of Healthcare Rights*. Available from: [safetyandquality.gov.au/publications-and-resources/resource-library/understanding-my-healthcare-rights-guide-consumers](https://safetyandquality.gov.au/publications-and-resources/resource-library/understanding-my-healthcare-rights-guide-consumers).

**Frequently asked questions about partnering with consumers in the NSQHS Standards** (2017). A set of questions and answers to help explain the Partnering with Consumers Standard. Available from: [safetyandquality.gov.au/our-work/partnering-consumers/partnering-consumers-nsqhs-standards/frequently-asked-questions-about-partnering-consumers](https://safetyandquality.gov.au/our-work/partnering-consumers/partnering-consumers-nsqhs-standards/frequently-asked-questions-about-partnering-consumers).

**Information about person-centred care** (2018). An overview of person-centred care. Available from: [safetyandquality.gov.au/our-work/partnering-consumers/person-centred-care](https://safetyandquality.gov.au/our-work/partnering-consumers/person-centred-care).

**Attributes of person-centred healthcare organisations** (2018). A report describing the characteristics of organisations that deliver excellent person-centred care. For organisations, a self-assessment tool, presentation slides and case studies are available to help plan improvements. Available from: [safetyandquality.gov.au/our-work/partnering-consumers/person-centred-healthcare-organisations](https://safetyandquality.gov.au/our-work/partnering-consumers/person-centred-healthcare-organisations).

**Case studies for delivering person-centred care and implementing the Partnering with Consumers Standard** (2021). These case studies are designed to assist health service organisations to implement person-centred care and consumer partnerships. Available from: [safetyandquality.gov.au/our-work/partnering-consumers/case-studies-delivering-person-centred-care-and-implementing-partnering-consumers-standard](https://safetyandquality.gov.au/our-work/partnering-consumers/case-studies-delivering-person-centred-care-and-implementing-partnering-consumers-standard).

**Health literacy resources** including fact sheets on improving the health literacy environment. Available from: [safetyandquality.gov.au/our-work/patient-and-consumer-centred-care/health-literacy/tools-and-resources-for-health-service-organisations](https://safetyandquality.gov.au/our-work/patient-and-consumer-centred-care/health-literacy/tools-and-resources-for-health-service-organisations)

### From other organisations

**Putting the consumer first: Creating a consumer-centred health system for a 21st century Australia** (2016). The George Institute for Global Health. Available from: [georgeinstitute.org.au/sites/default/files/putting-the-consumer-first-apr16.pdf](https://georgeinstitute.org.au/sites/default/files/putting-the-consumer-first-apr16.pdf)

**Collaborative Pairs program**. Consumers Health Forum. A leadership development program that brings together a consumer, patient or community leader with a health service organisation, clinician or manager to develop new ways of working together. Available from: [chf.org.au/collaborative-pairs](https://chf.org.au/collaborative-pairs)

You can find more information on our website [safetyandquality.gov.au/our-work/partnering-consumers/person-centred-care](https://safetyandquality.gov.au/our-work/partnering-consumers/person-centred-care)

# Chapter 2

## The Standards and accreditation

This chapter takes a closer look at the Standards, their focus on partnering with consumers and how health service organisations are accredited. It explains:

- What are the Standards?
- What is the Partnering with Consumers Standard?
- How can consumers use the Partnering with Consumers Standard?
- What is accreditation?
- Where to find an organisation's accreditation result
- How consumers are involved in accreditation.



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## What are the Standards?

Our health system aims to give people the right care, in the right place, at the right time and cost. Most health care in Australia has good outcomes, but sometimes people don't get the care they need, or things go wrong, and people are harmed. The Standards describe what health service organisations need to do to help keep people safe. The Standards are there to:

- Improve the safety and quality of health care
- Protect people from harm.

The Commission has developed eight Standards, each with a set of actions that health service organisations must meet (see Figure 2 and the Appendix).

There is a strong focus on consumer partnerships throughout the Standards. This recognises that involving consumers leads to a more positive experience, higher-quality health care and improved safety.

**Figure 2:** National Safety and Quality Health Service Standards



## What is the Partnering with Consumers Standard?

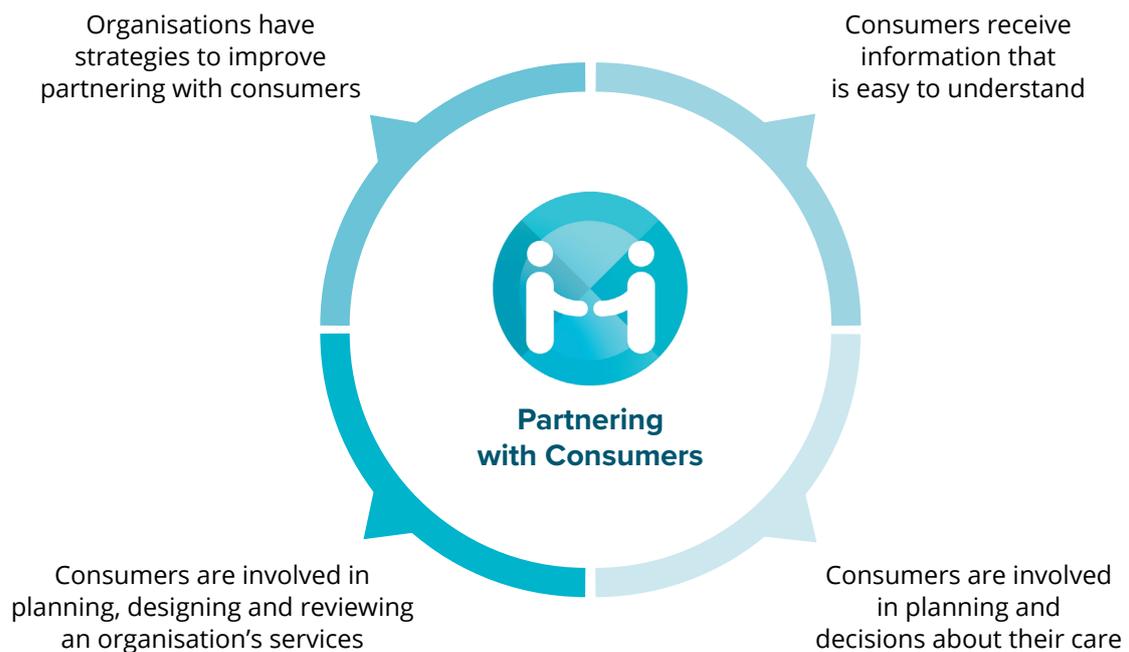
The Partnering with Consumers Standard aims to create health services that look after the needs and priorities of consumers. It does this by enabling active partnerships between consumers, clinicians and health service organisations, so they can work together (Figure 3). Health service organisations must:

- Involve consumers in planning, designing, measuring and evaluating the organisation's services
- Partner with consumers in planning and decisions about their own care
- Have strategies to improve partnering with consumers
- Build health literacy by giving consumers information that is easy to understand, so that they are able to make choices and decisions about their treatment.

The Partnering with Consumers Standard underpins all the other Standards. The Standards are needed for safe, high-quality and consumer-centred health services. Health service organisations should use the Standards to set up structures to make sure that consumers can take part in decision-making.

Health service organisations must partner with consumers to meet all the other Standards which each deal with a high-risk area of patient care.

Figure 3: Partnering with Consumers Standard



## How can consumers use the Partnering with Consumers Standard?

Consumers can use the Partnering with Consumers Standard in different ways – as individuals when meeting with a clinician about their care, or as consumer representatives at the health service organisation or system level. See Table 1 for

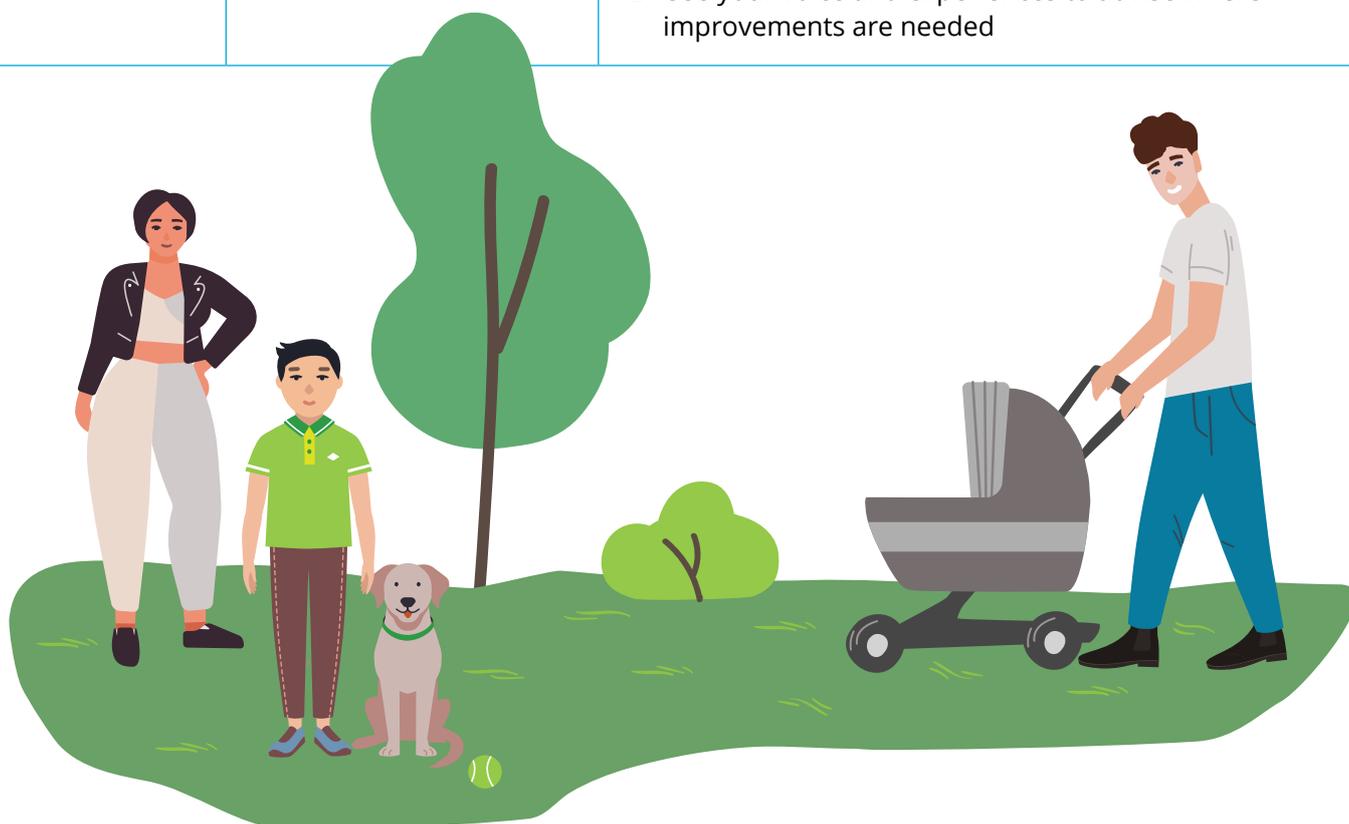
examples of how consumers can use the Partnering with Consumers Standard when participating in partnerships at different levels across the health system.

**Table 1:** Using the Partnering with Consumers Standard

Level	What it looks like in practice	How to use the Partnering with Consumers Standard
Individual	This is usually when a consumer (whether a patient, carer or family member) is meeting with a clinician or service provider about their own (or their family member's) health condition	<ul style="list-style-type: none"> <li>■ Ask questions and be involved in decision-making and planning about your care</li> <li>■ Be informed and understand the risks and benefits of diagnostic procedures, types of treatment, and medication side-effects to help you make decisions about your treatment</li> <li>■ Explain personal needs and circumstances, and what you want, so they are understood and are part of your treatment and care</li> <li>■ Ask for and expect to receive information in a way that suits your needs</li> <li>■ Ask to have an interpreter in your own language if needed</li> <li>■ Ask about the qualifications and experience of clinicians and/or the reasons for referring you to a specialist</li> <li>■ Look for other opinions where appropriate</li> <li>■ Ask to bring a friend or family member to appointments if it helps you understand what is being said or to make decisions</li> <li>■ When being discharged from a hospital or day procedure service, expect to receive information about why you came, the care you received, the plan of action when you leave and any follow-up appointments</li> </ul>

Level	What it looks like in practice	How to use the Partnering with Consumers Standard
<p><b>Service, program or department</b></p>	<p>This is usually when you are invited to be a member of a project advisory committee, planning or co-design group</p>	<ul style="list-style-type: none"> <li>■ Use your voice and experiences to give feedback to the health service organisation, including by appreciating good care and telling the organisation where improvements are needed</li> <li>■ Ask for an orientation session on the work you are being invited to advise on</li> <li>■ Ask the organisation for information about the Standards that best fits with the area you are working on</li> <li>■ Use the Standards to ask questions and raise issues</li> <li>■ Make sure that the health service organisation is accountable for the actions it has agreed to take by asking for regular updates on progress</li> </ul>
<p><b>Health service organisation</b></p>	<p>This is usually when you are invited to participate in governance, policy and planning committees (e.g. consumer advisory committees)</p>	<ul style="list-style-type: none"> <li>■ Ask for an orientation session about the work you are being invited to participate in</li> <li>■ Ask the organisation for information about how the work relates to the Standards</li> <li>■ Use the Standards to ask questions and raise issues</li> <li>■ Ask if the organisation has a consumer engagement framework and when it was developed</li> <li>■ Check if consumers had an opportunity to provide advice on how the consumer engagement framework was developed</li> <li>■ Ask how consumers are embedded at all levels within the organisation (individual, service, organisation)</li> <li>■ Use the Standards to talk about issues from a consumer point of view</li> </ul>

Level	What it looks like in practice	How to use the Partnering with Consumers Standard
Health system	<p>This is usually when you are working with a state, territory, regional or national organisation that informs policy and/ or makes decisions that affect everyone in that state, territory, region or all of Australia</p>	<ul style="list-style-type: none"> <li>■ Ask for an orientation session about the work you are being invited to participate in</li> <li>■ Ask the organisation for information about how the work relates to the Standards</li> <li>■ Ask questions about processes and structures to support the Standards, if appropriate</li> <li>■ Ask about the plan for engaging consumers in the project, including additional steps for seeking advice from diverse and hard-to-reach groups</li> <li>■ Make sure that the committee or body you are working with is inclusive and has diverse consumer views and experiences</li> <li>■ Make sure that you have access to the same information as other members, and that you get timely information</li> <li>■ Make sure that there is accountability by asking about progress on actions and how recommendations or decisions have been followed up</li> <li>■ Use your voice and experiences to advise where improvements are needed</li> </ul>



## What is accreditation?

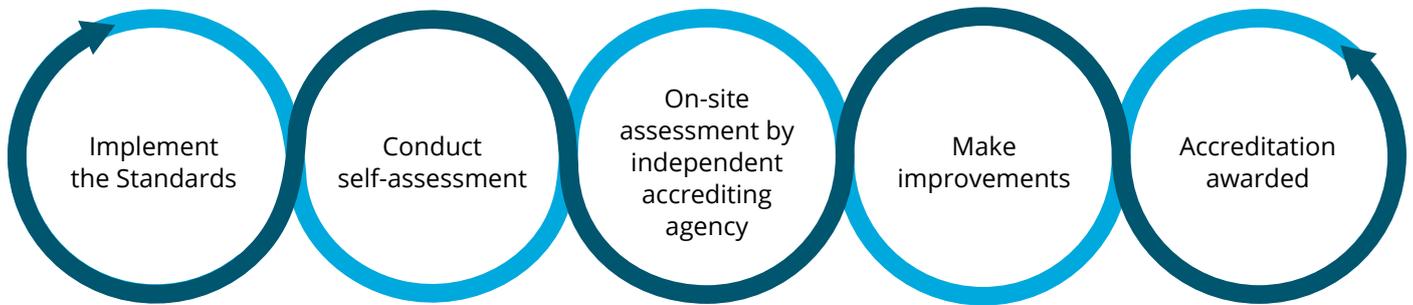
Accreditation is the process where a health service organisation is assessed by an independent organisation, to check their compliance with the Standards (Figure 4).

In Australia, all public and private hospitals, day procedure services, and most public dental practices must be accredited.

To become accredited, health service organisations must pass an assessment to show they have met all the Standards.

Accreditation means that a health service organisation is likely to be operating safely and competently, giving consumers confidence in using its services.

**Figure 4:** Accreditation cycle



## Where to find an organisation's accreditation result

The full results of a health service organisation's assessment are available on the Commission's Public Reporting web page at [safetyandquality.gov.au/consumers/public-reporting-hospital-performance-nsqhs-standards](https://safetyandquality.gov.au/consumers/public-reporting-hospital-performance-nsqhs-standards).

The web page has been developed with consumers, for consumers and aims to provide greater transparency about how health service organisations are performing against the Standards. Using this web page, consumers have the opportunity to be more informed and engaged in identifying, planning and evaluating improvements with health service organisations.

Consumers can also find accreditation results by viewing a health service organisation's accreditation certificate. An accreditation certificate or award is given to a health service organisation when it passes its accreditation assessment. Certificates are often displayed in the front entrance or in public waiting areas. The certificate will include the name of the health service organisation, date the accreditation assessment was performed and the accreditation expiry date. A QR code on the certificate can be used to link to additional information about the results of the accreditation assessment.

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## How consumers are involved in accreditation

Consumers can be involved at several stages of the accreditation process. A health service organisation may ask consumers to:

- Provide advice about safety and quality issues through complaints or feedback processes
- Participate in safety and quality or accreditation committees to provide advice on how to improve the organisation's processes
- Share their experiences as patients or carers, or their experiences as an advocate or representative on its committee, advisory body or governing board.

Consumers can also be trained to become assessors, who can review health service organisations' systems and processes against the Standards.

### Become an assessor

If you are interested in becoming a consumer assessor (also called a surveyor), you can contact an accrediting agency for more information. A list of approved accrediting agencies is on the Commission's website at:

[safetyandquality.gov.au/standards/nsqhs-standards/assessment-nsqhs-standards/approved-accrediting-agencies-contact-details](https://safetyandquality.gov.au/standards/nsqhs-standards/assessment-nsqhs-standards/approved-accrediting-agencies-contact-details)



### Reflective questions for consumers

- Have you read the consumer fact sheets about the Standards, accreditation and partnering with consumers (see [Further reading](#))?
- If you are a member of a committee, have you found out which of the Standards the committee works with?
- If you are a consumer representative or advocate for a health service organisation or committee, have the organisation's responsibilities for the Partnering with Consumers Standard been explained to you, and do you understand them?
- Have you asked about the role of consumers in the accreditation process?
- Do you have questions about, or need training on, how the Standards are used, accreditation, or any other quality and safety issues?
- How are you partnering with the health service organisation: Do you feel supported to share your experiences and that your advice is valued? If not, is there anything that you or the organisation can do to make the partnership more useful and effective?
- Have you read the *Australian Charter of Healthcare Rights* and the booklet *Understanding My Healthcare Rights: A guide for consumers* (see [Further reading](#) in Chapter 1)?

### Reflective questions about health service organisations

- Does the health service organisation have a plan for partnering with consumers at all levels of the organisation?
- Does the health service organisation's orientation and induction process for consumers explain the Standards and the accreditation process?
- Is there an information pack available for consumers and carers about the health service organisation's processes for partnering with consumers?
- Are consumer representatives/advocates given this Guide as part of their induction?
- Have consumers been told about, and given a copy of the *Australian Charter of Healthcare Rights* (the Charter) and the booklet *Understanding My Healthcare Rights: A guide for consumers*?
- Is the Charter accessible to all staff, consumers and the public?
- Are staff supported to understand the Charter and how to uphold the rights?
- Does the organisation have a consumer engagement coordinator or patient experience staff member?
- Has the organisation assessed the competency and training needs of staff so that they understand how best to support partnering with consumers?
- Are training and education materials about partnering with consumers easily accessible for staff?
- Are staff, including chairs of committees, given a copy of this Guide so they have a shared understanding of the consumer perspective?
- How are consumers involved in the accreditation process?

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## Further reading

### From the Commission

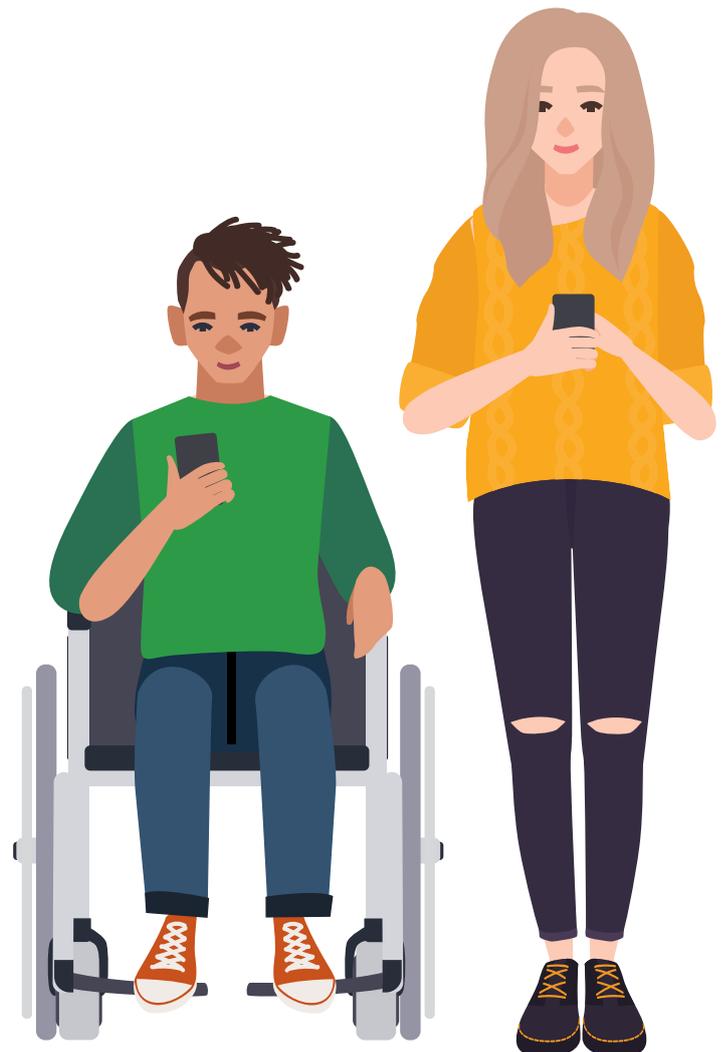
**Consumer Fact Sheet 1: Introduction to the National Safety and Quality Health Service Standards** (2018). A fact sheet to introduce the Standards and the *Australian Charter of Healthcare Rights*. Available from: [safetyandquality.gov.au/sites/default/files/migrated/Fact-sheet-1-Intro-to-the-National-Safety-and-Quality-in-Health-Service-Standards-2nd-ed.pdf](https://safetyandquality.gov.au/sites/default/files/migrated/Fact-sheet-1-Intro-to-the-National-Safety-and-Quality-in-Health-Service-Standards-2nd-ed.pdf).

**Consumer Fact Sheet 2: Accreditation of health service organisations** (2018). A fact sheet that provides an overview of how health service organisations are accredited in Australia. Available from: [safetyandquality.gov.au/sites/default/files/migrated/Fact-sheet-2-Accreditation-of-health-services-in-Australia.pdf](https://safetyandquality.gov.au/sites/default/files/migrated/Fact-sheet-2-Accreditation-of-health-services-in-Australia.pdf).

**Consumer Fact Sheet 3: Partnering with Consumers Standard** (2018). A fact sheet that provides an overview of the Partnering with Consumers Standard. Available from: [safetyandquality.gov.au/sites/default/files/migrated/Fact-sheet-3-Partnering-with-Consumers-Standard.pdf](https://safetyandquality.gov.au/sites/default/files/migrated/Fact-sheet-3-Partnering-with-Consumers-Standard.pdf).

### From other organisations

**Consumer Involvement Toolkit**, Cancer Australia. A toolkit for health service organisations, which includes a self-assessment tool and steps toward making a consumer engagement plan. Available from: [consumerinvolvement.canceraustralia.gov.au/service-managers/make-a-start](https://consumerinvolvement.canceraustralia.gov.au/service-managers/make-a-start).



# Chapter ③

## Partnering with consumers

This chapter aims to help consumers and health service organisations understand consumer partnerships and how they can be made more effective. It explains:

- What does partnering with consumers mean?
- Types of partnerships
- What does partnership look like in practice?
- Roles in supporting effective partnerships.



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## What does partnering with consumers mean?

Partnering with consumers means:

- Involving consumers, carers and/or their families in planning and decision-making about their own treatment and care
- Involving consumers in planning, decision-making, monitoring and reviewing a health service organisation's policies, procedures and the way it treats consumers.

### Partnership is about relationships

***'Need to build trust for the partnership to work.'***

Relationships between consumers, clinicians and the health service organisation must be built on mutual trust, respect and dignity. Effective partnerships have open and honest communication, and respect each other's opinions, beliefs, values and culture.

Building effective partnerships between consumers and health service organisations means:

- Recognising and acknowledging consumers' lived experience of their health condition and their journey through the health system, or that of the person they care for
- Recognising different consumer experiences in the same system, which may be due to different cultures, language, location, age, gender, disability, staffing or other reasons
- Being open to questions, as well as listening, learning and exploring possibilities
- Shared decision making between consumers and clinicians by discussing treatment options, listening to each other, and then using that information to make a decision
- Not just asking consumers to give feedback on a form, or for advice that is not used

- Developing strong consumer representatives and leaders by giving consumers the support, development and tools they need to take on leadership roles. Leadership roles may include becoming partners in research, delivering education or co-designing and planning services.

### Diversity is respected and health equity supported

Recognising and respecting differences in other people's views and lived experiences, and supporting their inclusion, is needed for partnerships to work well. The diversity of our community is a strength and includes people with different cultural backgrounds, religions, beliefs, sexual orientation, gender identity, ages, as well as those living with disabilities. Health service organisations need to consider and respond to this diversity in the way they communicate, partner with and care for the consumers they serve.

Recognising, respecting and responding to diversity is also important for improving health equity, so that everyone is able to reach their full potential for health and wellbeing. This includes fair and equal access to safe and high-quality care, regardless of where a person lives, their cultural background, religion, beliefs, medical conditions, disability, sexuality, age and socioeconomic status.

This is particularly important for Aboriginal and Torres Strait Islander peoples who remain disadvantaged in accessing health services, and experience poorer health outcomes than other Australians. Partnerships between health service organisations and local Aboriginal and Torres Strait Islander consumers and community representatives can help identify and remove barriers to culturally safe care.

## Types of partnerships

It is helpful to consider the type of partnerships operating in your health service organisation and how you and other consumer advocates can influence a move toward partnerships that have a higher level of consumer participation.

There are four main types of partnerships that develop between consumers and health service organisations.

The ideal partnership is a shared leadership approach. This is when consumers and health service organisations work together and engagement is high. There is respect, open communication, collaboration, shared information as well as shared leadership and decision-making. This way of engaging with consumers requires health service organisations move beyond a paternalistic approach to decision-making, which was often used in the past. Successful partnerships are non-hierarchical and recognise that consumers, clinicians and the health service organisation are all equal partners, sharing decisions about care.\*

### 1. Minimal partnership

This is where the service or clinician has put little effort into involving consumers and consumers do not feel that they are engaged, may feel powerless and marginalised. For example, the health service organisation may offer the services that it believes consumers want but has never asked consumers what they like and do not like about the service, and how they think it could be improved. The partnership is not meaningful.

### 2. Consumer-led partnership

This is where a consumer or a group of consumers actively advocates for change but does not get much engagement or response from the health service organisation. In this type of partnership, consumers may have raised complaints to a service or made submissions or petitions to a government agency with the hope of initiating improvements. Over time, if no improvements are made, consumers can become frustrated, and organisations can become less likely to listen. For example, after spending years calling for improved after-hours mental health services in a rural area, consumers escalate their complaint into a government petition because their concerns were not addressed.

### 3. Partnership/shared leadership

This is the type of partnership that can develop when consumers and health service organisations work together and engagement is high. There is respect, open communication, collaboration, information is shared, and leadership and decision-making are shared. For example, a health service organisation may invite consumers to join governance and project committees, and then work together to reach shared aims, or to design a new service.

### 4. Paternalistic

This type of partnership can develop when a health service organisation has a strong commitment to working with consumers, but only asks for feedback and advice from consumers when – and how – the organisation decides it is needed. In this type of partnership, a health service organisation may only work with consumers at a very basic level, without understanding their needs and partnering with them. For example, a health service organisation may ask consumers for feedback on a planning document after it has been written and there is little opportunity to provide meaningful input.

\* Coulter A. Paternalism or partnership? Patients have grown up – and there's no going back. *BMJ* 1999;319(7212):719–20



## What does partnership look like in practice?

There are multiple successful approaches to partnering with consumers. Table 2 shows different types of approaches, ranging from higher levels of consumer engagement and control to lower levels.

The examples can help you check where your organisation is operating and give ideas for activities your organisation could use to strengthen consumer engagement.

**Table 2:** Levels of consumer engagement

Engagement approach	Engagement level	Description	Examples
Consumer control	<p><b>HIGHEST</b></p> 	The organisation asks consumers, carers and the community to identify an issue, who then make all the key decisions on the development of solutions to deal with the issue, and the organisation supports them to accomplish this	Community-appointed management committees (e.g. Aboriginal community controlled health organisations)
Delegation		The organisation identifies an issue and presents this to consumers, carers and the community for them to make decisions or propose actions to deal with the issue	Shifting some or all the decision-making on particular issues to consumers. For example: spending on specific budget items, management of particular programs by consumers (e.g. mental health consumer advisory groups)
Partnership		The organisation identifies an issue and presents a tentative policy, plan or program that responds to the issue. The organisation seeks active involvement and feedback from consumers, carers and the community, which is incorporated into the plan	Strategic alliances built using a combination of methods (including those in information and consultation), such as: <ul style="list-style-type: none"> <li>■ Workshops</li> <li>■ Consumer representatives on committees or advisory groups</li> <li>■ Roundtables</li> <li>■ Patient forums</li> <li>■ Surveys</li> <li>■ Focus groups</li> </ul>

Engagement approach	Engagement level	Description	Examples
Consultation	 <b>LOWEST</b>	<p>The organisation identifies an issue and proposes a policy, plan or program that responds to the issue. It provides information to consumers, carers and the community on that proposal, and seeks views and comments to maximise acceptance</p>	<ul style="list-style-type: none"> <li>■ Workshops</li> <li>■ Consumer representatives on management committees or advisory groups</li> <li>■ Public meeting or patient forums</li> <li>■ Online discussion groups</li> <li>■ Circulation of proposal for comment</li> <li>■ Conferences or seminars</li> <li>■ Evaluation surveys</li> </ul>
Information		<p>The organisation develops or adopts a policy, plan or program, and provides information about this to consumers, carers and the community</p>	<ul style="list-style-type: none"> <li>■ Giving: flyers, mail-outs, fact sheets, brochures, newsletters, public displays, websites, public meetings</li> <li>■ Gathering: surveys, phone-ins, focus groups, in-depth interviews, suggestion boxes</li> </ul>

## Roles in supporting effective partnerships

The Partnering with Consumers Standard sets out how the relationship between consumers and health service organisations should work – as true partnerships, with shared leadership. While a health service organisation may decide how it wants to partner with consumers, consumers can influence

that relationship. Partnerships mean that there are commitments and responsibilities on both sides. Table 3 describes some of the ways both consumers and health service organisations can support effective partnerships.

**Table 3:** Roles in supporting effective partnerships

Level	What organisations can do	What consumers can do
Individual	<ul style="list-style-type: none"> <li>■ Encourage questions and be willing to answer them</li> <li>■ Provide clear information about potential benefits and harms of options for tests and treatment</li> <li>■ Consider consumer’s opinions, preferences, values and priorities</li> <li>■ Encourage self-monitoring and self-management</li> <li>■ Encourage shared decision making</li> <li>■ Be open to including friends or family members as part of the care team</li> <li>■ Understand, support and respect consumers’ culture, identities, beliefs and choices</li> </ul>	<ul style="list-style-type: none"> <li>■ Ask questions about your diagnosis and treatment options</li> <li>■ Share decisions about your care</li> <li>■ Be active in your own care</li> <li>■ Self-monitor and self-manage your own care as much as you can</li> <li>■ Ask to include your support people in your care</li> <li>■ If in doubt, get a second opinion</li> <li>■ Give the health service organisation feedback about care</li> </ul>

Level	What organisations can do	What consumers can do
Service, program or department	<ul style="list-style-type: none"> <li>■ Find ways to engage consumers in improving healthcare services</li> <li>■ Give consumers appropriate information on their roles and tell them how they add value to the project or committee</li> <li>■ Acknowledge and respect lived experience</li> <li>■ Listen and discuss issues, and be open to new ideas</li> <li>■ Provide an orientation to both the organisation and to the project/ committee</li> <li>■ Support consumers to do their roles. Look for and remove barriers to participation, including by having accessible and inclusive ways to communicate</li> </ul>	<ul style="list-style-type: none"> <li>■ Take time to understand the project and issues to be discussed</li> <li>■ Ask for an orientation and/ or training session about the organisation, the project and your role</li> <li>■ Be active in meetings and consultations</li> <li>■ Make suggestions and offer advice</li> <li>■ Suggest wider consultation with the community or local community groups if broader opinions need to be heard</li> <li>■ Respect the views of others</li> <li>■ Ask questions respectfully and offer constructive, balanced advice</li> <li>■ Ask for support to help you in meetings, including asking to have a carer present, and asking about accessibility and inclusive communication needs</li> </ul>



Level	What organisations can do	What consumers can do
<p><b>Health service organisation</b></p>	<p>As for the service program or department level, plus:</p> <ul style="list-style-type: none"> <li>■ Have policies and procedures to support partnerships with consumers</li> <li>■ Offer training to consumer representatives</li> <li>■ Train and support staff on how to support consumers</li> <li>■ With consumers, develop a consumer engagement strategy that describes how the organisation plans to partner with consumers in planning, designing, measuring and evaluating the health service organisation</li> <li>■ Offer development opportunities for consumer representatives – for example, invite consumers to attend networking events to expand their knowledge of issues or to present on the results of consumer-led initiatives</li> <li>■ Pay or reimburse consumers for their time whenever possible</li> <li>■ Use feedback from consumer representatives to continually improve partnerships</li> </ul>	<p>As for the service, program or department level, plus:</p> <ul style="list-style-type: none"> <li>■ Suggest ways to seek advice from the community, including diverse groups in the community</li> <li>■ Ask how consumers can help plan and review services delivered by the organisation</li> <li>■ Ask about opportunities to attend information sessions or forums to learn about specific issues</li> <li>■ Ask to meet with other consumer representatives to build networks, get support and be more aware of issues affecting consumers across the organisation</li> </ul>

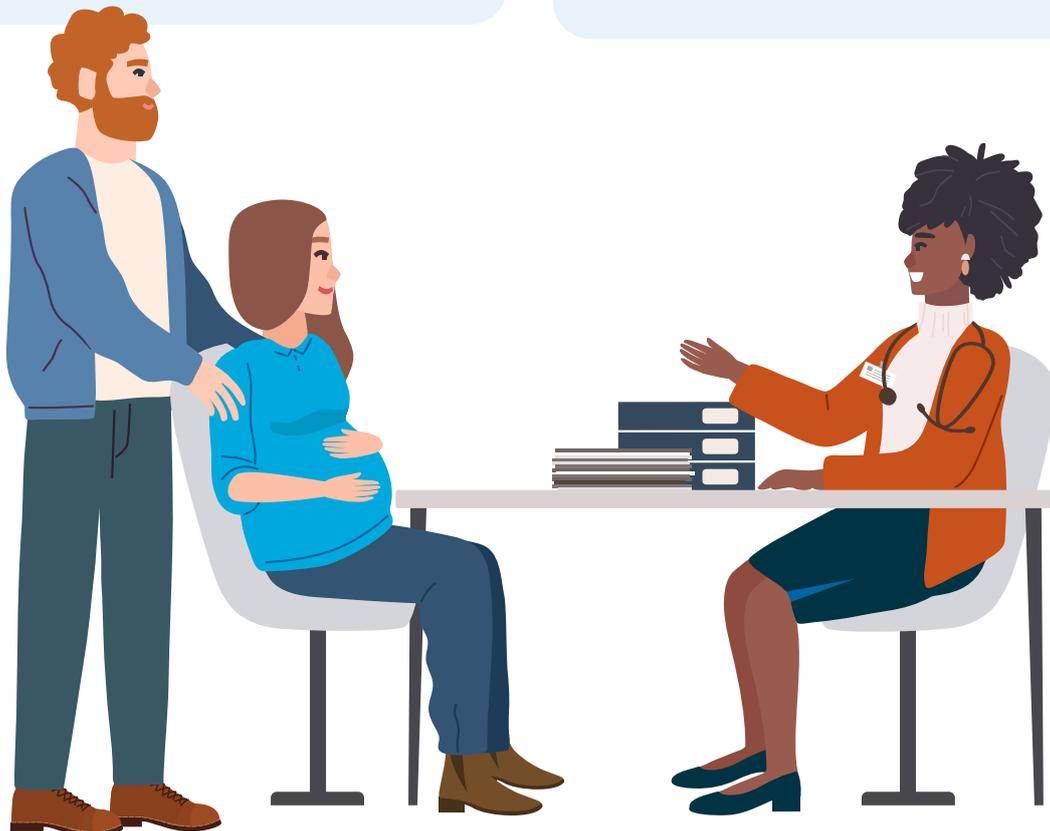
Level	What organisations can do	What consumers can do
Health system	<p>As for the health service organisation and service, program or department levels, plus:</p> <ul style="list-style-type: none"> <li>■ Engage a diverse mix of consumers</li> <li>■ Describe how you will engage consumers at a higher level and how the work benefits consumers</li> <li>■ Find out if there are national and/or state or territory policies that guide and support consumer engagement</li> <li>■ Make sure consumer representatives are given information and training to support them in their role</li> <li>■ Support consumers through briefings and debriefings</li> <li>■ Recognise consumer representatives are equals and support them to participate in high-level meetings</li> </ul>	<p>As for the health service organisation and service, program or department levels, plus:</p> <ul style="list-style-type: none"> <li>■ Develop skills in communicating the views of consumers to different audiences, including organisations and policy makers</li> <li>■ Ask for support and training</li> <li>■ Read and learn more about initiatives to support consumers in the organisation and across the state or territory</li> <li>■ Ask about opportunities to help train staff or to present at information sessions; sharing consumer experiences can help staff learn more about how decisions and policies affect consumers</li> </ul>

### Reflective questions for consumers

- Is the diversity of consumers recognised and supported so that they can actively contribute?
- Is the health service organisation working on building relationships with the local community to improve the way care is delivered?
- How are you invited to partner with health service organisations and what type of relationship do you have (minimal, consumer-led, partnership/shared leadership, paternalistic)?
- Is the partnership working well and are there things about the partnership that you would like to discuss with the health service organisation?
- How can you influence the way health service organisations partner with you?
- Have you looked at some of the key resources and links in [Further reading](#)?

### Reflective questions about health service organisations

- How would you describe the organisation's partnerships and relationships with consumers?
- Do you have a consumer engagement strategy in place to guide how the organisation involves consumers?
- How do you ensure partnerships reflect the diversity of consumers that use the health service organisation and the diversity within the local community?
- Which type of relationship does the organisation have with consumers (minimal, consumer-led, partnership, paternalistic)?
- How could you improve the way that the organisation partners with consumers?
- Is mentoring and training available for new consumer representatives?
- Have you looked at some of the key resources and links in [Further reading](#)?



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## Further reading

### From the Commission

**Case studies for delivering person-centred care and implementing the Partnering with Consumers Standard** (2021). These case studies are designed to assist health services to implement person-centred care and consumer partnerships. Available from: [safetyandquality.gov.au/our-work/partnering-consumers/case-studies-delivering-person-centred-care-and-implementing-partnering-consumers-standard](https://safetyandquality.gov.au/our-work/partnering-consumers/case-studies-delivering-person-centred-care-and-implementing-partnering-consumers-standard).

**NSQHS Standards User Guide for Measuring and Evaluating Partnering with Consumers** (2018). A tool for organisations to use when developing plans to monitor and evaluate how well they are implementing the Partnering with Consumers Standard. Available from: [safetyandquality.gov.au/publications-and-resources/resource-library/nsqhs-standards-user-guide-measuring-and-evaluating-partnering-consumers](https://safetyandquality.gov.au/publications-and-resources/resource-library/nsqhs-standards-user-guide-measuring-and-evaluating-partnering-consumers).

**Cognitive impairment resources** (2020). Information for people with cognitive impairment, their carers and family members. Resources to help health service organisations improve the quality of care and health outcomes for people with cognitive impairment or at risk of delirium. Available from: [safetyandquality.gov.au/our-work/cognitive-impairment/cognitive-impairment-resources](https://safetyandquality.gov.au/our-work/cognitive-impairment/cognitive-impairment-resources).

**NSQHS Standards User Guide for Aboriginal and Torres Strait Islander Health** (2017). There are six actions in the NSQHS Standards that specifically meet the needs of Aboriginal and Torres Strait Islander peoples. This guide provides practical strategies about what to consider in any health service organisation. It also provides practical examples from across Australia that demonstrate that these actions can be, and are being, implemented in health service organisations. Available from: [safetyandquality.gov.au/our-work/aboriginal-and-torres-strait-islander-peoples](https://safetyandquality.gov.au/our-work/aboriginal-and-torres-strait-islander-peoples).

### From other organisations

**Consumer Representatives Program resources**, Consumers Health Forum of Australia. Available from: [chf.org.au/representation/resources](https://chf.org.au/representation/resources).

**Consumers Toolkit: A toolkit to support consumers to engage**, Health Consumers NSW. Available from: [hcnsw.org.au/consumers-toolkit](https://hcnsw.org.au/consumers-toolkit).

**A Guide for Consumers: Partnering with Health Organisations** (2018), Health Consumers Queensland. Available from: [hcq.org.au/wp-content/uploads/2018/06/HCQ\\_ConsumerGuide.pdf](https://hcq.org.au/wp-content/uploads/2018/06/HCQ_ConsumerGuide.pdf).

**A Guide for Health Staff: Partnering with Consumers** (2018), Health Consumers Queensland. Available from: [hcq.org.au/wp-content/uploads/2018/06/HCQ\\_StaffGuide.pdf](https://hcq.org.au/wp-content/uploads/2018/06/HCQ_StaffGuide.pdf).

**Toolkit for Consumer Advocates** (2019), Health Issues Centre. Available from: [hic.org.au/toolkit-for-consumer-advocates](https://hic.org.au/toolkit-for-consumer-advocates).

**National Framework for Consumer Involvement in Cancer Control** (2011), Cancer Australia and Cancer Voices Australia. An example of a national organisation's framework for engaging consumers in their work. Available from: [canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/national-framework-consumer-involvement-cancer-control](https://canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/national-framework-consumer-involvement-cancer-control).

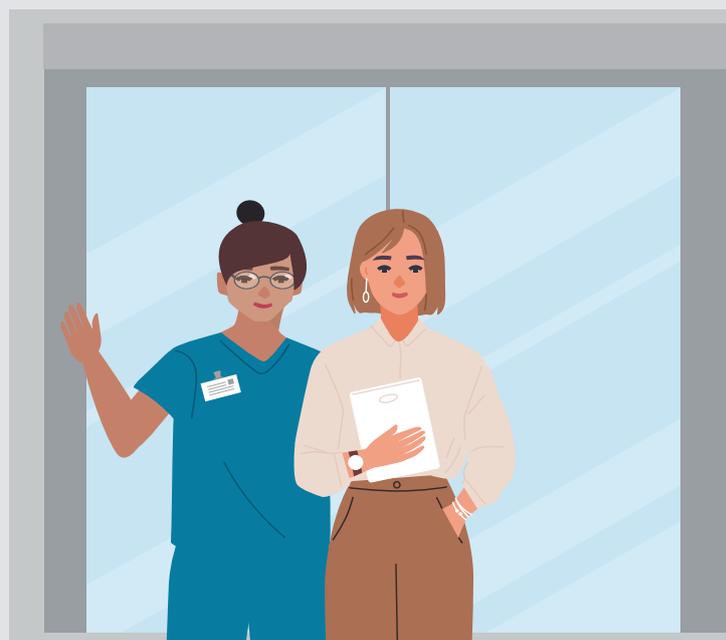
**Partnering in healthcare framework** (2019), Safer Care Victoria. An example of a statewide framework for engaging consumers. Available from: [safercare.vic.gov.au/publications/partnering-in-healthcare](https://safercare.vic.gov.au/publications/partnering-in-healthcare).

# Chapter 4

## Building skills and consumer leadership

This chapter discusses new and emerging roles for consumers and the challenges that these new roles may bring. It explains:

- Consumer leadership and roles for consumer leaders
- Partnership challenges
- Building skills and capabilities as a consumer.



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## Consumer leadership and roles for leaders

The Partnering with Consumers Standard has led to many new roles for consumers. As a result, many consumers may find themselves on a journey towards leading change. The Consumers Health Forum paper *Shifting Gears – Consumers*

*transforming health*\* identified that consumers are change agents and help organisations transform the way they deliver health services. Table 4 describes some of the key roles for consumers.

**Table 4:** Key roles for consumers in a person-centred health system

Level	Role	Description	Consumer responsibility
Individual	Expert patient	Consumer who wants to be active in making decisions about their own care	<ul style="list-style-type: none"><li>■ Is well informed</li><li>■ Is confident</li><li>■ Is highly motivated</li><li>■ Is empowered</li></ul>
Service, program or department	Consumer representative	Consumer who works with a health service to provide advice and feedback on a service or a quality improvement project	<ul style="list-style-type: none"><li>■ Shares their own experiences</li><li>■ Offers a unique perspective to inform improvements</li><li>■ Asks questions to make sure consumers are involved in identifying problems, how they affect consumers, and in planning and decision-making to find solutions</li></ul>

\* Available at: [chf.org.au/publications/shifting-gears-consumers-transforming-health](http://chf.org.au/publications/shifting-gears-consumers-transforming-health).

Level	Role	Description	Consumer responsibility
Health service organisation	Co-designer	Consumer who works with health service planners, providers, clinicians, managers and other stakeholders to co-design and create service models, clinical pathways and other projects	<ul style="list-style-type: none"> <li>■ Understands consumers' views and needs</li> <li>■ Has excellent communication and relationship skills</li> <li>■ Is confident</li> <li>■ Is calm</li> <li>■ Asks questions that help understand the issues</li> </ul>
	Research collaborator	Consumer who is a partner with researchers in deciding the research question, and in designing the methodology	<ul style="list-style-type: none"> <li>■ Understands the reason for the research, how it will be conducted, and how it will be used</li> <li>■ Brings their lived experience to the research so that the right questions are being asked</li> </ul>
	Educator	Consumer contributes to a curriculum or education program, and can co-deliver courses, such as training health professionals	<ul style="list-style-type: none"> <li>■ Uses lived experience to help others understand and relate to consumer needs and views</li> <li>■ Has skills in developing training programs</li> </ul>

<b>Level</b>	<b>Role</b>	<b>Description</b>	<b>Consumer responsibility</b>
<b>Health system</b>	Change agent	Consumer who can bring insights and wisdom to transform healthcare priorities, policy and spending	<ul style="list-style-type: none"> <li>■ Has skills in framing questions</li> <li>■ Draws on their experience</li> <li>■ Has good ideas for solutions</li> <li>■ Has skills in systems thinking</li> <li>■ Influences others</li> </ul>
	Policy influencer	Consumer who can bring their experience and understanding to make policy more inclusive and able to meet different experiences and expectations	<ul style="list-style-type: none"> <li>■ Understands the policy context</li> <li>■ Influences others</li> </ul>
	Governance steward	Consumer can join boards and high-level decision-making committees	<ul style="list-style-type: none"> <li>■ Has experience in, and understanding of, governance</li> <li>■ Offers independent advice and opinion from a consumer/ community point of view</li> <li>■ Understands and can analyse board reports</li> </ul>

## Partnering challenges

Consumers working with health service organisations often face hurdles and difficulties. These challenges to effective partnering will be different in each place, role, and service. Challenges may include:

- Not being part of the early planning or start of a project
- Being the only consumer on a large committee
- Not feeling welcome, valued, listened to, or feeling unable to ask questions
- Not getting enough support
- Feeling unprepared for the role, for example, not properly introduced or trained
- Lacking the right information or tools to do the role well
- Previously unseen documents being tabled at meetings for endorsement
- Poor organisational culture, including staff, managers or board members not understanding the role of consumer representatives or value of partnering with consumers
- The organisation not understanding how person-centred care is related to safe and high-quality care.

***'The culture of health service organisations needs to change to enable partnering with consumers to occur.'***

Consumers dealing with these challenges should:

- Remember relationships take time and effort on both sides
- Share concerns with the group, the committee Chair or a person in the organisation (for example, the Director of Community Engagement)
- Ask for a briefing from the health service organisation
- Ask for guidance from other experienced consumers, without breaking confidentiality
- Know it is reasonable to say 'no' to being involved if there is inadequate support to do the role
- Remember that consumers are the experts on lived experience, which is important and is supported by the Partnering with Consumers Standard
- Ask for extra time to consider a document that is shared at a meeting, that has not been seen before, or if they are not confident making a decision at the meeting
- Share information from the Commission and other trusted sources to support improvement
- Share this Guide with others in the health service to start a positive discussion
- Advocate for staff, managers and board members to have training on the Partnering with Consumers Standard, so that they can better support consumers.

Creating a positive and person-centred organisational culture takes time and ownership from everyone within the organisation. There are some practical resources available that support building a positive organisational culture (see [Further reading](#) for practical ideas such as beginning meetings with a consumer story as a reminder about what is important).

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## Building skills and capabilities

There are many pathways for consumers to build the skills they need as consumer representatives, advocates and partners with health service organisations. Consumers can:

- Look for training that will help build skills and confidence. A good start would be to contact a state or territory consumer health organisation, that can train people in consumer advocacy and leadership, or point people in the right direction
  - Ask the health service organisation about paying for training and development to support the consumer advocacy/representative role
  - Contact state and territory consumer health organisations to find guides about the consumer advocacy role and webinars about current healthcare issues important to consumers
  - Prepare for meetings by researching the issues to be discussed and making notes on any reading material sent out before meetings
  - Network with other consumers to get their ideas and suggestions for ways to improve partnerships with consumers
  - Find more experienced consumer representatives and advocates to act as mentors or to provide advice and support
  - Ask the health service organisation about development opportunities – for example, attending workshops or conferences about safety and quality issues and presenting at staff training courses by sharing own experiences of care.
- Health service organisations can also help consumers to fulfill their roles and develop further by offering:
- Orientation and induction processes
  - A review session three to six months after starting in the role
  - Briefings and debriefings around meetings and activities
  - Payments that recognise and value their contributions
  - Mentoring programs, a buddy system or similar program for new and emerging representatives and advocates
  - Development opportunities for consumers in leadership roles; consumers can be considered for leadership roles and supported with leadership training to perform at this level
  - Access to a network of consumers as a community of practice
  - The support of a dedicated member of staff or team (for example, consumer consultants or peer advisors) that is responsible for supporting consumer representatives and helping consumers develop in their roles.

### Reflective questions for consumers

- Are you experiencing any challenges in your current role?
- How would you like to grow and develop as a consumer representative, advocate or leader?
- What training and development opportunities are available?
- Have you considered joining your state or territory consumer health organisation and the Consumers Health Forum?
- Are you looking after yourself?

### Reflective questions about health service organisations

- Does the organisation have a positive, person-centred culture?
- How does the organisation involve consumers and are there any challenges?
- Does the organisation have a plan that describes the process for supporting and developing the skills and capability of consumer representatives and advocates?
- Have you talked to consumers about training and development opportunities?
- Do you have supports in place for the network of consumers?
- How are you helping consumers to partner with the organisation?
- Do staff, including managers, have access to training on how to support delivery of care that aligns with partnering with consumers?



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## Further reading

### From the Commission

**Attributes of person-centred healthcare organisations** (2018). A report describing the characteristics of organisations that deliver excellent person-centred care. For organisations, a self-assessment tool, presentation slides and case studies are available to help plan improvements. Available from: [safetyandquality.gov.au/our-work/partnering-consumers/person-centred-healthcare-organisations](https://safetyandquality.gov.au/our-work/partnering-consumers/person-centred-healthcare-organisations).

**Case studies for delivering person-centred care and implementing the Partnering with Consumers Standard** (2021). These case studies are designed to assist health services to implement person-centred care and consumer partnerships. Available from: [safetyandquality.gov.au/our-work/partnering-consumers/case-studies-delivering-person-centred-care-and-implementing-partnering-consumers-standard](https://safetyandquality.gov.au/our-work/partnering-consumers/case-studies-delivering-person-centred-care-and-implementing-partnering-consumers-standard).

### From other organisations

**Shifting Gears – Consumers transforming health** (2018). A report that describes the shifts that need to occur to ensure our health system is fit-for-purpose. Describes current and future roles for consumers in the health system in order to achieve innovation and improvement. Available from: [chf.org.au/publications/shifting-gears-consumers-transforming-health](https://chf.org.au/publications/shifting-gears-consumers-transforming-health).

**‘Bite Sized’ Exercises and Discussion Prompts to Reinforce Culture** (2017), Planetree. These exercises are designed to be concise enough to be incorporated into brief huddles or team meetings. Available from: [resources.planetree.org/wp-content/uploads/2017/03/PT-Bite-Sized-Exercises-to-Reinforce-Culture-2017.pdf](https://resources.planetree.org/wp-content/uploads/2017/03/PT-Bite-Sized-Exercises-to-Reinforce-Culture-2017.pdf).

# Glossary

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**Australian Charter of Healthcare Rights:** specifies the key rights of consumers when seeking or receiving healthcare services. It was endorsed by health ministers in 2008. A second edition was released in 2019.

**carer:** a person who provides personal care, support and assistance to another individual who needs it because they have a disability, medical condition (including a terminal or chronic illness) or mental illness, or they are frail or aged. A person is not a carer merely because they are a spouse, de facto partner, parent, child, other relative or guardian of a person, or live with a person who needs care. A person is not considered a carer if they are paid, a volunteer for an organisation, or caring as part of a training or education program.

**clinical governance:** an integrated component of corporate governance of health service organisations. It ensures that everyone – from frontline clinicians to managers and members of governing bodies, such as boards – is accountable to patients and the community for assuring the delivery of safe, effective and high-quality services. Clinical governance systems provide confidence to the community and the health service organisation that systems are in place to deliver safe and high-quality health care.

**clinician:** a healthcare provider who is trained as a health practitioner, including registered and non-registered practitioners. They may include nurses, doctors, allied health practitioners, technicians, scientists and other people who provide health care, and students who provide health care under supervision.

**consumer:** a consumer is a person, or a carer of a person, who has used, or may use, health services. A healthcare consumer may also act as a consumer representative or advocate to give a consumer view, contribute consumer experiences, advocate for the interests of current and potential health service users, and take part in decision-making processes.

**consumer representative or advocate:** a consumer advocate is a person who offers a consumer perspective and consumer experiences, and who advocates and takes part in decision-making processes in the interests of health service users.

**governance:** the way an organisation is managed, directed and held accountable for achieving its goals. Governance arrangements include the structures, systems and processes that control how an organisation operates. This can include the board, constitution, sub-committees and policies, that work to:

- Deliver valuable client services
- Manage risk
- Make sure accountability mechanisms are set up
- Manage issues as they come up.

**health literacy:** has two components – individual health literacy and the health literacy environment. Individual health literacy is the skills, knowledge, motivation and capacity of a consumer to access, understand, appraise and apply information to make effective decisions about health and health care, and take appropriate action. The health literacy environment is the infrastructure, policies, processes, materials, people and relationships that make up the health system, which affect the ways in which consumers find and use health-related information.

**health service organisation:** involves a group of clinicians and others working together in a system to deliver health care to patients in any place or setting, including pharmacies, clinics, outpatient clinics, hospitals, community settings, general practices and clinicians' rooms. It delivers health services, including administration and finances.

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**health system:** the whole structure of health service delivery, including Australian, state and territory, public and private, community and not-for-profit sectors. There are many funding roles and responsibilities across the system. They all need to work together to deliver comprehensive and integrated health care to consumers.

**partnering with consumers:** when consumers work together in a collaborative relationship with clinicians and/or the health service organisation. This may happen in different ways and at different levels, including a patient or carer with their clinician, at an organisational level on a committee or project, and at a system level with consumers and groups in the community. Partnering with consumers requires health service organisations to involve consumers and their families/carers in all parts of their care, and in planning and delivering services.

**patient:** a person who is receiving care in a health service organisation.

**person-centred care:** healthcare that is respectful to the patient, their family and carers, and responds to the person's preferences, needs and values.

**shared decision making:** a consultation process where a clinician and a patient make a health decision together after discussing the options, and their benefits and harms. The clinician should also have considered the patient's values, preferences and other circumstances.

**Standards:** also known within the health system as the National Safety and Quality Health Service Standards or NSQHS Standards. The Standards have been developed by the Australian Commission on Safety and Quality in Health Care to guide health service organisations to deliver their services. They have been designed to protect the public from harm and to improve the quality of health services. All health service organisations must comply with the Standards.

**workforce:** all people working in a health service organisation, including clinicians and any other employed or contracted locum, agency, student, volunteer, peer and support workers. Members of the workforce have roles and responsibilities for care and support of patients.

# Important websites

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## Australian Commission on Safety and Quality in Health Care

[safetyandquality.gov.au](https://safetyandquality.gov.au)

This website provides detailed information on the Standards, accreditation and the *Australian Charter of Healthcare Rights*. It includes fact sheets, user guides, posters and other resources.

## Consumers Health Forum of Australia (CHF)

[chf.org.au](https://chf.org.au)

CHF is the national peak body for consumers in Australia. This website for consumers offers information on national policy and issues important to health consumers.

## State and territory health consumer peak organisations

These organisations have a network of consumers who can work with health service organisations. Most of the peak organisations offer training for consumers who would like to be advocates. The consumer organisations have lots of helpful resources and programs.

### Australian Capital Territory

Health Care Consumers' Association:  
[hcca.org.au](https://hcca.org.au)

### New South Wales

Health Consumers NSW:  
[hcnsw.org.au](https://hcnsw.org.au)

### Queensland

Health Consumers Queensland:  
[hcq.org.au](https://hcq.org.au)

### Tasmania

Health Consumers Tasmania:  
[healthconsumerstas.org.au](https://healthconsumerstas.org.au)

### Victoria

Health Issues Centre:  
[hic.org.au](https://hic.org.au)

### Western Australia

Health Consumers' Council:  
[hconc.org.au](https://hconc.org.au)

# Acknowledgments

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The Australian Commission on Safety and Quality in Health Care (the Commission) engaged the Consumers Health Forum of Australia (CHF) to develop this Guide. The Partnering with Consumers Standard is regarded as fundamental to all the other National Safety and Quality Health Service Standards. This project reflects the Commission's commitment to supporting consumer understanding of the Standards, and the vital role of consumer partnerships in delivering safe and high-quality health care in Australia.

CHF and consumers co-designed this Guide, with direction from a consumer-led Project Advisory Committee, comprising:

- John Borovac
- Peter Button
- Melissa Cadzow
- Maria Dimopoulos
- Lana Earle-Bandaralage
- Rebecca Edwards
- Debra Letica
- Brian Osborne
- Sabi Nabi
- Sharon Taylor.

CHF engaged a consultant, Jennie Parham, who worked with the Project Advisory Committee to co-design this Guide. A wide variety of consumers were consulted, from diverse consumer groups and demographics, different states and territories and urban, rural and regional areas in developing the content, format and design of this Guide. Advice was also sought from consumer representatives and staff from the following organisations:

- State and territory health consumer peak organisations
- The Rural and Remote Special Interest Group (CHF)
- The Quality and Safety Special Interest Group (CHF)
- The Youth Health Forum (CHF)
- Safer Care Victoria
- The NSW Agency for Clinical Innovation.

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This Guide will help both consumers and health service organisations to foster and develop effective partnerships that drive person-centred care in the health system.

# Appendix

## National Safety and Quality Health Service Standards



Standard	Purpose	Criteria
 <b>Clinical Governance</b>	To make sure that a clinical governance framework is in place and the workforce is competent and skilled in providing safe and high-quality care	<ul style="list-style-type: none"> <li>■ Governance, leadership and culture</li> <li>■ Patient safety and quality systems</li> <li>■ Clinical performance and effectiveness</li> <li>■ Safe environment for the delivery of care</li> </ul>
 <b>Partnering with Consumers</b>	To make sure that health services partner with consumers in their own care as well as the design, delivery and evaluation of health services	<ul style="list-style-type: none"> <li>■ Clinical governance and quality improvement systems to support partnering with consumers</li> <li>■ Partnering with patients in their own care</li> <li>■ Health literacy</li> <li>■ Partnering with consumers in organisational design and governance</li> </ul>
 <b>Preventing and Controlling Infections</b>	To reduce the risk of patients getting preventable infections, effectively manage them if they occur and limit the development of antimicrobial resistance	<ul style="list-style-type: none"> <li>■ Clinical governance and quality improvement systems are in place to prevent and control infections, and support antimicrobial stewardship and sustainable use of infection prevention and control resources</li> <li>■ Infection prevention and control systems</li> <li>■ Reprocessing of reusable equipment and devices</li> <li>■ Antimicrobial stewardship</li> </ul>
 <b>Medication Safety</b>	To make sure that medicines are safely prescribed and dispensed, and patients are given appropriate information about their medicines	<ul style="list-style-type: none"> <li>■ Clinical governance and quality improvement to support medication management</li> <li>■ Documentation of patient information</li> <li>■ Continuity of medication management</li> <li>■ Medication management processes</li> </ul>

Standard	Purpose	Criteria
 <b>Comprehensive Care</b>	<p>To make sure that consumers receive comprehensive care that is targeted to their goals and needs, and that the risk of patient harm is managed</p>	<ul style="list-style-type: none"> <li>■ Clinical governance and quality improvement to support comprehensive care</li> <li>■ Developing the comprehensive care plan</li> <li>■ Delivering comprehensive care</li> <li>■ Minimising patient harm</li> </ul>
 <b>Communicating for Safety</b>	<p>To make sure that there is an appropriate level of coordination and communication between service providers, patients and their carers/family members</p>	<ul style="list-style-type: none"> <li>■ Clinical governance and quality improvement to support effective communication</li> <li>■ Correct identification and procedure matching</li> <li>■ Communication at clinical handover</li> <li>■ Communication of critical information</li> <li>■ Documentation of information</li> </ul>
 <b>Blood Management</b>	<p>To make sure that patients' own blood is optimised and conserved, and any blood products they receive are appropriate and safe</p>	<ul style="list-style-type: none"> <li>■ Clinical governance and quality improvement to support blood management</li> <li>■ Prescribing and clinical use of blood and blood products</li> <li>■ Managing the availability and safety of blood and blood products</li> </ul>
 <b>Recognising and Responding to Acute Deterioration</b>	<p>To make sure that acute deterioration in a patient's physical, mental or cognitive condition is recognised promptly and appropriate action is taken</p>	<ul style="list-style-type: none"> <li>■ Clinical governance and quality improvement to support recognition and response systems</li> <li>■ Detecting and recognising acute deterioration, and escalating care</li> <li>■ Responding to acute deterioration</li> </ul>



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