

A Guide for Consumers

Partnering with Health Organisations



HCCQ

**HEALTH
CONSUMERS**
QUEENSLAND

Acknowledgement of Traditional Owners

The Board and staff of Health Consumers Queensland acknowledges the Australian Aboriginal and Torres Strait Islander peoples of this nation. We acknowledge the traditional custodians of the lands on which our organisation is located and where we conduct our business. We pay our respects to ancestors and Elders, past, present and future for they hold the memories, traditions, culture and hopes of Aboriginal and Torres Strait Islander Australia.

May 2018

This document may be downloaded, printed and reproduced in an unaltered form for personal and non-commercial uses.
Please acknowledge Health Consumers Queensland as the source when doing so.

Suggested citation:

A Guide for Consumers: Partnering with Health Organisations 2018.
Brisbane: Health Consumers Queensland.

Cover photo:

Front row, left to right: Stephanie King, Helen Mees, Sue Hogan, Gracelyn Smallwood and John Gagen.
Back row, left to right: Mark Tucker-Evans, Andrew Blythe, Hamza Vayani and Douglas Porter.

We would like to recognise John Gagen, who passed away in September 2017, for his valued contribution to the improvement of the healthcare system during his many years as a consumer representative.

Acknowledgements

Researched and written by Reema Naresh for Health Consumers Queensland, May 2018.
Special thanks to Anne Curtis, Jo Smethurst and Georgina Lawson for their contribution and editorial expertise. Our heartfelt thanks to health staff and consumer representatives who have shared their photos, experience and learnings to support the writing of this Guide.

Proudly supported by



Queensland
Government



Contents

Introduction	4
What is consumer partnering?	5
Understanding Queensland's health system	6
The Consumer and Community Engagement Framework	10
Why are consumer partnerships valuable?	13
The role of a consumer representative	14
Your role and responsibilities	15
Your consumer representative partnership journey	17
Is consumer partnering for me?	17
How to get your first role	18
Your consumer representative skills and experience	18
Before your first meeting	21
Your first meeting	22
After a meeting	25
Down the track	25
When it's not working	26
Your wellbeing	27
Thinking about the future	28
Health Consumers Queensland	29
Who are we?	29
Why we wrote this guide	29
What support can I get from Health Consumers Queensland?	29
Further reading and references	30

Introduction

A Guide for Consumers: Partnering with Health Organisations is for people who are motivated to create positive change in Queensland's health system through their own personal experience and knowledge.

This guide is primarily written for health consumer representatives. A health consumer representative (consumer representative) is someone who has taken up a formal, specific role to advocate on behalf of other consumers. For more informal health partnership activities you can participate in please see *Other ways of partnering* on page 18. A lot of the information in this guide can be used to support other consumer activities within

the health system, for example, the sections *Is consumer partnering for me* and *Your consumer partnering skills and experience* can assist you to think about whether partnering is for you.

Whatever type of activity you participate in, the overall aim will be to improve healthcare for all. Consumer representatives give voice to consumer perspectives and take part in decision making on behalf of all consumers.

It takes a committed and motivated person to become a consumer representative and be part of the work being done throughout the health system to improve health outcomes for all Queenslanders. You will make a difference to the people and families who use health services. Thank you for your contribution.

You might call yourself a health consumer, health advocate, consumer consultant or consumer and carer representative. There are many names for this role but the outcome is the same – your experience and insights can help to bring positive systemic changes to the design, development and implementation of health services for all.

You can use this Guide as a quick reference tool and dip in and out as you need. It has been written to be read a section at a time as you need.

This Guide will:

- outline the Australian health system
- help you understand consumer partnering in health organisations
- explore meeting processes and consumer roles
- provide information on support and self-care.

HEALTH CONSUMER REPRESENTATIVE KEY TIPS

Becoming a consumer representative is a journey based on **understanding, being informed, speaking up** and **networking**.

Understand



Ask questions about your role and the purpose of committee. Understand what you can and cannot do, and the level of influence that you can have.



Be informed

Find out as much as you can about the issue being discussed to support your role. Do your own research, read more about your area of interest, talk to other consumers, to your family and your friends. Highlight gaps in services or care.



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.



Network

Be connected to other consumers and carers with lived experience. Get to know other committee members. Partnering is relationship-based work and the more you connect with others the more effective your involvement will be.

What is consumer partnering?

Partnering is about enabling health consumers to influence the way health organisations plan, organise, deliver, monitor and evaluate their services. Your role as a consumer is based on the fundamental idea that the people affected by a decision have a right to participate in making that decision.

Consumer partnering is known by many names including consumer and community engagement, consumer participation, consumer collaboration and co-design. When we developed the *Consumer and Community Engagement Framework*, Health Consumers Queensland used the term “engagement”, but the term “consumer partnering” describes it more clearly. That partnerships need to be two-way, equal, respectful and cooperative.

Health consumers today expect greater accountability and transparency from health organisations, as well as the opportunity to directly impact and improve the health and wellbeing of ourselves, our families and our communities.

While the idea of partnering with consumers is not new, health organisations are embracing the concept and practice. It can require significant cultural shifts in health organisations and structured support for consumer representatives to facilitate active involvement in engagement processes.

There are many benefits of successful partnering in the health sector such as the delivery of more appropriate, safe and higher quality healthcare through more efficient and cost effective services.

Good partnerships are built on strong foundations and there are a number of charters, frameworks and standards

in place to support consumers in their partnership roles. There are several resources on the Health Consumers Queensland website which can provide a deeper understanding of the history and context of consumer partnerships. Some of these resources are referenced at the end of this guide.



Katherine Moodie Consumer Representative - Barrett Inquiry.
Co-presenting at Global Conference on Integrated Care 'Sharing Wisdom: Integrated Care - A work in progress' in Singapore.

Understanding Queensland's health system

The health system is complex. It is important to understand it if you want to make a difference as a consumer representative.

Australians have access to one of the world's best public health systems. Even though we have a good health care system, we can always make it better, more fair and accessible for everyone.

There are many parts to our health system; such as the regulation of health professionals, the complaints systems, standards and accreditation that hospitals must meet, Primary Health Networks, and health and medical research.

At its core, healthcare delivery in Australia can be divided into three areas: **primary care, secondary care** and **tertiary care**.

In terms of healthcare delivery, we can seek healthcare from many different providers

and often these providers are funded in different ways:

- Care from general practitioners (GP) is largely funded through Medicare by the Commonwealth Government
- Public hospitals are funded by the State Government
- Private hospitals can be for-profit or not-for-profit
- Aboriginal Community Controlled Health Organisations provide primary health care services; they are community owned and controlled.
- Community care can be provided by a range of different organisations with different funding sources.

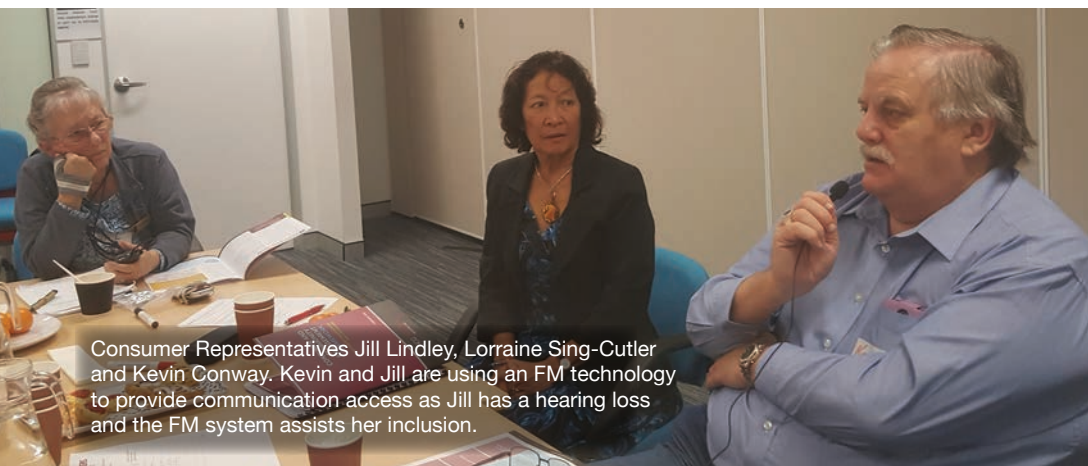
It's important to know: who is accountable?

A brief understanding of who the providers and funders of health care are allows a consumer representative to understand their level of influence and who the key players are in the work they are getting involved in.

Is it a Commonwealth issue and the Federal Minister for Health in Canberra is accountable for the use of taxpayer money?

Or is it a public hospital/ state government issue in which case the local Hospital and Health Board or the Minister for Health in Queensland, is accountable to the community?

If it is a private hospital or community care organisation, they will have their own accountability, typically in the form of clinical governance committees and a board.



Consumer Representatives Jill Lindley, Lorraine Sing-Cutler and Kevin Conway. Kevin and Jill are using an FM technology to provide communication access as Jill has a hearing loss and the FM system assists her inclusion.

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

Within Queensland you may be involved with the public or the private health system. Partnering can happen at an individual, service, network and system level.

- Ask your health organisation's contact person to explain this to you further if required.
- Ask for organisational maps, service area maps, service listings and flow charts that explain how your involvement will impact and where you fit in.
- If you receive a large amount of complex information to read, ask to have some time with someone who can go through the information with you highlighting important things to know and explain anything you are unsure about.



Primary care

...is the day-to-day essential health care given by a health care provider. A primary care provider is the gateway for continuing the care for patients within a health care system, and coordinates other specialist care that the patient may need. Primary care can include general practice, allied health services, community health and community pharmacy.



Secondary care

...is often acute healthcare provided by medical specialists in a hospital or other secondary care settings. Patients are usually referred from a primary care professional such as a GP or come through the Emergency Department.



Tertiary care

...is similar to secondary care, in that its care provided in a hospital, but it is the next level of care in a facility that has personnel and facilities for advanced medical investigation and treatment.

For example, if a baby is very sick and in need of specialist care, the baby can be transferred from their local hospital to Brisbane's Lady Cilento Children's Hospital. Here the baby will receive intensive treatment by appropriately skilled health professionals with special facilities and treatment options.

Some of Queensland's public hospitals provide both tertiary care as well as secondary, for example The Prince Charles Hospital provides specialist cardiac care for adults all over Queensland.

A health consumer's journey through the health system

This is the story of a consumer called James who is using Queensland's health system. It shows how a patient may receive different types of health care on their journey. We share it so that you can apply what primary, secondary and tertiary health care can mean in reality.

This consumer journey also gives a snap shot of what integrated care might look like in an ideal world. For example, in this story James's care is coordinated by his general practitioner. He is able to move between the different levels of care easily, his medical records are easily accessible to all health professionals he sees, his final discharge would link him back to his general practitioner and a community based health facility to further support his health and wellbeing.

Developing health systems that provide integrated and people-centred care has the potential to generate significant benefits to people's health outcomes. For people receiving care it will improve: access to care, health and clinical outcomes, health literacy and self-care. It will also increase satisfaction of care. For the health system it will increase job satisfaction for health workers, improve efficiency of services, and reduce overall costs.

Think about your own journey in the health system and see if you can identify some of these levels of care.



Primary care

James saw his General Practitioner (GP) as his first point of contact in to the health system to find out what was causing his occasional, mild chest pains. The GP referred him to a cardiologist.



Secondary care

The cardiologist works in private practice and is based at a private hospital.

After an ultrasound the cardiologist suspected James had experienced a 'silent heart attack' and wanted to admit him to a hospital.

There are two options here that James could take, either private or public hospital. This cardiologist has visiting rights to both public and private hospitals to treat patients.

James and his wife soon discover that their private health insurance does not include cover for cardiac care and they cannot afford James to be admitted into a private hospital.

James and his wife decide to access the public hospital system so are not out-of-pocket for any of the care they receive.



Tertiary care

Further testing revealed that James needed some specialist surgical procedures. He would need a referral to a tertiary care facility. It so happened in this case the hospital provided secondary and tertiary health care. Not all hospitals can provide tertiary care.

James was provided specialist care by a cardiac interventionist and had an angiogram and a number of stents inserted.



Primary care

After being discharged from the hospital, James continued regular visits to his GP, who supported and coordinated his care with the nurses at a clinic attached to the hospital. James has now returned to primary care until his situation changes.

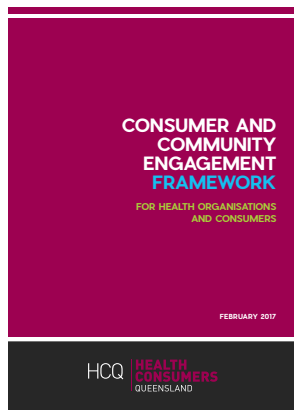
Definitions

Integrated health services: Health services that are managed and delivered so that people receive a continuum of 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.¹

People-centred care: An approach to care that consciously adopts individuals', carers', families' and communities' perspectives as participants in, and beneficiaries of, trusted health systems that are organised around the comprehensive needs of people rather than individual diseases, and respects social preferences. People-centred care also requires that patients have the education and support they need to make decisions and participate in their own care and that carers are able to attain maximal function within a supportive working environment. People-centred care is broader than patient and person-centred care, encompassing not only clinical encounters, but also including attention to the health of people in their communities and their crucial role in shaping health policy and health services.¹

The Consumer and Community Engagement Framework

Health Consumers Queensland's *Consumer and Community Engagement Framework* outlines the building blocks for partnerships between staff in organisations and their consumer representatives.

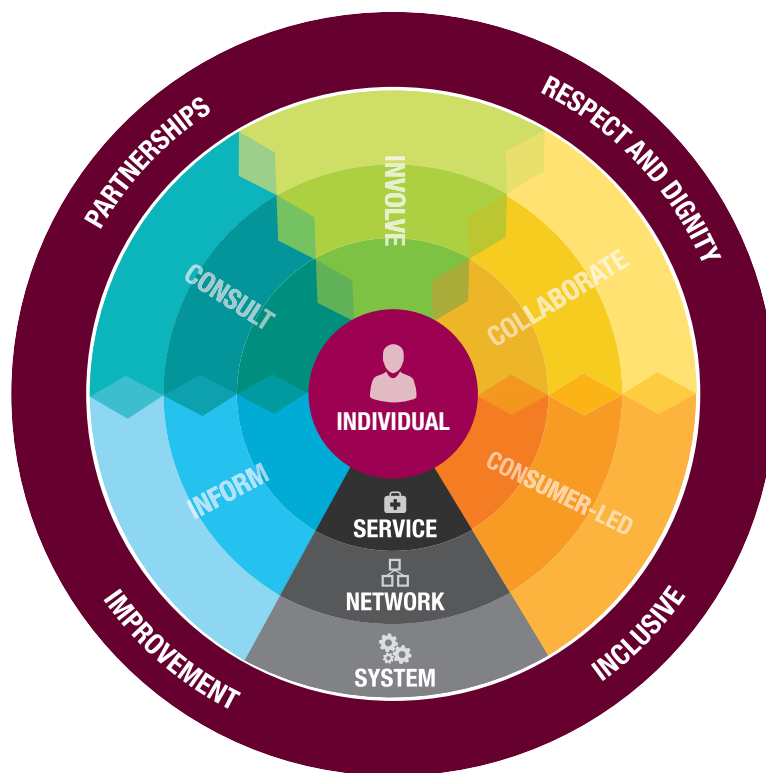


There is no one 'right' way to partner with consumers. Every health organisation operates differently with a specific set of objectives and clients to care for and support. There are however a number of principles and methods which when used can form a common foundation to build successful partnerships on.

There are four specific parts of the Framework you can use to guide your partnering: where partnering can happen, when to partner, the engagement spectrum and the principles for partnership. The relationship between these parts is represented in the Framework diagram.

Where partnering can happen

It's important to understand the level you are partnering at to understand your role better – is it at an individual level, service-specific, network-wide or the broader health system? It helps to be clear about where in the health system your partnerships are. This can then help you to frame your ideas and suggestions based on the purpose of the committee or project.



The Consumer and Community Engagement Framework

Ask about the level you are partnering at to understand your role and level of influence better.

The Framework breaks down the partnership opportunities into four levels:

Individual – Engagement in individual care sees consumers as partners in their own (or loved ones) healthcare and treatment. It is referred to as person-centred care.

Service – Service level engagement is focused on partnerships that impact on the planning, delivery, evaluation and monitoring of programs and services at a facility level.

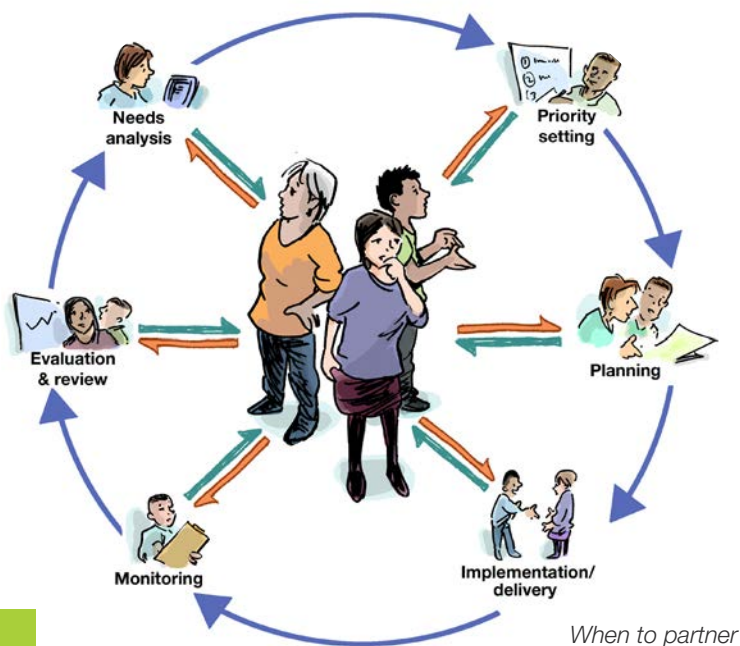
Network – Regional engagement processes as health organisations seek input into broader plans across their service area.

System – Engagement on health policy, reform and legislation influence and change the health system across local, state and Commonwealth jurisdictions.

When to partner

Understanding when partnering can take place is a practical and valuable step. From priority setting for strategic planning of a statewide service or an entire health region, to developing health literate information, and to making decisions about their own care, consumers should be involved.

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.



Think about when you have been invited to be involved. Where does it fit on the diagram on this page? How does it relate to the engagement spectrum (next page)?

The Engagement Spectrum

Consumer engagement activities can range from information and consultation sessions, where consumers’ influence on decision-making is more passive; to more active partnering at the collaboration and consumer-led opportunities.

It is expected that health organisations will be very clear about what level of influence you can have as a consumer representative and how your input will be used, in order to avoid frustration or disappointment. If you feel that your partnerships are always based in one place on the spectrum, maybe you can suggest some changes. Consumers’ level of influence can change depending on the project and/or phase of the project and other circumstances.



Principles for partnership

In consultation with health professionals and consumers it was agreed that the principles for effective consumer partnerships to work are: **partnership**, **respect and dignity**, **inclusive**, and **improvement**.

When consumer representatives and health staff are guided by these four principles then strong foundations for consumer and community engagement can occur.

Are any of the four principles missing in the partnerships you are a part of?

Partnership Working relationships between engagement partners are built on transparent and accountable processes. The purpose of consumer and community engagement is to shape service delivery to better meet consumer and community needs. Engagement takes place at all levels of the service: planning, design, delivery, evaluation and monitoring.

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 organisation engages through outreach and is respectful of existing community resources and expertise.

Respect and dignity Engagement partners value each other’s perspectives, knowledge and beliefs and develop relationships based on clear and open communication and shared goals. Partnerships focus on solutions and support the participation of consumers and community.

Improvement All engagement activities are evaluated by health staff and consumers and findings implemented for continuous improvement. Ongoing training and development opportunities are provided to support the capability building of all engagement partners.

Why are consumer partnerships valuable?

What can you do as a consumer to help re-inspire health staff about why they chose to work in health?

Through consumer partnerships, many organisations are ensuring they are meeting the health care needs of the community. It allows staff and health

professionals to connect with the people they are providing care for.

Organisations with strong consumer partnerships understand the benefits consumer and community engagement deliver:

- ✓ more effective and efficient service delivery
- ✓ identification of unmet needs and gaps due to unseen barriers
- ✓ improved access and equity
- ✓ more sustainable and innovative services
- ✓ increased staff and consumer morale
- ✓ better health and wellbeing outcomes for individuals and the broader community.

Australian hospitals and health services including day hospitals and dental clinics are accredited against the National Safety and Quality Standards. A revised version of the Standards was launched in November 2017 for implementation by health organisations in 2019. Of the eight standards, *Standard 1: Clinical Governance* together with *Standard 2: Partnering with Consumers*, set the overarching requirements for the effective implementation of all other standards.

Standard 2 aims to ensure that consumers are partners in the design, delivery and evaluation of healthcare systems and services; and that 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. The revised standard recognises the importance of involving patients in their own care and providing clear communication to patients.

How can you as a consumer be part of creating a culture of partnering in health organisations?

Case study: consumers on recruitment panels for health staff

Caboolture Hospital has invited consumers to sit on their interview panels for the recruitment of new staff. Consumers are:

- selected based on their consumer experience in the relevant field and comfort in an interview setting
- supported in the process where they get all relevant material including details of the interview panel, resumés and applications
- introduced to the panel if it is their first time working with that particular group of staff, and
- included in the debrief and decision-making about the shortlist of candidates.

Consumers are assured that their role is “to listen to the interviewee and ask themselves if they would want that person as their doctor/nurse/pharmacist/person making decisions about their future hospital stay”.

Staff recruited through this process have a greater understanding of the importance of consumers and can easily see consumers are firmly embedded in the Caboolture Hospital system.

The role of a consumer representative

Your role as a health consumer representative is to provide advice and feedback on health services, policy, systems and service reform and improvement from a consumer perspective.

While anyone can be considered a consumer through their past, current or future use of health services, there are additional expectations and responsibilities in a consumer representative role.

It is the lived experience and personal insights that make a consumer's perspective so valuable. The consumer voice can be a powerful tool when

it comes to influencing decisions, treatments and policies.

One of the most important things a consumer representative can do is to ask questions. You are not expected to have all the answers but instead to challenge and engage those around you to look at a situation, program or problem from a person-centred perspective.

**Your passion is what drives and inspires you. What is your passion?
What do you want to see change in the Queensland health system?**

If you are an Aboriginal or Torres Strait Islander or a person from a culturally and linguistically diverse background, your unique and personal perspective as a consumer representative is important. By questioning the cultural safety or cultural appropriateness of a service or program you can make a critical difference to the future health outcomes of your community.

If you have specific needs – whether it is cultural or physical or emotional – please speak with your health organisation contact person so they are aware of your needs and can ensure they are met, so that you are best supported to participate effectively.

Questions are a powerful tool

Take every opportunity to ask questions. Here are some example questions you could ask in partnership activities. There are no wrong questions.

- 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?

Your role and responsibilities

Consumer partnering is **relationship-based work** built on a foundation of **partnership, respect and dignity, inclusiveness, and improvement**.

As a consumer representative it is important that you do your part to be informed and educated about the process you are stepping into. The health organisation you are working with also has a responsibility to ensure they are supporting you in this process by providing clear information about your role and what is expected of you.

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. As a consumer representative, you cannot be expected to represent all perspectives, but you do have the opportunity to ask questions and raise viewpoints for people not represented at the table.

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.

Your responsibilities

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

It is important to remember that you may deal with **confidential** material at times. If you are unsure about what you can or cannot discuss outside your consumer representative role, ask the committee chair to clarify. You are bound by the same rules of confidentiality as other members of the committee.

A **conflict of interest** can occur when there is a real or perceived conflict between a person's duties and responsibilities of roles they hold professionally or privately outside of the consumer representative position. You should raise any potential conflicts with the chair prior to the meeting and be led by their advice.



Bruce Teakle, Maternity Consumer Representative with his family at home in Mt Glorious.

What support will I get from the health organisation I am partnering with?

Your time and expertise is valued and you should expect as a consumer representative to:

- be **treated fairly** and with **respect**
- receive an **orientation** to your role and the health organisation
- receive **information** early so that you can read and prepare for meetings and to have medical terminology and technical information and acronyms explained in simple language
- receive **information** about the terms of your appointment, length of commitment, and time required for the project you will be involved in and the meeting itself
- be able to **ask questions** before, during and after the meeting
- be provided with a list of **contact details** of committee members and consumer engagement staff
- understand the organisation's **reimbursement policies and processes** which may cover items such as parking and travel expenses, child care or carer support, and remuneration for your time spent at meetings, preparation and pre-reading for the meeting
- **feedback** on the outcomes and impact of your involvement in the committee
- be able to add **items to the agenda**
- be **able to disagree** and have this formally acknowledged in the minutes
- be included and involved in **decision making**
- be offered **training and development opportunities**
- be able to **speak up about your own specific needs** or the person you care for, before the meeting so that you are supported to be able to actively participate. These needs may be dietary, accessibility related, medication requirements and its effect on you, hearing loops and hearing assistance, cultural or emotional.

In the event you feel you are not receiving adequate support or assistance, don't hesitate to speak to the chair of the committee, the committee secretariat or a consumer engagement support staff member. You could also reach out to other committee members for advice and support.

Health Consumers Queensland's position on payment of consumers

Each health organisation may have a different policy around payment and reimbursement of consumers. As a consumer you have the right to be informed of this policy (or lack of) before you begin partnering. You can then make an informed decision about whether or not you are willing to invest your time in any given partnership.

- Health Consumer's Queensland recommends that no consumer should be financially disadvantaged as a result of their contribution to a health organisation. At a minimum the organisation should cover out-of-pocket expenses such as travel, accommodation, childminding, respite care costs, or printing.
- Health Consumers Queensland recommends that you receive a sitting fee for your time, expertise and contribution. Please speak to your health organisation contact person about their policy or contact Health Consumers Queensland for a copy of an up-to-date Position Statement on Remuneration and Reimbursement.
- You may be employed, receive a pension or benefit. It is your responsibility to investigate the impact of remuneration payments for representative roles on your other income. Health organisation staff cannot give financial advice. The Australian Tax Office can be contacted for legal and financial advice. Free legal advice on Centrelink matters in Queensland can be sought from Basic Rights Queensland, 1800 358 511 <http://brq.org.au/>

Have there been times where you feel disempowered to ask for help with your role? Reflect on these and think about who and how you can ask for help next time.

Your consumer representative partnership journey

The role of a consumer representative can be challenging but it can also be one of the most rewarding experiences, knowing that you are helping to affect positive change in Queensland's health system and improving the health care experience for other consumers.

Is consumer partnering for me?

It's important to understand that there are limits to what you can influence, and that change takes time.

Be clear on what you want to get out of your experience as a consumer representative and ensure that you are there for the right reasons. Remember that you are an expert in your own story and experience. Your opinion is highly valuable and should be respected.

It is also okay for you to question everything and not have all the solutions – your role is to challenge the current system and provide a unique perspective on what is and isn't working in the health system.

**“I want to
make things easier
and better for others
by using my experience
and knowledge.”**

Jeannine Kimber,
Carer Representative,
from Brisbane

10 reflective questions

- 1 Why do I really want to do this?
- 2 How much do I want to be involved?
Think time and resources.
- 3 How might this impact or improve my health and wellbeing?
- 4 How does my family feel about me doing this work?
- 5 What areas of health and health systems do I want to be involved in?
- 6 Where will I get help and support when I start?
- 7 Will there be expenses that arise from this work that I cannot meet?
- 8 Do I just want to give feedback or make a complaint or give a compliment?
- 9 Am I using partnering as a way to tell and retell my story, to seek some kind of resolution or closure?
- 10 Are the partnership processes going to be culturally appropriate for me?

Other ways of partnering

If sitting on a committee is not for you, there are many other ways you can choose to partner with health organisations and have your say. You can:

- provide feedback based on your patient/carer experience through surveys
- join or participate in focus groups
- attend forums, symposiums or public meetings
- write submissions to reviews
- review brochures, websites, policy documents and guidelines
- seek employment as a peer support worker
- get involved in the training/ professional development/ orientation of staff and volunteers
- be part of selection panels for the recruitment of staff, or selection of research projects or innovation fund projects.

How to get your first role

There are a number of 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 via their webpage, in order 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 state-wide 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 notification about consumer representative vacancies, relevant resources, training opportunities and much more.

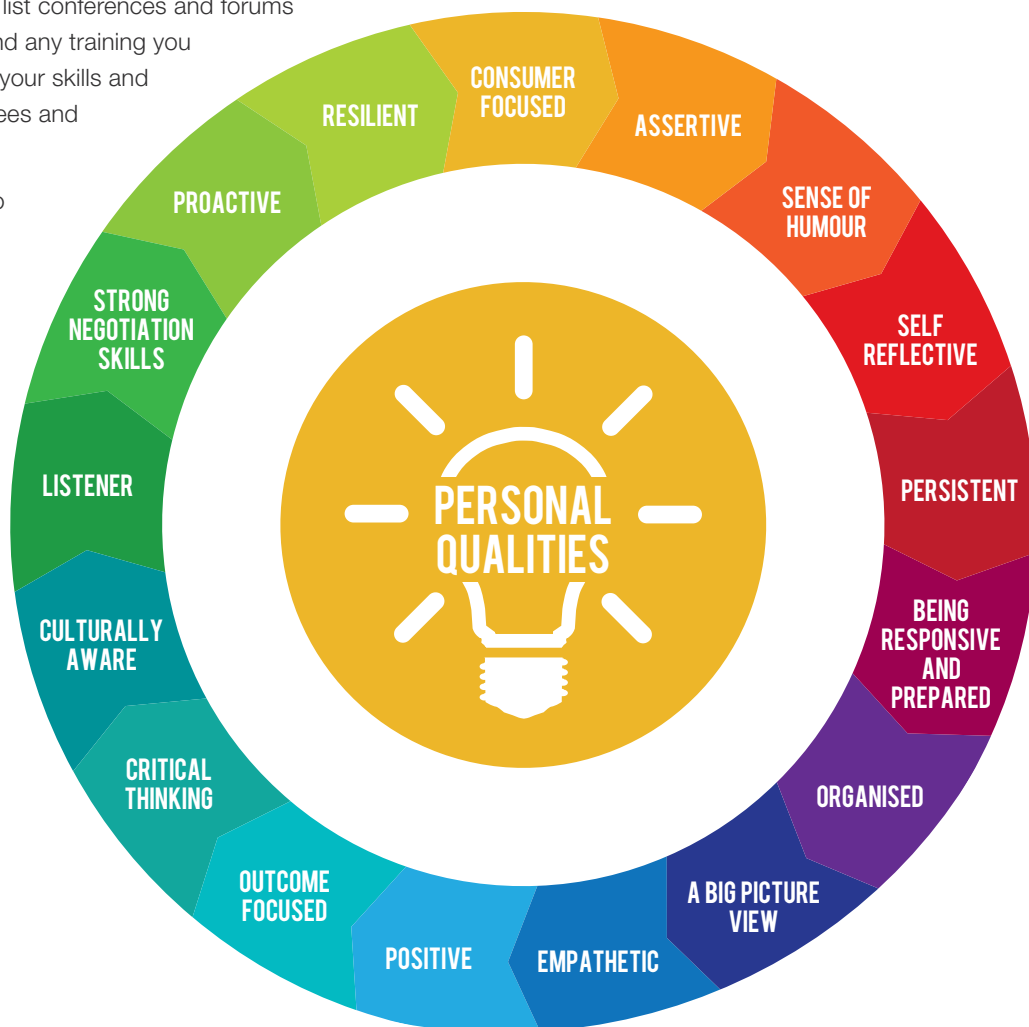


John Palmer.
Consumer
Representative
from Longreach.

Your consumer representative skills and experience

When you apply for a job you usually have a resumé to showcase your knowledge, skills, abilities and experiences. When you apply for a consumer representative role you will be asked to show why you are ideal 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.

Which of these **personal qualities** do you have? Which of these qualities would you like to cultivate and learn to be a more effective consumer representative? Understanding your own strengths and areas for improvement can help you to become a more effective representative.





Janelle Colquhoun, from Brisbane is an accomplished opera singer and experienced consumer representative.

Here are some ideas to get you started or to help you write about your skills and experience.

To begin, create a **brief description or one-line explanation** about yourself and why you would make a great health consumer representative. Think about those personal qualities listed on the previous page – what best describes you?

Next up, detail your **personal healthcare experience**. Include information about any other boards or committees you are part of, community group or professional organisation memberships – this can include both health or 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.

Do you at times feel shy to speak about yourself? Be proud and identify what you have achieved and what you are capable of.

Already a consumer representative?

If you are already on a committee, follow the questions in the *Self Assessment for Consumer Representatives* which can be found on Health Consumers Queensland's webpage www.hcq.org.au. This assessment tool can help you to reflect on where you are at in your consumer partnering journey and to find any gaps or areas for development.

Health organisations provide staff training that you may be able to participate in,

such as orientation, patient-centred care, cultural awareness training or even how to use Microsoft Word. When you are proactive in identifying what you can offer and what areas you need help in, this shows that you want to grow and actively contribute. Stay connected with Health Consumers Queensland, by visiting our website, and reading our regular eNews and eAlerts to keep up-to-date about upcoming training programs and consumer partnership roles.

Before your first meeting

Administration and paperwork

There can be a large amount of paperwork sometimes involved when working with health organisations. You can ask for help in completing any forms or documents. Some of these are just one-off documents to get you into the system and ensure that all health and safety and other requirements are met. There will be some ongoing paperwork you will need to do, for example, claiming travel expenses. Make sure you speak to the consumer engagement staff or the committee secretariat about what is required if you are unsure.

Orientation

Before you begin or do something new, it is always useful to have an orientation. An orientation helps you learn what you are about to step into. When we know where we are and what we have to do, our ability to contribute and to be constructive and creative comes with ease. An orientation also brings a sense of comfort about the new space that you will be working in.

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. Know the exact address of where you have to be and figure out 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 need to call a committee member if you get lost or if there have been any last-minute changes.

If you have not been offered an orientation, ask for this to occur preferably before your first meeting.

Preparation time

Being involved in a committee means you will need to set aside some time to prepare yourself and plan what you need to do. Take every opportunity to grow and learn in your new role. You can access online research (e.g. the Cochrane Library database), workshops, 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 particular point of view or idea – what is your angle?

A quick checklist

- ✓ Is all the administrative paperwork that was required completed?
- ✓ Have you done any pre-reading, highlighting concerns and noting questions?
- ✓ Have you read the organisation's consumer and community engagement strategy or policy? Is there anything you need to have clarified?
- ✓ Have you had some contact from the chairperson or have you made time to meet them?
- ✓ Have you looked at the organisation's webpage to understand their vision, values and general business?
- ✓ Get a good night's sleep, take a water bottle, notepaper, pens and any other things that will make you feel comfortable.

A word on networking

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.

Networking with and meeting the chair of your committee is essential before your first meeting. Over time you can get to know the other members you will be working with. You can ask to do this outside of meeting times and when it is convenient for the members. 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.

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 share knowledge about consumer-centred services and initiatives. You can also help each other with advice and support.

It's useful to maintain your networks. 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!



A smile,
a strong



hand shake and

enthusiasm to



learn about others
will set you up as



an expert networker.

Your first meeting²

- **Introduce** yourself confidently and briefly. Remember your personal experience is a big part of why you were selected but your ability to 'see the bigger picture' and how you can contribute will be greatly appreciated by health staff.
- Make a note of who the other members are as they introduce themselves; often their names may be listed on the agenda. It will be hard to remember all **names** immediately but keeping brief notes will help. You can also suggest that everyone wears name tags.
- Try to **sit** near the chair of the committee or close to the centre of the group. Being in the middle, you are more likely to be included and referred to. If there is another consumer at the meeting, it can help to sit away from each other as you will be more inclined to meet new people and start new conversations or you may wish to sit together to support each other. Be sure to share your new insights with your fellow consumer afterwards.
- **Listen** to the contributions of others and note who is supportive of the consumer perspective – take the time to get to know these people as they can become great allies. It is just as important to get to know those who appear resistant to consumer perspectives. Often these can be fruitful and productive relationships as you each learn new perspectives and help each other to understand and address any misconceptions.
- Make the most of any breaks to **network** and build relationships. Identify any experienced consumers and make sure you introduce yourself.
- Be careful of committing to anything you either don't have time to do or aren't sure you can do. **Ask** for more information about what is involved or if you can discuss what's involved after the meeting. Keep notes of anything you agree to do before the next meeting (see the box *Questions are a powerful tool* on page 14 for some example questions you can ask).

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.

Adapted with permission from Health Consumers New South Wales: Tips on getting started as a consumer rep.

**“As a health consumer
I share my experience and
knowledge across my various
networks and educate other consumers,
so that they know how the system operates
and what is available to them and what
their rights are. I feel my role is like a
bridge between the community and
the health system.**

**Through my
lived experience I
am able to educate health
organisations to create a better
and more supportive health system.
A system that is not only clinically
safe but that is socially, culturally
and emotionally safe
for everybody.”**

Sharon Boyce.
Consumer Representative from Toowoomba.



Sharon Boyce.

How does a committee work?

Committee work is based around discussion and debate within a meeting structure. Committees have terms of reference, agendas, certain work scopes and time constraints. Good committees often have strategic plans or work plans as documents to show their agreed purpose and actions. You can request to view any such documents before you start, or during your term.

It is likely you will be the only consumer sitting at the table, or one of only two with the rest of the committee comprised of health professionals or government staff. This can be daunting, and for some this might be a stimulating challenge. Give yourself time to adjust.

Some health organisations will arrange a staff buddy or mentor for you. At the very least a staff member should be identified as your “go to”, to help you – whether it is to chase up your late payment of expenses and remuneration or explain the background to a project. It is also worthwhile connecting up outside of the meeting with an experienced consumer representative to get some helpful tips and guidance. For example, you could ask if you could phone them before the next meeting to discuss any questions you have about your role.

Meeting minutes

For most committees, a record of each committee meeting will be kept. These records are called **minutes** and reflect what was said, what decisions were made and what actions need follow-up.

If something you said has not been noted in the minutes you have a chance before the next meeting to ensure that it is noted. Before the next meeting begins the Chair will ask if the previous minutes are accurate and at that time you can raise anything missed, and an amendment can be made.

Present – the names of everyone present.

Apologies – the names of people who were unable to attend and have sent apologies.

Previous minutes – the minutes of the previous meeting are presented to the meeting; committee members need to ensure that they are a ‘true and accurate’ record of the meeting.

Business arising – the discussion of any business arising from decisions made at the last meeting to keep everyone up to date, this is useful for checking on the progress of projects and to remind members of the tasks they agreed to carry out.

New business – items not on the current agenda.

Action items – things that need to be done before the next meeting or specific date.

**Meeting terms...
it's like learning a
new language**

After a meeting

After a meeting it is always a good idea to organise a debrief or an opportunity to catch up with the chairperson of the committee and the other consumer representative (if there is one).

- This is when you can clarify anything that was not clear or if there was something you missed.
- Ask any questions you might have noted during the meeting.
- Remember that anything said in the meeting is minuted, however a debrief with the chairperson is not minuted so you may want to write out some notes during or after to keep accurate records of conversations.
- Hopefully the chairperson will check-in with you to see how everything is going. If the chairperson is unavailable, ask to meet with another experienced committee member.

Down the track

Some committees or working groups have short lifespans while others are ongoing. Once you are settled into your role it's a good idea to reflect on your journey, perhaps every six months, and ask yourself:

- Am I making a difference?
- Is this work making a difference?
- Does the consumer voice need to be supported by another consumer representative being appointed? What kind of background could they bring to expand the diversity of consumer representation on the committee?
- Do I still have the time/capacity/motivation to be the consumer on this group?
- How can I support or mentor other consumers in this role?
- Are we evaluating what we are doing, including the consumer partnerships?
- Am I being given opportunities I would like, such as co-presenting at a conference on an initiative or program of work achieved?



Stephanie King with baby
Evie Rose. Consumer
Representative from Mt Isa.

When it's not working

Most organisations will be eager to learn and engage with their consumer representatives, but for some the partnership might be new and they may appear resistant to change or still be developing and implementing good partnership principles.

Have you been in a situation where you have felt you are unable to contribute? Think about what you did and reflect on what you can do if this happens again.

If you feel that you are not being respected, or that your opinion is not being heard, or feel unsupported in your role, you should reach out to your committee's key contact or chairperson to raise any concerns you have. Often the organisation is simply unaware of how you are feeling but will work to rectify the situation if brought to their attention.

Self reflection and analysis is a good habit to get into. Reflect upon whether there is anything you can do

differently. Can you seek support to improve your communication skills so that your messages are more likely heard by health organisation staff? Clearly understand your own goals and motivations. Consider if there is a gap between your desire to influence, and the level of influence a health organisation is willing or able to offer you. Keep your desire to make a difference at the core of your work and always remember consumer partnering is relationship based work which needs attention and effort on both sides.

Sometimes despite efforts made on your part and the health organisation, you might still come to the conclusion to leave your partnership role. Providing detailed feedback can help the organisation improve their partnership opportunities and to assist any future consumer representatives in the role.

Health Consumers Queensland staff are also available for advice or further assistance to ensure that you feel supported and valued in your role.

"When things were not working it really helped to identify the purpose of my involvement. Being a consumer and sharing one's experience, is certainly a purpose. I reflect deeper and ask myself "what is going to really 'rock my boat' by being on this committee..."

What also helped me was identifying someone on the committee to speak to about these matters and to have a mentor/coach outside the health organisation...

...My learning was that the all-giving consumer representative is not doing themselves a favour. We also need to believe we are making a difference to ourselves."

Lorraine Sing-Cutler.
Consumer Representative from Brisbane.

Your wellbeing



Self-care

Choosing to be involved in systemic change can be challenging. You may not see the results quickly or even for the entire time you serve on particular committees.

As one experienced consumer 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!”.

Look after yourself; take time to rest, rejuvenate, eat well and be physically active. Consider people in your network and family who can support you as well as the health organisation you are involved with. Reach out and ask for help if you need it.



Physical and mental health

There will be times where your physical or mental health might affect your ability to be present at a meeting. Health organisations need to know if you need additional support or accommodations. Ask if you can teleconference in, or provide feedback before the meeting by reading papers. You can still be involved without being present at all times.



Emotional health

In your role as a consumer representative you will deal with many different personalities, some of whom you may disagree with. Your role is to bring a fresh perspective and to challenge or question a situation.

This process in itself can be very emotionally and mentally draining.

“Continue to self-monitor your response and its quality. If the experience as a consumer is impacting on you negatively talk it over with your contact person and resolve to take appropriate action from there.”

Jim Madden. Consumer Representative from Toowoomba.

Think about ways you can manage this. Do you have mindful practices you can do to let go of any negativity or heaviness as you leave a meeting? What can you do that allows your mind to de-stress? How do you support your mental and emotional wellbeing? Everyone has their own way to look after themselves, find out what is yours and make sure that it is part of your daily routine.

If you find that things are not working for you then perhaps it is time to take a break or pull back your involvement. Be savvy and assertive about what you can give and not give. It is your time and expertise, and if you are not able to participate then that is okay, there will be more opportunities. It is about creating a balance in your life that works best for you.

Body and mind scan – take a moment now to scan and reflect how you are feeling in your body and mind in relation to your consumer representative role.

Thinking about the future

Over the years in your various roles as consumer representative you would have built up considerable experience and expertise about how to partner effectively.

These invaluable learnings and knowledge would be very useful for someone who might be just starting their partnering journey with health organisations. Have you considered mentoring new and emerging consumer representatives? Please contact Health Consumers Queensland if this is something you have an interest in. Your guidance would support the next generation of consumer representatives to continue the work you feel so passionate about.

Partnering with health organisations to bring about systemic change can lead to many new opportunities. You may also consider taking on a paid role in a consumer, community or health organisation, serving on a board or even consider becoming an academic.

Thank you for your dedication and commitment to this work. All the best in your journey and always remember you can contact Health Consumers Queensland for support and help.



From left to right: Wyomie Robertson, Consumer Representative, Reema Naresh, Project Officer-Health Consumers Queensland, Stephanie King, Consumer Representative, Chelsea Rolfe, Consumer Representative and Melissa Fox, CEO-Health Consumers Queensland at the Growing Deadly Families, a Healthy Start for Young Children, 2017.

Health Consumers Queensland

Health Consumers Queensland is the peak organisation representing the interests of health consumers and carers in the state. Health Consumers Queensland is a not-for-profit organisation and a registered health promotion charity that believes in improving health outcomes for all Queenslanders.

Who we are

Our priority focus is on consumer engagement that influences and leads improvements and delivers better health outcomes for all Queenslanders. We achieve this through our Queensland-wide health consumer network, tailored training and skills development programs, and maximising opportunities for consumer representation at all levels of the health system. We believe partnering with consumers is very important, as consumers see things from a different viewpoint and only they can bring that unique perspective.

Why we wrote this guide

This guide was designed to help health consumers become strong and confident consumer representatives. It follows on from the *Consumer and Community Engagement Framework* which provides the who, what, why and when of consumer partnering. This guide for consumers, and a second guide for health staff, aims to provide the 'how to' of partnering.

Health Consumers Queensland is grateful for the input from experienced and new consumers and staff who provided their feedback through discussions, focus groups and online surveys to help shape the contents of this document.

What support can I get from Health Consumers Queensland?

You can contact Health Consumers Queensland for support, advice and information about consumer partnerships. Our contact details are on the back cover.

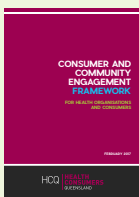
You can join the Health Consumers Queensland's state-wide consumer network and receive regular information about opportunities to get involved as well as access information and resources to build your knowledge about consumer partnerships and the health system. Consumer representative opportunities promoted through the HCQ network provide the chance to give feedback and input on health policy, planning, and service provision within Queensland and nationally.

Further reading



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. You can access it on this web link:

<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 engagement spectrum that identifies the level of influence consumers have. It can be used as a foundation document to begin the partnering process. Here is the link for the Framework:

<http://www.hcq.org.au/our-work/framework/>



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 policy and framework aims to close the life expectancy gap and halve the gap in mortality rates of Indigenous children under five within a decade. You can access it on this web link:

https://www.health.qld.gov.au/atsihealth/close_gap



National Safety and Quality Health Service Standards – Standard 2: Partnering with Consumers requires effective and meaningful engagement of consumers in planning, designing and evaluating services. You can access it on this web link:

<https://www.safetyandquality.gov.au/our-work/assessment-to-the-nsqhs-standards/>



National Standards for Mental Health Services – Specific health service standards exist that can be applied to all mental health services, including government, non-government and private sectors across Australia. Within them *Standard 3: Consumer and carer participation* has seven criteria aimed at consumers and carers being actively involved in the development, planning, delivery and evaluation of services. You can access it on this web link:

<http://www.health.gov.au/internet/main/publishing.nsf/content/mental-pubs-n-servst10>

Australian Commission on Safety and Quality in Health Care. Check out the National Priorities tab for many useful resources like the Atlas of Healthcare Variation.
<https://www.safetyandquality.gov.au/>

Australian Institute of Family Studies produces high quality, responsive and impartial research in to the wellbeing of Australian families.
<https://aifs.gov.au/cfca/publications>

Australian Institute of Health and Welfare is Australia's leading health and welfare statistics agency. You can find evidence on a wide range of health matters to enable stronger decision making for better services.
<https://www.aihw.gov.au/>

Consumers Health Forum of Australia (CHF). The CHF of Australia is the national peak body representing the interests of Australian healthcare consumers. CHF works to achieve safe, quality, timely healthcare for all Australians, supported by accessible health information and systems.
<https://www.chf.org.au/>

International Alliance of Patient's Organizations (IAPO). IAPO is a global voice for people who suffer from any disease, disability, illness, impairment or syndrome and everything IAPO does is focused on promoting patient-centred healthcare.
<https://www.iapo.org.uk/>

International Association for Public Participation (IAP2). IAP2 is an international member association which seeks to promote and improve the practice of public participation or community engagement, incorporating individuals,

governments, institutions and other entities that affect the public interest throughout the world.
<https://www.iap2.org.au/Home>

Queensland Health website. You will find state-wide policy documents, strategic overviews and data that may be useful for consumer representatives.
<https://www.health.qld.gov.au/system-governance>

The Chief Health Officer's yearly report on the health of Queenslanders.
<https://www.health.qld.gov.au/research-reports/reports/public-health/cho-report>

References

- ¹ **World Health Organisation**, Report by the Secretariat, 69th World Health Assembly. Provisional agenda item 16.1. 2016. *Framework on integrated, people-centred health services*. [Online]. Available at: http://apps.who.int/gb/ebwha/pdf_files/WHA69/A69_39-en.pdf?ua=1
- ² **Health Consumers New South Wales.** (2017, August 29). Health Consumers New South Wales. Retrieved from *Tips on getting started as a consumer rep.* [Online]. Available at: <http://www.hcnsw.org.au/pages/tips-on-getting-started-as-a-consumer-rep-.html>
- ³ **Cancer Australia (2009).** *Consumer participation guide*, Cancer Australia: Canberra. https://canceraustralia.gov.au/system/tdf/publications/consumer_training_and_mentoring1_504af023a08ae.pdf?file=1&type=node&id=2823



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

Level 9, 217 George Street, Brisbane, QLD 4000
PO Box 12474 George Street, Brisbane, QLD 4003
f healthconsumersqueensland t HCQconsumerorg
Email: info@hcq.org.au Phone: 07 3012 9090