HCQ
HEALTH CONSUMERS
QUEENSLAND

A Guide for Consumers

Partnering with Health Organisations

Acknowledgement of Traditional Owners

Health Consumers Queensland acknowledges the First Nations peoples who are the traditional custodians of the land on which we live, work, and play. We pay our respects to Elders past and present of the Aboriginal and Torres Strait Islander peoples as cultural authorities of the world's two oldest living cultures.

Use of term First Nations

Health Consumers Queensland has chosen to use the term First Nations to refer to Aboriginal people and Torres Strait Islander people throughout this document. The authors recognise and respect the differing opinions held by Aboriginal people and Torres Strait Islander people about terminology used to describe their culture and has chosen the term First Nations for inclusivity.

Health Consumers Queensland recognises the difference between Aboriginal peoples' and Torres Strait Islander peoples' culture and the diversity within language groups, clans and tribes within Australia.

First published May 2018. Revised November 2025.

Suggested citation:

A Guide for Consumers – Partnering with Health Organisations 2025. Health Consumers Queensland, Brisbane.

Acknowledgements

In developing *A Guide for Consumers – Partnering with Health Organisations* we have collaborated with health consumers and carer representatives. We would like to thank all those who contributed to the document including consumers and Queensland Hospital and Health Service engagement staff.

Proudly supported by

Queensland Government

Health Consumers Queensland is a not-for-profit organisation and health promotion charity registered with the Australian Charities and Not-for-profits Commission (ACNC).

Contents

1. Introduction

About Health Consumers Queensland

Health Consumers Queensland (HCQ) is the peak body representing consumers of the health system, their loved ones and carers in Queensland. By elevating and amplifying the diverse voices and lived experiences of consumers, and by advocating on their behalf, we are building more responsive public and private health services and systems for all Queenslanders.

Health Consumers Queensland is a leader in consumer engagement and participation, and we build on our strengths and capabilities to address emerging challenges faced by the health system and the evolving needs of consumers. We represent diverse groups of people who come from different backgrounds, cultures, genders, sexualities, bodies, and abilities, recognising that these perspectives are essential in shaping our health service delivery, planning, and evaluation.

We are committed to building and supporting a network of consumer representatives that reflects our community's richness – including rural, regional, and remote areas; varied faith, language, educational, and socio-economic groups; and all ages. In particular, we uphold strong, respectful, and genuine partnerships with Aboriginal and Torres Strait Islander communities, ensuring that First Nations voices remain at the forefront of decisions affecting their healthcare.

Purpose of the Guide

A Guide for Consumers – Partnering with Health Organisations gives practical, step-by-step advice for anyone who wants to partner with healthcare services to improve care. You might be called a health consumer, a health advocate, a consumer consultant or a consumer/carer representative. This guide is helpful no matter where you are in your partnering journey including:

- People who are curious about what it means to partner with healthcare services
- Newcomers who want to start representing patient needs but aren't sure how
- Experienced consumers looking to refresh their knowledge or find solutions to specific challenges they're facing.

This Guide complements our *Consumer and Community Engagement Framework* and sits alongside our health staff-focused guide, *A Guide for Health Staff – Partnering with Consumers*. Together, the Guides provide advice and practical information to make consumer partnerships more productive and effective.

How to use the Guide

The guide is divided into 7 separate sections that provide information, practical guidance and the opportunity to reflect. It is designed for you to be able to dip in, depending on your interests, experiences and what's important to you.

Throughout this Guide, Health Consumers Queensland will share opportunities to learn more through:

Real-world examples

Questions to ask

Things to keep in mind

Further reading and resources can be found in Section 7 with an introductory glossary.

We thank you for your commitment to making a difference in people's lives and the contribution you make as a health consumer in Queensland.

2. What does it take to be a consumer representative?

Who is a consumer representative?

A **'consumer representative'** is someone who ***represents the viewpoint of consumers*** who access health services and/or are impacted by policies, research and changes to the health system. Consumer representatives give voice to consumer perspectives by providing feedback and advice, as well as taking part in decision-making on behalf of all consumers.

Consumer representatives can also be known as Advocates, Consumer Leaders, Consumer Advisors, Community Champions or Consumer Consultants. Keep in mind that every organisation is different and may have their own interpretation of what these words mean to them, their community and for the work they do.

Patient and Consumer – What's the difference?

- The term **'patient'** is used to refer to a person who is ***receiving*** healthcare services.
- The term **'consumer'** is used to refer to a person who ***has used or may use*** a healthcare service. All people who access public, private and community health services, as well as their family and carers, are health consumers.

> **"Consumer Representatives are community members who choose to get involved with the health service more systematically in service improvement activities to represent the voice of consumers."**
>
> – from *Patient Experience Journal*[1]

Consumer representative role and responsibilities

Health consumer representatives draw on their lived experience and insights to help shape and improve the planning, design, delivery, measurement, and evaluation of healthcare systems for the benefit of all.

Key elements of your role may include:

Experience and insight: The consumer voice is a powerful tool in influencing healthcare decisions. Your lived experience and community insight make your perspective uniquely valuable. While you are not expected to represent every viewpoint, you can ask questions and raise perspectives that might otherwise be missed at the table. Your lived experience is core to the consumer role.

Listen and enquire: As a consumer representative, it's important to stay informed and curious. This means understanding the context of the work you're involved in – whether it's the health issue at hand, the purpose of the activity, or the potential impact on other consumers. This isn't about being an expert, but about being actively engaged and willing to learn which is key to making meaningful contributions.

Build relationships: Consumer partnering is grounded in relationships built on partnership, respect, dignity, inclusion, and a shared commitment to improvement. To be effective, invest in building positive relationships with health staff, fellow consumers, and your community. Trust takes time – and ongoing effort – to establish and maintain. Partnerships work best when there is trust.

Keep in mind: You don't need to have a health background or know everything about the health system to be a consumer representative. Everyone is learning – including health staff and other consumer representatives. Consumer representatives are not employees or paid consultants. They don't work for a health organisation. Instead, many represent different groups or communities and this gives them a good understanding of people's experiences and needs.

Question and challenge: One of the most important things a consumer representative can do is to ask questions. You are not expected to have all the answers. Instead, your role is to challenge assumptions and encourage those around you to look at things from a person-centred perspective.

Commitment and motivation: Anyone who uses health services is a consumer, but being a **consumer representative** carries additional responsibilities. It requires commitment, motivation, and a willingness to contribute to the ongoing work of improving health outcomes and experiences for all Queenslanders.

Every one of us is a health consumer. At some point, we all have accessed, or will access, health services...

...healthcare professionals, and other government employees, cannot hold these roles and represent consumers at the same time.

Only those people whose primary experience is as a consumer can represent consumer views because their perspective is not conflated with their other roles in health.

Skills, knowledge and experience

Knowing your skills, knowledge, and lived experience can help you contribute effectively as a consumer representative. Knowing your strengths may also help you to apply for consumer representative roles.

Use our self-assessment tool – tick what skills, knowledge and experience you have, highlight what you want to build on, and reflect on how your strengths contribute to your role.

Skills

You may have developed skills through work, volunteering, hobbies or life experience that help you participate, influence, and collaborate effectively. Consider skills such as:

- Communication (written, verbal, public speaking)
- Listening and empathy
- Problem-solving and creative thinking
- Teamwork and collaboration
- Leadership and initiative.

Knowledge

Your knowledge may be formal or informal and could be related to your life experience, the environment you are working in and the systems you are influencing. For example:

- Health system and service navigation
- Community perspectives and diverse voices
- Consumer rights and responsibilities
- Research and evidence-based decision making
- Cultural awareness
- Speaking another language.

Knowledge can be formal or informal and is always growing.

Experience

Your personal, lived, and learned experience is what makes your voice unique and may include:

- Using health services (as a patient or carer)
- Supporting others in healthcare settings
- Participating in community or advocacy groups
- Learning through adversity or challenge
- Navigating systems (e.g. NDIS, aged care, mental health)
- Understanding under-represented or marginalised perspectives.

There is no 'right' type of experience – what matters is your insight and your willingness to contribute.

"I became a consumer representative to give back to the community in some way the knowledge and skills I had gained by interfacing with community members on a daily basis who were from many different cultures from around the world, and from being appointed to positions which gave me the privilege of teaching/educating the next generation of health care professionals at all levels in different countries and in many towns in Queensland."

– Dawn Hay, member Central Queensland Hospital and Health Service Consumer and Community Advisory Committee

Consumer representative self-assessment tool

Purpose: This tool will help you identify the skills, experience and knowledge you might bring to your consumer representative role. It will also help you to reflect on your current strengths and identify areas you'd like to grow in as a consumer representative. There are no right or wrong answers – this is about self-awareness and development.

Instructions:

For each item, tick the box that best represents where you are now.

Section 1: Skills	I feel confident in this	I'm developing this	I'd like support with this
Communication (verbal/written)	☐	☐	☐
Listening and empathy	☐	☐	☐
Problem-solving	☐	☐	☐
Creative thinking	☐	☐	☐
Teamwork and collaboration	☐	☐	☐
Negotiation and conflict resolution	☐	☐	☐
Time management and organisation	☐	☐	☐
Analysis and attention to detail	☐	☐	☐
Adaptability and learning	☐	☐	☐
Leadership and initiative	☐	☐	☐

Section 2: Knowledge	I feel confident in this	I'm developing this	I'd like support with this
Health system understanding	☐	☐	☐
Community perspectives	☐	☐	☐
Consumer rights and responsibilities	☐	☐	☐
Cultural awareness and inclusion	☐	☐	☐
Research and evidence use	☐	☐	☐
Speaking another language (optional)	☐	☐	☐

Section 3: Experience	Yes	Not yet, but I'm interested
I've used health services as a patient/carer	☐	☐
I've supported others in a healthcare setting	☐	☐
I've been involved in community or advocacy groups	☐	☐
I have experience with navigating complex systems (e.g. NDIS, aged care, mental health)	☐	☐
I bring insight from a marginalised or under-represented perspective	☐	☐

Section 4: Personal Qualities	This sounds like me	I'd like to grow this
Empathetic	☐	☐
Open	☐	☐
Curious	☐	☐
Patient	☐	☐
Optimistic	☐	☐
Confident	☐	☐
Determined	☐	☐
Respectful	☐	☐

Reflection

What are three strengths you bring to this role?	1.
	2.
	3.
What is one area you'd like to develop further?	
What support, learning, or mentoring would help you grow in this role?	

3. What is consumer partnering?

Principles for partnering

Consumer partnering is the term we use at Health Consumers Queensland to describe the ongoing, respectful collaboration between consumers and the health system. While it's sometimes called *consumer and community engagement, consumer participation, consumer collaboration*, or *co-design*, we use partnering because it reflects an enduring commitment – not just a one-off activity.

At its heart, consumer partnering is based on a simple, powerful principle: people affected by a decision have the right to be involved in making that decision.

"Nothing about us without us"

This well-known call to action, with roots in industrial unions, disability rights and political movements, highlights the importance of consumers being actively involved in shaping decisions that affect them.

The term *person-centred care* also reflects this principle, where consumers are partners in their own (or loved ones') healthcare and treatment. Research shows that partnering with consumers delivers positive results for both health organisations and health consumers/carers, better health outcomes for all and more accessible and responsive services.

Health Consumers Queensland's *Consumer and Community Engagement Framework* (the Framework) outlines the building blocks for partnerships between staff in health organisations and consumer representatives. The Framework has 4 guiding principles to underpin all consumer and community partnerships:

1. **Intentional Partnering** is not a one-off event but rather an ongoing process integrated into the everyday work of health organisations. Partnership activities are carefully considered, and all participants are working with a shared purpose and understanding about outcomes.
2. **Respect and dignity** is essential between engagement partners who value each other's perspectives, knowledge and beliefs and develop relationships based on clear and open communication, transparent processes and shared goals. Partnerships focus on solutions and support the participation of consumers and community.
3. **Inclusive Engagement** processes are accessible, flexible and designed to promote partnerships with populations that reflect the diversity of their communities and identified health needs. The health service engages through outreach and is respectful of existing community resources and expertise.
4. **Improvement** occurs when engagement activities are evaluated by health staff and consumers and findings implemented. Ongoing training and development opportunities are provided to support the capability building of all engagement partners.

> **"Collaborative decision-making helps to solve problems, or challenge existing strategies or policies to promote change and provide better health services."**
>
> – Dawn Hay, member Central Queensland Hospital and Health Service Consumer and Community Advisory Committee

Health literacy

Health literacy is about how people understand information about health and healthcare, and how they apply that information to their lives, use it to make decisions and act on it. Health literacy is important because it shapes people's health and the safety and quality of healthcare. Low levels of health literacy affect an individual's ability to make informed decisions, which then has a negative impact on their health outcomes. It also impacts consumer representatives in their roles.

As health information and systems become increasingly complex and harder to understand building health literacy in the community is becoming critically important to productive reciprocal relationships with health organisations. Consumer representatives have a valuable role to play in that process by informing and supporting the design and dissemination of better health information.

Definition of health literacy

In its paper *Health Literacy – Taking action to improve safety and quality*[2] the Australian Commission on Safety and Quality in Health Care (the Commission) separates health literacy into 2 components:

1. Individual health literacy is the skills, knowledge, motivation and capacity of a person to access, understand, appraise and apply information to make effective decisions about health and healthcare and take appropriate action.
2. The health literacy environment is the infrastructure, policies, processes, materials, people and relationships that make up the health system and have an impact on the way in which people access, understand, appraise and apply health-related information and services.

Consumer rights

The Australian health system is supported by a strong foundation of legislation and the Australian Charter of Healthcare Rights which outline what consumers, or someone they care for, can expect when receiving healthcare. These rights apply to all people in all places where healthcare is provided in Australia and legislation covers a long list of service delivery at both a national and state level, from the Medicare health insurance scheme and the National Disability Insurance Scheme (NDIS) to Aged Care, and health practitioner regulations. Understanding the legislation that governs any health services or partnering activities you may be engaged with is important for a health consumer to act with confidence.

The Australian Charter of Health Care Rights (2nd ed) states that consumers have a right to be included in decisions and choices about their care and the right to participate in health service planning. It specifies 7 key rights of patients and consumers when they are seeking or receiving healthcare services. The second edition has an increased focus on person-centred care, shared decision making and empowering consumers to take an active role in their healthcare. The Charter applies to all health settings in Australia (private or public hospitals, general practice and other community environments).

The National Safety and Quality Health Service Standards (NSQHS) developed by the Commission in collaboration with the Australian Government, states and territories, private sector providers, clinical experts, patients and carers, aim to protect the public from harm and to improve the quality of health service provision.

Standard 2: Partnering with Consumers aims to ensure that consumers are partners in planning, design, delivery, measurement and evaluation of systems and services. It requires all patients are given the opportunity to be partners in their own care. This Standard, together with the Clinical Governance Standard, underpins all the other standards.

Importantly, Standard 2 recognises that: "Consumer partnerships should be meaningful and not tokenistic. To maximise the contribution of partnerships, consumers need to be seen and treated as people with expert skills and knowledge".[3]

All public and private hospitals, day procedure services and public dental practices are required to be accredited to the National Safety and Quality Health Service (NSQHS) Standards. Many other healthcare facilities will also choose to be accredited to improve the safety and quality of healthcare provision. The NSQHS Standards have been an important driver of the growing focus on consumer and community engagement in Australia.

Consumer Partnering to Build Better Care: The Queensland Pelvic Mesh Service Story

The Queensland Pelvic Mesh Service illustrates what *Standard 2: Partnering with Consumers* means in real life. The service was created after women had chronic health problems as a result of pelvic mesh implants. Health Consumers Queensland supported a group of the women to share their experiences and stories which directly influenced both the service model and the creation of patient decision support resources. This ensured the final healthcare service was built around what these women, and others like them, really needed and wanted.

When to partner

Health sector services and organisations should work with consumer representatives throughout a project – at the beginning, middle and end. Good partnering takes place early and should incorporate all aspects of a project or program, from initial planning, implementation and monitoring, through to evaluation and review. As a consumer representative, here's how you might be involved:

Stage	What this means	How you might contribute
Needs analysis	Identifying problems and what communities need.	Share lived experience, highlight gaps in care.
Priority setting	Deciding what issues to work on first.	Advise based on community needs and urgency.
Development	Designing the service or resource.	Offer feedback, suggest improvements, co-design.
Implementation	Putting the service or program into action.	Identify potential barriers and support rollout.
Evaluation	Reviewing what worked and what didn't.	Help assess effectiveness and suggest changes.

Where to partner

Consumer partnerships can happen across an organisation and system simultaneously on many different projects and initiatives. The Health Consumers Queensland *Consumer and Community Engagement Framework* breaks down the partnership opportunities into 4 levels:

1. **Individual** – Engagement in individual care sees consumers as partners in their own (or loved ones') healthcare and treatment. It is often called person-centred care.
2. **Service** – Service level engagement is focused on partnerships that impact programs and services at a facility level in a Hospital and Health Service or a unit within the Department of Health.
3. **Network** – Regional engagement processes as health organisations seek input into broader plans across their service area.
4. **System** – Engagement on health policy, reform and legislation that influences and changes the health system across state and federal jurisdictions.

Listening, learning, and collaborating: partnering for success

Here's an example of how partnering between consumers and a health service or organisation could work.

When consumers reached out to a health service for support – many expressing concerns about navigating the complaints process or accessing specific medications – it became clear that people were struggling to make their voices heard in the healthcare system.

By analysing de-identified data from these calls, the service uncovered common themes and barriers. Rather than act alone, the health service partnered directly with consumers to co-design a self-advocacy toolkit. This practical resource enabled individuals to navigate health services more confidently, understand their rights and responsibilities, and build respectful, collaborative relationships with providers.

The voices of consumers didn't stop at the toolkit. Insights and recommendations were shared with regional health services, helping them to understand the real experiences of people in their communities.

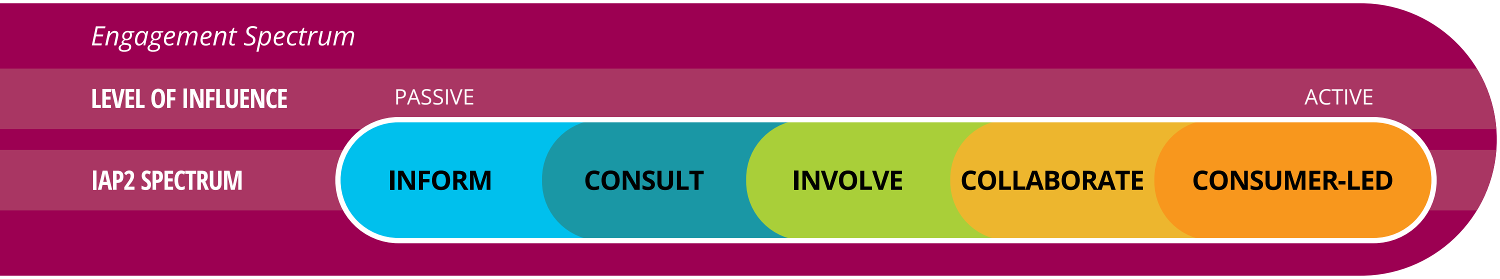
Evaluation of the toolkit's outcomes demonstrated its value, and this evidence was shared with state and national bodies to show just how critical – and effective – self-advocacy can be in transforming care.

Understanding levels of engagement

As a health consumer representative, it's important to understand that engagement with health organisations can happen in many ways – and at different levels. Sometimes, you might simply be consulted for your opinion, while at other times, you may be invited to work in full partnership with health professionals to co-design services or solutions.

The IAP2 Public Participation Spectrum, developed by the Engagement Institute[4], is widely used in Australia to describe these different levels of engagement. This spectrum (below) has been adapted with approval to reflect opportunities for consumer-led engagement.

No matter where an activity sits on the spectrum – from basic information sharing to full co-design – 3 key things should be clear: the Purpose, the Impact, and the Decision-making power involved.



Engagement Spectrum

Purpose

The purpose is the reason the organisation is engaging with consumers. Before you accept an opportunity, make sure you understand why your voice is being included and whether that purpose aligns with your own values and goals.

If it doesn't feel right, it's okay to say no. In fact, providing respectful feedback about why the purpose doesn't align can help health organisations improve future engagement.

Impact

Think about the impact your involvement might have. Will your input shape decisions, influence how services are designed, or bring attention to community needs? Knowing the likely impact can help you decide what role you want to take and what you may need to prepare.

Impact can include things like:

- Advising on how accessible a website or app is
- Helping an organisation better connect with community groups
- Sharing lived experience to influence service improvement.

Decision-making

Ask yourself 'What say will I have in decisions being made?' You might be:

- Informed but not involved in decision-making
- Consulted, where your views are considered
- Collaborating or co-designing, where you're a full decision-making partner.

Questions to ask

- What is the purpose of involving consumers in this activity?
- What impact will my involvement have?
- What decision-making power will I have?
- If this is co-design, will I and other consumers make decisions equally with others – or will decisions be made by others behind the scenes?

Keep in mind:
Every project can involve different levels of engagement. A good organisation will clearly explain how your input will be used and whether you're being asked to co-design or simply give advice. Clarity helps everyone avoid confusion, frustration, and wasted effort.

How consumers can partner

There are many ways consumers can contribute through partnering, ranging from one-off opportunities to ongoing roles. These include:

- Providing feedback based on your experience as a patient, carer or community member (e.g. surveys, comment cards)
- Reviewing resources such as brochures, websites, policy documents or clinical guidelines
- Participating in workshops or focus groups to provide input on services or initiatives
- Attending events such as forums, symposiums or public meetings
- Raising awareness through public speaking, community presentations, online campaigns or education sessions
- Contributing to research by reviewing grant applications or offering input on study design from a consumer perspective
- Taking part in recruitment by serving on staff or project selection panels
- Helping train health staff or volunteers by sharing consumer perspectives in education sessions
- Hosting community conversations to bring people together around a health issue or idea
- Joining committees or advisory groups, such as:
    - Hospital and Health Service (HHS) engagement advisory bodies
    - Working, steering, reference or consumer advisory groups
    - Patient Safety and Quality committees
    - Clinical advisory boards for government or non-government organisations
- Co-designing a service or project with other health professionals or co-creating projects in collaboration with health staff.

Can engagement levels change?

Yes. Your influence might vary depending on the project stage or the organisation's needs. If you feel your involvement is always at the same level (for example, always consultation but never collaboration), it's okay to ask why. You can request a conversation to explore other opportunities for greater involvement.

And remember: if an opportunity doesn't match your goals or values, it's always your right to respectfully decline.

Reflection

Use these questions to reflect on your current or future role as a consumer representative:

- Do I understand how consumers are (or were) involved at each stage of a project?
- What difference could greater consumer involvement make?
- What knowledge or lived experience could I (and others) bring to each stage?

Consumer level of influence in practice

Here are 3 examples of engagement and what a consumer might expect from their participation. However, not all activities will use the same approach and level of engagement, that is not all project groups, or advisory groups will operate in the same way.

All consumer engagement activities and partnerships provide opportunities for us to learn and try new ways to work together. If you are unsure of what contribution you will have ask the health organisation you are partnering with for clarification.

	Consumer activity	Level of engagement	Consumer involvement
EXAMPLE 1	Participate in a review of fact sheets	Consult	Consumer and carer representatives will provide feedback on draft fact sheets developed by health staff, work together with clinicians and support workers as equitable partners throughout the project, and decisions about how you work together are made together.
EXAMPLE 2	Participate for a 1–2-year term on a Consumer Advisory Council	Involve	Staff and executive decision-makers across the organisation meet regularly with this Consumer Advisory Council to inform them of the organisation's strategic and operation plans. Consumer representatives provide insights and perspectives to support the organisation's decision-making and planning for programs and services.
EXAMPLE 3	Participate as a project team member to review and amend a service model's procedures	Collaborate	Consumers who have provided feedback about a service work in partnership with clinicians throughout the project, and all decisions are made together.

For more information on levels of influence, please see Health Consumers Queensland's *Consumer and Community Engagement Framework*.

4. Understanding the health system

Overview of Queensland's health system

As a consumer representative you could be representing people living with various health conditions, people with different lived experiences, or people living in different parts of the state. Understanding more about the health system can help you understand the challenges community and health staff may face, or the support and care available.

Australia's health system is a mix of public and private services and can be complex to navigate. Most health services are funded by the federal or state and territory governments, with many health services provided by privately owned businesses such as GP surgeries, specialist clinics, pharmacies, dental clinics and private hospitals. Services are delivered and supported by a range of health professionals including doctors, nurses, dentists, allied health professionals, and administrative staff.

Queensland Health is the largest Queensland Government Department, with more than 270,000 employees[5]. Queensland Health consists of the Department of Health and 16 separate Hospital and Health Services – known as HHSs – which manage the state's public hospitals and public health services, overseeing local healthcare delivery, including community health centres. The Department of Health is responsible for governance, policy, funding and monitoring performance.

Primary Health Networks (PHNs), established in 2015 by the Department of Health, Disability and Ageing) PHNs coordinate primary healthcare services to ensure communities receive appropriate care. There are 31 PHNs across Australia, with 7 in Queensland.

Aboriginal Community Controlled Health Organisations (ACCHOs), are healthcare services governed and managed by Aboriginal and Torres Strait Islander people, providing comprehensive, culturally informed care for Aboriginal and Torres Strait Islander people that focus on social, emotional, and cultural wellbeing as well as physical health. There are 30 ACCHOs in Queensland.

Private health services in Queensland offer hospital care, specialist consultations, elective surgeries, and diagnostic services, requiring private health insurance.

Other parts of the health system include regulation of health professionals, complaints systems, standards and accreditation for hospitals, and health and medical research.

Responsibilities of each level of government

Knowing what health organisations are accountable for helps you advocate effectively as a consumer representative. The main roles of each level of government in Australia's health system are:

The Australian Government

- develops national health policy
- funds medical services through Medicare and medicines through the Pharmaceutical Benefits Scheme (PBS) and provides funds to states and territories for public hospital services
- funds population-specific services, including community-controlled Aboriginal and Torres Strait Islander primary health care, health services for veterans, and aged care
- funds the national immunisation scheme
- funds health and medical research
- regulates medicines and medical devices
- supports access to, and regulates, private health insurance.

State and territory governments

- fund and manage public hospitals, regulate and license private hospitals and other health premises
- regulate products with health impacts such as alcohol and tobacco
- regulate the prescribing and administration of medications
- deliver community-based and preventive services (for example, cancer screening and immunisation), ambulance services, and address complaints.

Local governments in some jurisdictions can be involved in

- delivery of community and home-based health and support services
- environmental health services (for example, waste disposal, water fluoridation)
- public health activities.

Additionally, all levels of government have shared responsibilities, including education and training of health professionals, regulation of the health workforce, food standards and safety, improving the safety and quality of health care and funding of programs and services.[6]

Keep in mind:
You can learn more about the health system by registering for one of HCQ's online information sessions or training courses. Contact the Consumer Engagement Team: Call (07) 3012 9090 or email info@hcq.org.au

The consumer journey

This is the story of Julie who is a consumer of Queensland's health system and it shows how a patient may receive different types of healthcare on their journey. It is an example of what primary, secondary and tertiary healthcare can mean.

This consumer journey also gives a snapshot of what integrated care might look like. For example, Julie's care is coordinated by her general practitioner. In the course of her treatment she moves between different levels of care, her medical records are accessible to the health professionals she sees, and her final discharge links her back to her general practitioner and a community-based health facility to further support her health and wellbeing.

Primary care

Julie has been generally healthy and active, and an avid runner for more than 10 years. She consults her General Practitioner (GP) to find out what is causing increasingly painful and debilitating knee pain after she has made several attempts to seek pain relief, including medication and visits to a physiotherapist, without success. As Julie does not have private health insurance, her GP refers her to her nearest public hospital for a specialist assessment.

Secondary care

Julie receives a comprehensive assessment from a medical specialist at her local hospital. Following an x-ray the specialist confirms Julie shows signs of advanced damage to her knee joint and recommends Julie consider knee replacement surgery.

As Julie's condition is not life-threatening she is added to a waitlist for elective surgery. However, her symptoms have become so debilitating that she is placed on a Category-2 waitlist which means the wait time should be no more than 90 days.

Julie is provided with some pain relief strategies to follow until her surgery.

Tertiary care

Julie receives notification of her surgery and the pre-surgery plan outlining what she must do before she arrives at the hospital. In the public hospital system, the patient does not choose their surgeon, one is appointed to them.

Primary care

After being discharged from the hospital following her surgery, Julie returns to her GP to review the post-operative recovery plan, which includes regular physiotherapy sessions to assist her restoration to normal mobility. Her GP will continue to monitor her recovery.

5. Becoming a consumer representative

Where to start

There are a few ways to begin your consumer partnership journey with a health organisation. One of the easiest ways is to speak with a staff member at any health organisation, hospital, Primary Health Network or research institute you might be personally involved with or interested in.

Many health organisations have their own network of consumers they develop and call on when there is an opening for consumer involvement. Sometimes these roles are advertised internally so ask to be added to their database or register on their website to receive newsletters or alerts about upcoming consumer opportunities.

Another way to get your first role is to become a member of Health Consumers Queensland's statewide network of health consumers and carers. Through Health Consumers Queensland, health organisations can advertise their consumer representative roles which could be a position on a health-related committee, reference group, advisory body, specific project or participation in a forum. Network members are then invited to submit an expression of interest and apply for the position. Network members receive regular notifications about consumer representative vacancies, relevant resources, training opportunities and much more.

Applying for opportunities

When you apply for a consumer representative role you will be asked to show why you are a good fit for the role by listing information such as your lived health experience, interest in the project, your connections to the community and any experience you have had as a consumer representative. You may also want to list conferences and forums you have attended or presented at and any training you have done. You can regularly update your skills and experience to include all the committees and groups you have been involved with.

To begin, **create a brief description or one-line explanation** about yourself and why you would make a great health consumer representative. Think about the personal qualities that best describe you.

Next up, **detail your personal healthcare experience**. Include information about any other boards or committees you are on, community groups or professional organisation memberships – this can include both health and non-health related experiences. Include any other connections or networks you might be part of that could help to show why you would be well-suited for a representative role.

Now you can outline your unique **skills and abilities**. This could be your links to networks or community connections that give you broader insights or views into issues; or the fact that you are assertive, comfortable in new environments and confident to speak in public.

Detail any further **experience or achievements** you have had that have helped shape you and could assist in your representative role. This could include working in successful partnerships or diverse populations, or any achievements or changes you were able to implement in past committee roles.

Finally, list out your qualifications and training. Include any conferences or forums you've attended that would be relevant.

Building community connections

Networking is important to build relationships with key people who will support your role. It is about establishing a connection, through identifying a shared vision or interests. Developing and maintaining networks with other consumers and carers is very important. Not only will it ensure you are aware of experiences of other users of health services, you can also share knowledge about consumer-centred services and initiatives. You can also help each other with advice and support.

If you are a consumer representative for several years, you never know who you might bump into and partner with again on a project or committee. One of the most important ways you can be an effective consumer representative is by connecting with other consumers and carers with lived experience. This is what gives you a deeper insight and inspires you to ask the questions that people in the health system may not think about.

Networking with and meeting the chair of your committee or group as well as the other members is important too. You can ask to do this outside of meeting times. Let them know of your intention to get to know them and their work so that you are better able to work together and support each other.

"Building connections within the community is a significant part of the consumer representative role, as it provides insight into community needs. Networking is used to connect with others and understand those needs. An important first step is discovering and participating in community forums and events as this offers opportunities to hear community viewpoints. Networking can be both fun and rewarding, enjoy the experiences."

– Marney Perna, health consumer representative, Brisbane

5 top tips to being a confident networker

1. Identify local groups where your community meets
2. Go with the intention to be of service to others
3. Take business cards to share
4. Write down the person's question or topic of interest on their business card (and keep a list of people who could be interested in common topics)
5. Have fun and always follow up.

Tips shared by Marney Perna, health consumer representative, Brisbane

Keep in mind:
Partnering is relationship-based work and the more you connect with others the more effective your involvement will be.

The engagement process

BEFORE PARTNERING

Understand and be informed

As a health consumer representative, it is important to understand the context of your work.

- Ask questions about your role and the purpose of the activity
- Look at the organisation's website to understand their vision, values and general business
- Understand what you can and cannot do, and the level of influence that you can have.
- Find out as much as you can about the issue being discussed. Do your own research and talk to other consumers, your family and your friends.
- If you receive a large amount of complex information to read, ask to have some time with someone who can highlight important things to know and explain anything you are unsure about.

Administration and paperwork

There can sometimes be a large amount of administration involved when working with health organisations. Most of this will be one-off documents to get you into the system and ensure that all requirements are met. For example, you may be asked to read and sign a Code of Conduct, or Non-Disclosure/Confidentiality agreement. There might also be some ongoing paperwork you will need to do such as claiming travel expenses.

You can ask for help with completing any forms or documents. Make sure you speak to your staff contact about what is required if you are unsure.

Even though consumer representatives aren't staff, confidentiality and conflict of interest requirements still apply.

Confidentiality: Sometimes, you might be given private or sensitive information. If you're ever unsure about what you can or can't share, ask the organisation for guidance.

Conflicts of interest: This is when your other work or personal roles might affect – or appear to affect – your ability to speak independently as a consumer rep. If you think there might be a conflict, talk to the organisation before getting involved in the activity.

Consumer payments

Health Consumers Queensland (HCQ) recommends that consumer representatives should be remunerated for their time, expertise and contributions and should not be financially disadvantaged because of their contribution to a health organisation. HCQ has a formal position statement outlining recommendations for this on our website or contact us for a copy.

Health services may have different policies about the remuneration of consumers. Find out what the remuneration policy is beforehand, to make an informed decision about whether you are willing to invest your time in partnering. Consider any financial impact that may occur and whether remuneration payments may affect your other income. For example, you may be receiving a pension or a benefit. Neither HCQ nor health organisation staff can give financial advice. The Australian Taxation Office can be contacted for legal and financial advice. In Queensland, free information on Centrelink matters can be sought from Basic Rights Queensland, 1800 358 511 https://brq.org.au/

Orientation

Every health organisation has their own process of how a consumer is recruited and inducted into their role. Orientation allows you to learn about the health organisation, the context and the background of your new role so that you are informed and able to participate fully.

Ask for a map of the venue or access one online if possible. Figure out exactly where you need to be, where you can park and what you may have to pay. Keep receipts to claim your expenses. Have a contact phone number handy in case you get lost or if there have been any last-minute changes.

If you have not been offered an orientation, ask to have one before your first meeting.

Preparation time

Being involved in a consumer representative activity often means you will need to set aside some time to prepare yourself and plan what you need to do. Take every opportunity to learn and grow in your new role. You can access legitimate information and research online and network with experienced consumers to learn from their experience.

Spend some time thinking about ideas you might want to raise; find evidence and research to support your ideas. Ask for items to be added to the agenda if there is something you want addressed. Think about how you are going to raise your point of view or idea – what is your angle?

As a consumer representative, you are there for a particular reason, so a concise and powerful introduction tells your listener who you are, what experience you have that means you have something worthwhile to contribute, and what your intention is. It is an efficient way of making your relevance to the topic known and building trust and respect.

Support needs

As a consumer representative, you should express any support needs before the activity so that you can actively and effectively participate. For example, if you may require a support person to participate, or specific tech requirements, or you may have dietary, accessibility related, or medication needs, let your contact person know. Health organisations should be providing an inclusive environment for participation.

Cultural support

If you are a First Nations person or from a culturally or linguistically diverse (CALD) background, your voice and lived experience bring essential insight to consumer partnerships. Your perspective helps shape services that are more culturally safe, respectful, and responsive – not just for you, but for your whole community.

Before you get involved, it's okay – and important – to ask:

- How will I be supported culturally in this role?
- What steps are being taken to ensure this space is culturally safe for me?

By asking these questions, you are not only advocating for yourself, but also helping pave the way for better, more inclusive care for others in your community. Organisations have a responsibility to provide appropriate cultural support and ensure you feel safe, respected, and heard throughout your involvement.

Lived experience can be powerful for achieving system change but it must come with careful considerations. Organisations must ensure that health consumers and consumer representatives are:

- informed about why they are being invited or asked to share their story and what the organisation will do with it. An organisation may want to share a story on social media to raise awareness about a health issue, inform decision-makers, or gain more understanding about consumer experiences
- provided a safe and comfortable environment so they feel supported to share without judgement and where they have privacy
- provided with support resources if needed. This may include counselling services or being connected with suitable support groups, to help process emotions before and after sharing
- acknowledged for what they have shared. This includes the challenges or distress, as well as their strength and resiliency
- in control of how they wish to share their story. Language preferences, environment needs (such as lighting, chairs, and sensory needs), and the audience that people are comfortable sharing with will vary
- followed up to ask how they are feeling after sharing their story, and whether they would like to be connected with support services. Organisations should also follow up to keep consumer representatives informed about the impact that sharing their story has made.

Keep in mind:
Not all consumer representative activities require the sharing of lived experience and, in some cases, it may not be helpful or appropriate. If you haven't been directly asked to share your lived experience, then check with your staff contact to find out ahead of time whether this will be required or an option.

DURING PARTNERING

Your role

Consumer representatives are recruited for many different reasons but ultimately you are there to provide a unique perspective, whether that is your own individual viewpoint, or that of a particular consumer or community organisation or health population.

Consider how you feel about a situation or program and then, if possible, consider others who might not have a voice in the discussion. Be mindful not to speak for others but highlight that other people may have very different perspectives and experiences that need to be considered.

You can do this by asking questions or encouraging discussions so that the perspectives of the following, as a starting point, are considered:

- Aboriginal and Torres Strait Islander peoples and their communities
- culturally and linguistically diverse people and communities
- lesbian, gay, bisexual, gender diverse and intersex people
- children and youth
- people with a disability
- people living in rural, remote and urban areas.

If you feel that another perspective is not being represented, suggest that wider consumer and community engagement is needed on the issue. Remember as a consumer representative you are not required to personally undertake this consultation.

Speak up

Speak of your experience. Speak up for consumer rights and for consumers. You are not expected to have all the answers or solutions but are there to ask critical questions.

As part of your role you will attend meetings, read papers, notes and other information as required, and participate, question and contribute where possible.

Do not be deterred if your first meeting seems overwhelming and unproductive. The journey of a consumer representative is about learning and being open to new opportunities. Relationships take time to build, and you will become more comfortable and confident after each meeting.

Authenticity

Being authentic is important. When we are authentic, we are true to ourselves and the goals we have. When people are true to themselves, their interactions are more sincere and meaningful. This can help encourage others to do the same. As a consumer representative you add value through your authenticity and how you and your community navigate the health system.

Boundaries

The ability to set and maintain healthy boundaries is important as a consumer representative. Boundaries communicate the scope of your role and what you need to feel safe and respected. Sometimes, maintaining boundaries can be challenging if we feel we are disappointing someone or not meeting expectations. It is okay to let people know in what way you do not feel comfortable, how you feel best able to participate, or whether you do not feel comfortable discussing a certain topic. Healthy boundaries include all people respecting each other.

Questions to ask

Take every opportunity to ask questions. Here are some example questions you could ask during partnership activities.

- What if we thought about this in a different way?
- How have other regions tackled similar problems?
- Is this decision being made with evidence or with opinion?
- Can you explain that term to me please?
- Have you spoken to other consumers about this?
- Will the benefits or disadvantages likely apply to other communities/areas at any stage?
- How does this practice compare with evidence-based models of care and requirements of National Safety and Quality Health Service Standards?
- Who are the consumers that will be impacted by this? What are the benefits or disadvantages for them?
- Have you considered other aspects of safety, other than clinical safety? What about emotional, spiritual and cultural safety and appropriateness?

Pre-meeting checklist:

When you have been recruited to join an engagement activity, follow this basic checklist to make sure you are prepared and comfortable ahead of the meeting.

1. **Check the organisation's website**

   Get familiar with their vision, values, and key services. This helps you understand their goals and language.

2. **Read the organisation's consumer engagement strategy or policy**

   Understand how the organisation partners with consumers. If anything's unclear, ask!

3. **Complete required paperwork**

   Make sure all required forms, agreements, or onboarding steps are done.

4. **Review pre-reading material**

   Read through meeting papers or background info. Highlight anything unclear and note questions you'd like to ask.

5. **Contact with the chairperson**

   Have they introduced themselves? If not, consider requesting a short meeting or introduction before your first session.

6. **Personal preparation**

   Bring water, paper, pens, glasses, or anything else that will help you feel comfortable and confident. A good night's sleep goes a long way too!

Top tips for a successful meeting

These small actions can help you feel more at ease and make a strong contribution.

1. Introduce yourself. Share a short introduction about who you are and why consumer voice matters to you.
2. Where to sit. If in-person, sit near the chairperson if you can – it helps with engagement. If online, turn your camera on and arrive a few minutes early to check tech.
3. Take notes. Jot down key points, acronyms, or any follow-up tasks. Don't worry if you miss something – you can always ask!
4. Understand meeting terms such as:
   - Minutes – summary of what was discussed and decided
   - TOR – Terms of Reference, explains the group's purpose and rules
   - Seconding – formally supporting a motion or proposal
   - Observer – person invited to attend the meeting but may only speak with permission of the Chair and does not have voting rights
   - Action items – tasks assigned during the meeting.
5. Clarify actions. Before the meeting ends, check if there are any actions for you to follow up on and who you can contact if you have questions later.
6. Speak up – but don't feel pressured. You don't need to have all the answers. Share your perspective when it feels relevant and know that listening is also a valuable contribution.
7. Follow-up if unsure. If something wasn't clear during the meeting (such as acronyms, context, or decisions), it's absolutely fine to follow up afterwards with the chairperson or contact person.
8. Ask about support. Check if there's a consumer support person or buddy available, especially for your first few meetings.
9. Meeting papers and agenda. Confirm you have access to the agenda and any background documents in advance – and know who to contact if you don't.
10. Schedule check. Make sure you have the right time and date in your calendar (and the right time zone if it's online!)
11. Feedback is welcome. Organisations appreciate feedback from consumers – not just about services, but about how meetings are run. Don't hesitate to offer suggestions.

AFTER PARTNERING

Check in with the health organisation

Depending on the activity, it can sometimes be a good idea to organise a debrief or an opportunity to catch up with the staff contact at the health organisation, as well as any other consumer representatives involved.

This gives you a chance to clarify anything that was not clear and ask any questions you might have noted during the activity.

Check in with yourself

Some activities have short lifespans while others are ongoing. After you've spent some time in the consumer representative role, it's a good idea to reflect on your journey. As well as when you're starting out, every 6 months or so you should ask yourself:

- Am I making a difference?
- Is this work making a difference?
- Are we evaluating what we are doing, including the consumer partnerships?
- Does the consumer voice need to be supported by another consumer representative being present? What kind of background could they bring to expand the diversity of consumer representation at the activities I've been involved in?
- Do I still have the time, capacity and motivation to be a consumer representative?
- Am I seeing consumer representative opportunities I would like to be involved in?
- How can I support or mentor other consumers in this role?

6. Making partnering work

Partnering expectations

Your time and expertise are valuable.

During the partnering experience consumer representatives should:

- Be **treated fairly and with respect**
- Be provided with **clear information** about your role and what is expected of you
- Understand the organisation's **remuneration** and reimbursement policies
- Be provided with the **contact details** of at least one staff member
- Receive an **orientation** to your role and the health organisation
- Receive information early so that you can read and **prepare**
- Have medical terminology, technical information and acronyms explained in **simple language**
- Be able to ask questions before, during and after the activity
- Be **able to disagree** and have this formally acknowledged (where appropriate)
- Be **included and involved** in decision-making (where appropriate)
- Be offered **training and development** opportunities (where appropriate)
- Receive **feedback** on the outcomes and impact of your involvement in the activity.

Every organisation is at a different stage in its journey with consumer partnerships. Some may be eager to learn and engage with their consumer representatives and for others partnering may still be new or they may seem resistant to change.

Questions to ask

You can better understand the expectations of your role in any partnering activity by asking these questions:

1. What resources or learnings can I access to support my participation?

Reason: Gain clarification on what resources or information would support your role as a consumer representative and whether it is a requirement for the role. You can also ask about whether participating in further learning is remunerated and if so, at what payment rate.

2. Are there meetings about the activity where I will not be included?

Reason: It is important you have the information you need to participate and make informed decisions. There may be meetings or communications about the project that consumer representatives or other stakeholders are not included in. This could be for a variety of reasons. Some meetings could be for decision-makers, some may include staff discussing confidential or sensitive information. There also may be meetings where it would be helpful to include consumer representatives, such as a project management update on timelines as this could impact your availability.

3. Are there specific tasks or topics where you would like me to have more decision-making involvement?

Reason: Provide an opportunity for the health organisation to consider where consumer representatives can influence or shape the activity and formally document this to provide clarity.

4. How will I gain feedback on my participation?

Reason: As a consumer representative it is helpful to know how you will gain feedback on your participation; whether you will receive verbal or written updates or whether you will have an opportunity to share where you think you can have more impact or where other consumer voices should be included.

“It is challenging and rewarding [to be appointed to an advisory committee]. There are two sides to it. It does take time, but you can make change or assist in making change happen. As a representative, it’s not just about being a consumer. Lived experience is very important but so is awareness of what is happening in your community and how you can alleviate issues to get better outcomes in the health system. You don’t need clinical experience but doing a bit of research and background preparation before meetings is a good start. Understanding the challenges on both sides, including the demands on health staff every day, and looking for the positive angles is also a good approach.”

- Russell Thomas, consumer representative and Chair, Central Queensland Hospital and Health Service Consumer and Community Advisory Committee

When it’s not working

Start by speaking with your key contact at the health organisation. They might not be aware of how you’re feeling and can often help resolve issues once they know.

Still not working? If you decide to step away from the role, that’s okay. Your wellbeing matters. Before leaving, consider offering feedback – this helps improve the experience for others in future.

Need more support? Health Consumers Queensland is here to help. Contact us anytime for guidance or to talk through your options.

Wellbeing and self-care

Choosing to be involved in systemic change can be challenging. Being part of change can be slow, frustrating, and emotionally taxing. You won’t always see immediate results – but your voice still matters.

Practical self-care tips:

- Schedule time to rest, eat well, stay active
- Build a support network – family, friends, other consumer representatives
- Practice mindfulness, journaling, or anything that helps you to de-stress after meetings
- Speak up early if you need help or feel overwhelmed.

If you’re feeling emotionally drained or physically unwell, it’s okay to:

- Take a break from your role, ask if you can pause your involvement
- Adjust your involvement (for example, join meetings by phone or online, or send written input) – it might not be necessary to always be present
- Say no – your time and energy are valuable.

As one experienced consumer has said, “This is slow work; if you don’t start the process now then no one will have even begun to talk about these issues, and a few years would have passed in the meantime with nothing done about it!”

7. Glossary and reading

Glossary of terms

Across the health system, there are many terms and acronyms that are often used by clinicians, administrators and policymakers. Here, we provide an introductory list of frequently used terms and resources where you can find more information.

Consumer and Community Engagement terms

Partnering: Health Consumers Queensland uses the term 'partnering' to describe the ongoing, respectful collaboration between consumers and the health system because it reflects an enduring commitment that involves participation in, and sometimes leading, health service decision-making; policy and service design; service delivery and evaluation.

Consumer (Health Consumer): Any person who uses, has used or may use health services or is a carer for someone who uses health services.

Carer: A person who provides unpaid care and support to a family member or friend who has a disability, chronic illness, mental health condition, or is elderly and frail.

Consumer representative: A consumer who actively promotes and supports the interests and rights of other consumers, particularly in healthcare and research settings.

Patient: An individual who receives or has received medical care or treatment.

Lived or living experience: First-hand experience and knowledge gained by having personally managed a particular health condition, disability or social issue, past or ongoing. Lived experience can provide valuable and unique insights into the realities and challenges faced by consumers and carers.

Community: A group of people who share a common interest or identity. This may include:

- cultural background
- geographic location
- shared health issue
- shared demographics.

Advisory committee: A group of people, representing different points of view who give advice to the organisation or department which established it.

Steering committee: A group that provides guiding information to an organisation, division, or department.

Working group: A sub-committee (i.e. a small group of committee members) who work on a specific issue or problem and then report back to the main committee.

Consumer council: A group that ensures consumers, community members and people with lived experience contribute to the activities and objectives of an organisation or government department and allows consumers to make representations to that organisation or department.

Systemic advocacy: Provides active support to improve and make a system work better, for example advising a housing department on accessible features.

Individual advocacy: Supports the healthcare rights of individuals by working alongside and/or speaking, acting or writing on behalf of the advocacy client.

Reimbursement: Refund or repayment of money a consumer representative spent on certain things during an engagement activity, such as travel costs or printing.

Remuneration: Payment for a consumer representative's attendance at a meeting or participation in a consumer engagement activity.

Terms of Reference (ToR): The Terms of Reference describe the structure, the purpose and guidelines of the activity, project or committee.

Person-centred care: The person-centred approach treats each person respectfully as an individual human being, and not just as a condition to be treated. It involves seeking out and understanding what is important to the patient, their families, carers and support people, fostering trust and establishing mutual respect. It also means working together to share decisions and plan care. It also means working together to share decisions and plan care.[7]

Values-based care: This healthcare delivery model prioritises improving patient outcomes and experiences while managing costs effectively. It shifts the focus from simply providing services (volume) to achieving the best possible results for patients based on a combination of data-driven decision-making, patient engagement, and coordinated care to enhance value for both patients and the healthcare system.

Consumer-led: This model of care and engagement empowers individuals to actively manage their health and wellbeing, moving away from a traditional, provider-centric model. Consumer-led engagement recognises the importance of involving patients, their families, carers and loved ones, and community leaders in the development of healthcare policy, planning, decision-making and design of the processes and services that impact health consumers.

Co-design: This process and approach involves all stakeholders working as equals in leadership, design, delivery, and decision-making. Essentially, it is the creation of solutions by and for people impacted by those decisions. Co-design is different from consultation, because co-designers have an active role in contributing to the process on an ongoing basis.[8]

Medicare: Australia's universal healthcare scheme which provides access to a wide range of health and hospital services at low or no cost to all Australian citizens, permanent residents, and some overseas visitors.

My Health Record: This secure, online summary of an individual's health information in Australia is managed by the Australian Digital Health Agency and allows the patient and their healthcare providers to access and share health information such as medications, medical history and more to improve the quality of care.

Integrated health care: Health services that are managed and delivered so that people receive a continuum of care including health promotion, disease prevention, diagnosis, treatment, disease-management, rehabilitation and palliative care services, coordinated across the different levels and sites of care within and beyond the health sector, and according to their needs throughout the life course

Primary care: The day-to-day essential health care given by a health care provider. A primary healthcare provider is often a person's first contact with the health system and coordinates other specialist care that the patient may need. Primary healthcare can include general practice (a GP), nurse, allied health services, community health and pharmacists.

Secondary care: This refers to more specialised medical services. It is often acute healthcare provided in a hospital or by other medical services. Patients are usually referred from a primary healthcare professional such as a GP or come through the Emergency Department of a hospital.

Tertiary care: This involves very specialised medical care provided in hospitals or medical facilities. It often involves advanced and complex medical investigation, procedures and treatments.

PROMS (patient-reported outcome measures): PROMS AND PREMS are used to measure the wellbeing of patients. These tools help assess the quality of care and the impact of treatments on a patient. PROMS measure patient-specific health outcomes. Common examples are pain, fatigue, mobility and other physical symptoms.

PREMS (patient-reported experience measures): These focus on the patient's overall experience of their healthcare, including their opinions about the care they have received and their perceptions about the impact of treatment.

Ryan's Rule: This 3-step process supports patients, families and carers to raise concerns if a patient's health condition is getting worse or not improving as well as expected. Ryan's Rule applies to all patients admitted to any Queensland Health public hospital, including the emergency department, and in some Hospital in the Home (HITH) services.[9]

Further Reading

The Australian Institute of Health and Welfare (AIHW) has also developed a glossary which can support you with medical terminology when visiting your doctor. View AIHW's Australia's Health Glossary online at
https://www.aihw.gov.au/reports-data/australias-health/summaries/glossary

Australian Clinical Trials Alliance Glossary for research and consumer involvement and engagement activities
https://involvementtoolkit.clinicaltrialsalliance.org.au/glossary/

Australian Commission on Safety and Quality in Health Care
https://www.safetyandquality.gov.au/publications-and-resources/resource-library/nsqpch-standards-guide-healthcare-services/glossary

Health Care Consumers Association, Australian Capital Territory (ACT) has compiled a glossary of inclusive terms
https://www.hcca.org.au/wp-content/uploads/2023/05/Inclusive-Health-Care-Glossary.pdf
and a more general list of key terms for consumer representatives
https://www.hcca.org.au/wp-content/uploads/2024/06/Glossary-of-Terms-for-Consumer-Representatives-2024.pdf

Consumers Health Forum of Australia has collated a list of helpful resources at https://www.chf.org.au/resources

Overview of the Queensland Health System https://www.health.qld.gov.au/system-governance/health-system

Australian Charter of Healthcare Rights describes the rights of patients and other people using the Australian health system. These rights are essential to make sure that, wherever and whenever care is provided, it is of high quality and is safe.
https://www.safetyandquality.gov.au/national-priorities/charter-of-healthcare-rights/

Consumer and Community Engagement Framework for Health Organisations and Consumers. The goal of the framework is to encourage health organisations to embed consumer and community engagement in their work. The framework describes when and where partnering can take place, the principles that underpin it and the level of influence consumers have in the partnering process. It can be used as a foundation document to begin the partnering process.
https://www.hcq.org.au/wp-content/uploads/2017/03/HCQ-CCE-Framework-2017.pdf

Making Tracks towards closing the gap in health outcomes for Indigenous Queenslanders by 2033. Policy and Accountability Framework. There is a gap between the health status of Aboriginal and Torres Strait Islander Australians and the total Australian population. This framework aims to close the life expectancy gap and halve the gap in mortality rates of Indigenous children under five within a decade. https://www.health.qld.gov.au/__data/assets/pdf_file/0030/159852/making_tracks_pol.pdf

National Safety and Quality Health Service Standards. Read about Standard 2: Partnering with Consumers, which outlines requirements for effective and meaningful engagement of consumers in planning, designing and evaluating services. You can access it online at: https://www.safetyandquality.gov.au/our-work/assessment-to-the-nsqhs-standards/

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

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

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

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

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

National Standards in Mental Health Services. The implementation of the second edition of the NSQHS Standards provides a robust framework for safety and quality in mental health services in public and private hospitals, and community services provided by local health networks. Two new resources to support implementation of the NSQHS Standards: https://www.safetyandquality.gov.au/publications-and-resources/resource-library/nsqhs-standards-user-guide-health-services-providing-care-people-mental-health-issues and

https://www.safetyandquality.gov.au/publications-and-resources/resource-library/map-nsqhs-standards-second-edition-national-standards-mental-health-services

Queensland Health website. Find information about health services, news, campaigns, state-wide policy documents, strategic overviews and data that may be useful for consumer representatives at https://www.health.qld.gov.au/system-governance

The Chief Health Officer's Report. Find out what the Chief Health Officer has to say about the current state of population health in Queensland. Read past and current reports from the CHO. https://www.choreport.health.qld.gov.au/

Department of Health, Disability and Ageng. The Australian Health System – describes the structure of the health system including federal, state, public and private health. Gain further insights into the roles each plays in planning, funding and delivering health information, services and treatment. https://www.health.gov.au/about-us/the-australian-health-system

References

1. Wales CR, Lababedi JA, Coles A, Lee P, Clarke E. *Consumer representative experiences of partnership with health workers in Australia.* Patient Experience Journal. 2021; 8(3):64-78. doi: 10.35680/2372-0247.1523.
2. https://www.safetyandquality.gov.au/sites/default/files/migrated/Health-Literacy-Taking-action-to-improve-safety-and-quality.pdf
3. *Partnering with Consumers Standard | Australian Commission on Safety and Quality in Health Care* https://www.safetyandquality.gov.au/standards/nsqhs-standards/partnering-consumers-standard
4. The Engagement Institute, International Association for Public Participation Australasia Limited (IAP2 Australasia). https://engagementinstitute.org.au/resources/iap2-public-participation-spectrum/
5. https://www.forgov.qld.gov.au/pay-benefits-and-policy/state-of-the-sector-report/our-workforce-in-profile
6. https://www.aihw.gov.au/reports/australias-health/health-system-overview
7. Person-centred care | Australian Commission on Safety and Quality in Health Care https://www.safetyandquality.gov.au/our-work/partnering-consumers/person-centred-care#:~:text=up%20to%20date-,Overview,trust%20and%20establishing%20mutual%20respect
8. Approach 3: Co-design. How to apply co-design to ensure the needs and priorities of all rare disease stakeholders are included. - Rare Voices Australia https://rarevoices.org.au/taking-action-together-toolkit/section-3-approaches-and-tools-to-support-effective-advocacy/approach-3-co-design/#:~:text=What%20is%20co%2Ddesign?,process%20on%20an%20ongoing%20basis.
9. https://www.qld.gov.au/health/support/shared-decision-making/ryans-rule#what

Consumer Experience Recognition Statement

Health Consumers Queensland is proud to acknowledge the value consumer representatives contribute to the improvement of health system accessibility, services and outcomes.

As a member of the national peak body representing the interests of health consumers, Consumers Health Forum Australia, we join them in sharing a Consumer Experience Recognition Statement, developed in consultation with consumers, that reflects our shared vision to advocate for consumer-centred healthcare for all communities without discrimination.

We acknowledge and deeply respect the lived and living experiences of health consumers, carers, families, and communities across Australia.

We recognise the right of every person to equitable access to healthcare, regardless of their background or circumstances.

We value the lived experience expertise and personal commitment of consumer health advocates working to influence change.

We seek to elevate the voices of those who have navigated the complexities of the health system and partner with them to drive meaningful and inclusive change.

HCQ

HEALTH CONSUMERS QUEENSLAND

An electronic version of this publication can be found at
www.hcq.org.au

Level 3, 340 Adelaide Street, Brisbane, QLD 4000
GPO Box 1328 George Street, Brisbane, QLD 4000
healthconsumersqueensland
health-consumers-queensland
Email: info@hcq.org.au
Phone: 07 3012 9090

A Guide for Consumers: Partnering with Health Organisations
Edition 2, December 2025