



A Guide for Consumers:

Partnering with Health
Organisations in the ACT

Acknowledgement of Traditional Owners

The Health Care Consumers' Association of the ACT (HCCA) acknowledges the traditional custodians of the land our organisation is located on and on which we work, the Ngunnawal people. We acknowledge and respect their continuing culture and the contribution they make to the life of this city and region. We pay our respects to their ancestors and elders, past, present, and emerging, as they hold the traditions, culture, and hopes of Aboriginal and Torres Strait Islander Australians.

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Glossary

Acute – care for the treatment of a sudden or short-term illness

Cardiologist – a doctor that specialises in the heart and blood vessels

Carers - people who provide unpaid care and support to family members and friends

Confidentiality agreement – an agreement signed when sensitive information needs to be shared to make sure that the person or organisation who gains access to sensitive information doesn't disclose it to someone else

Consumers – are people who have accessed health care or services. They include patients, their friends, families, carers and members of the general public

General practitioner – is a doctor who specialises in general medical practice, they are usually the first point of contact in the health system for most people

Health literacy - Health literacy is the combined knowledge, skills, confidence and motivation used to make sound decisions about your health in the context of everyday life.¹

Medicare - is the universal health insurance scheme that gives Australian residents access to healthcare

Primary health network - are independent organisations that we fund to coordinate primary health care in their region. They assess the needs of their community and commission health services for people in their region

Visiting rights - When a doctor or midwife has visiting rights at a hospital it means they have an agreement with that hospital to provide health care to patients using that hospital's premises and resources.

¹ Health Care Consumers' Association (2022). Health Literacy Position Statement.
<<https://www.hcca.org.au/publication/health-literacy-position-statement/>>

A Guide for Consumers: Partnering with Health Organisations in the ACT

A Guide for Consumers: Partnering with Health Organisations in the ACT is for people who are motivated to advocate for positive change in the ACT's health system, drawing on their own personal experience and knowledge.

A **health care consumer representative** (or **consumer representative**) is someone who has taken up a formal, specific role, in partnership with a health service, provide a consumer perspective. This Guide is written with consumer representatives in mind. For more informal health partnership activities you can participate in, please see [Other ways of participating \(page 36\)](#).

Much of the information in this guide can be used to support any partnership between **consumers** and health services within the health system. Whatever type of activity you participate in, the overall aim will be to improve healthcare for everyone. 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 a part of work being done to improve the health system. You will make an important difference to the people who use health services and their families and **carers**.

Thank you for your contribution. You might call yourself a health consumer representative, patient advocate, or consumer and carer representative. There are many names for this role, but the purpose is the same – **your experience and insights guide positive changes to the design, development, implementation, and governance of health services**.

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 to offer guidance in your consumer role. This Guide has been prepared by the Health Care Consumers' Association of the ACT (HCCA) and contains information tailored to the ACT and region, based on the Health Consumers Queensland guide.

THIS GUIDE:

1

Outlines the Australian and ACT health system

2

Helps you understand consumer partnerships in health organisations

3

Explores meeting processes and consumer roles

4

Provides information on support and self-care

Glossary terms in this Guide are highlighted in **maroon** and the glossary can be found on page 4.



CO-DESIGN *genuine*
consumer partnering
CONSUMER cooperative
REPRESENTATION
community engagement CONSUMER
RESPECTFUL COLLABORATION
ACCOUNTABILITY *transparency*

What is consumer representation?

Consumer representation is about health care consumers influencing the way health organisations plan, organise, deliver, monitor, and evaluate their services. Your role as a consumer representative is based on the principle that *the people affected by a decision have a right to participate in making that decision.*

Consumer representation is known by many names including consumer and community engagement, consumer partnering, consumer collaboration, and co-design. The partnerships between consumers and health services need to be genuine, respectful, and cooperative. Health consumers increasingly 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 increasingly embracing the concept and practice – in fact **Partnering with Consumers** is Standard 2 of the *National Safety and Quality Health Service Standards*².

It can require significant cultural shifts in health services for consumers to become active participants in planning and decision-making. There are many benefits of successful consumer partnerships in the health sector, such as the delivery of more appropriate, safer, and higher-quality healthcare, and more efficient and cost-effective services.

² Australian Commission on Safety and Quality in Health Care n.d., *Implementation of the NSQHS Standards*, <<https://www.safetyandquality.gov.au/standards/nsqhs-standards/implementation-nsqhs-standards#second-edition>>.

Good partnerships are built on strong foundations and there are several charters, frameworks, and standards that can support consumers in their partnership roles. There are many resources 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.

“

I think consumer representation is about having the consumer voice at the table, someone who can put forward a different point of view. I think a lot of health service staff and doctors really care about their patients and their clients. However, consumers can bring their own personal experiences and they may just see things a little bit differently, and I think it's really rewarding that you can share your experiences and know that they might change processes, or someone's behaviour, so that there are better outcomes for other people who may be going through the same thing as you in the future.

- *Leia Earnshaw, Consumer Representative*



Understanding the ACT 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, safer, and more accessible for everyone.

There are many parts that make up our health system: public and private health services, **Medicare**, the regulation of health professionals, complaints systems, standards of accreditation that health services must meet, our **Primary Health Network** (known in Canberra as Capital Health Network), and health and medical research.

HEALTHCARE DELIVERY IN AUSTRALIA CAN BE DIVIDED INTO THREE AREAS:



**Primary
care**



**Secondary
care**



**Tertiary
care**

See the next section to learn more about each level of care.

CONSUMERS CAN SEEK HEALTHCARE FROM MANY DIFFERENT PROVIDERS, AND THESE PROVIDERS CAN BE FUNDED IN DIFFERENT WAYS:

- Care from general practitioners is largely funded through Medicare by the Commonwealth Government and consumer co-payments.
- Public hospitals are funded by the ACT Government and the Australian Government. They are managed by the ACT Government.
- Private hospitals can be for-profit or not-for-profit, and operate with a mix of funding sources including government funding.
- Aboriginal Community Controlled Health Organisations provide primary health care services; they are community owned and controlled.
- Community-based health care can be provided by a range of different organisations with different funding sources. They can be run by government or non-government organisations.

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. For example:

- Is it a Commonwealth issue, such as an aged care facility, and the Commonwealth Department of Health and the Federal Minister for Health are accountable?
- Is it a public hospital issue, in which case Canberra Health Services and ACT Health Directorate, or the Minister for Health or Minister for Mental Health, are accountable?
- If it is a private hospital or community service organisation (such as Directions Health Service, Meridian, Woden Community Services, Calvary, Anglicare) they will have their own accountability, typically in the form of clinical governance committees and a board.

IN THE ACT, THE TERRITORY GOVERNMENT IS RESPONSIBLE FOR:

- Managing and administering public hospitals
- Delivering preventive services such as breast cancer screening and immunisation programs
- Funding and managing community and mental health services
- Public dental clinics
- Ambulance and emergency services
- Patient transport and subsidy schemes
- Food safety and handling regulation
- Regulating, inspecting, licensing, and monitoring health premises

As a health consumer representative, it is important to understand the context of your work. Within the ACT 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 YOU NEED MORE INFORMATION ABOUT WHERE THEIR ORGANISATION FITS INTO THE SYSTEM.

- Ask for organisational charts, service area maps, service listings, and flow-charts that explain what impact your involvement will have 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, highlight 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 patient care within a health care system, and coordinates any specialist care that the patient may need. Primary care can include general practice, walk-in centres, Emergency Departments, 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 setting. 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 it is care provided in a hospital, but it is the next level of care in a facility that can do advanced medical investigation and treatment. For example, if a baby is very sick and in need of specialist care, the baby can be transferred to the Neonatal Intensive Care unit at Canberra Hospital. Here the baby will receive intensive treatment by appropriately skilled health professionals with specialist facilities and treatment options. The Canberra Hospital provides both secondary care and tertiary care. Other hospitals in the ACT provide secondary care only.

A Health Consumer's Journey through the Health System

James's Story

This is the story of a consumer called James who is using the ACT's health system. It shows how a patient may receive health care from primary, secondary, and tertiary health care services on their journey. It also provides a snapshot of what integrated care might look like in an ideal world. In this story James's care is coordinated by his general practitioner. He can move between the different levels of care easily, his medical records are accessible to all health professionals he sees, and his final discharge links him back to his general practitioner and a community-based health facility to provide ongoing support.

It is important to note that health care consumers may not experience the same smooth transitions between different types/ levels of care in real life

PRIMARY CARE

James was experiencing occasional, mild chest pains.

As his first point of contact in the health system, James saw his **General Practitioner** (GP). The GP listened to James's concerns and assessed James before referring him to a cardiologist.

SECONDARY CARE

The cardiologist James was referred to 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 care. This cardiologist has **visiting rights** to both public and private hospitals to treat patients. James called his private health insurer and learnt that cardiac care is not covered by his insurance. James couldn't afford to be admitted into a private hospital. James decided to access the public hospital system, so he didn't have to pay extra for any of the care he receives.

TERTIARY CARE:

Further testing revealed that James needed some specialist surgical procedures that could only be performed at 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 ongoing care from the nurses at a clinic attached to the hospital. James has now returned to primary care until his situation changes.



CONSIDER...

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



Key Concepts for Consumer Representatives

Integrated and person-centred care are themes that often arise in consumer representation.



INTEGRATED HEALTH CARE:

Integrated health care is about giving patients (consumers) seamless, coordinated, efficient and effective care that responds to all their health needs across their lifespan. Integrated healthcare systems consider how to best enable patients to access the care they need and move between different levels of care and different providers without compromising the quality of care they receive. The practice of integrated care by health services and professionals involves collaboration and cooperation between providers and services across primary, secondary, and tertiary care.²



PERSON-CENTRED CARE:

Person-centred care is central to safe, high-quality healthcare. It is care that is respectful of, and responsive to, the preferences, needs and values of the individual patient. It involves seeking out, and understanding what is important to the patient, fostering trust, establishing mutual respect and working together to share decisions and plan care.

Key dimensions of person-centred care include respect, emotional support, physical comfort, information and communication, continuity and transition of care between different providers, care coordination, involvement of carers and family, and access to care³. Person-centred care sees the people using health services as equal partners in planning, delivering, and monitoring health care to make sure it meets their needs. This means putting people and their carers at the centre of decisions and seeing them as experts, working alongside health care professionals to get the best outcome.

³ Australian Commission on Safety and Quality in Health Care n.d., *Person-centred care*, <<https://www.safetyandquality.gov.au/our-work/partnering-consumers/person-centred-care>>.

Why does it matter?

For people receiving care, **integrated and person-centred care** will improve their: access to care, health and clinical outcomes, **health literacy** and self-care. It will also increase their satisfaction with their care.

For the health system, **integrated and person-centred care** will increase job satisfaction for health workers, improve efficiency of services, and reduce overall costs. It will also increase consumer satisfaction with their care.





The HCCA Consumer Participation Framework

HCCA's [Consumer and Community Participation Framework](#)⁴ outlines the principles of, and expectations for, partnerships between health organisations and consumer representatives.

Consumers and the community can participate across all aspects of the health care system – quality and safety, service delivery, workforce, communications, infrastructure, and digital health – through their own care, health policy, research, planning and design, and health service governance.

There is no one 'right' way to partner with consumers. Every health organisation and project operates differently, with a unique set of objectives and consumers. There are, however, guiding principles and methods which can form a common foundation to build successful partnerships on.

You can use the Framework to guide your participation as a consumer representative and to help to understand the context of this work.

⁴ Health Care Consumers' Association 2021, 'Consumer and Community Participation Framework', <<https://www.hcca.org.au/wp-content/uploads/2021/03/7.-2-Consumer-and-Community-Participation-Framework.pdf>>.

Principles for partnership

When consumer representatives and health staff are guided by these five principles, consumer and community engagement is built on strong foundations.

1

RIGHT TO PARTICIPATE:

Consumer representation is based on the principle that health care consumers have a right to have a say in the way their health care is designed and delivered. The Australian Charter of Healthcare Rights states that consumers have a right to comment on their care and participate in decisions that affect them⁵.

2

MEANINGFUL PARTICIPATION:

Partners value each other's perspectives, knowledge, and beliefs. Partnerships focus on solutions and support the participation of consumers and community. This means:

- invitations to participate are genuine and thoughtfully planned; they are not tokenistic,
- the consumer voice is respected and authentically represented, and
- information provided to consumers and the community is accurate and helpful; it does not seek to manipulate opinion or quash concerns.

3

TRANSPARENT PARTICIPATION:

Relationships are based on clear and open communication and shared goals. This means that participants understand:

- how their input will be used,
- the limits of their influence,
- how their input *might* influence a decision, action, policy, or research outcomes, and
- the final outcome of their input – that is, *how or if* it influenced a decision, action, policy, or research outcome.

⁵ Australian Commission on Safety and Quality in Health Care 2020, *Australian Charter of Healthcare Rights (second edition)*, <<https://www.safetyandquality.gov.au/publications-and-resources/resource-library/australian-charter-healthcare-rights-second-edition-a4-accessible>>.

4**PARTICIPATION IS SUPPORTED:**

Processes are accessible, flexible, and designed to promote partnerships that reflect the diversity of consumers and their health needs. Consumer representatives are supported by:

- one-on-one support to consumer representatives (with a staff member or an experienced consumer representative mentor)
- access to information and resources
- assistance to individuals to enable them to participate, actively addressing any barriers to participation, including financial barriers and accessibility barriers.

5**INCLUSIVE:**

Consumer participation activities should include the diversity of the ACT and surrounding region, and the diversity of health care needs. The health organisation actively considers and seeks advice on the diversity of the community and is thoughtful about selecting participation mechanisms which are appropriate for these communities.

**CONSIDER...**

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





When to partner

Understanding when partnering can take place is a practical and valuable step.

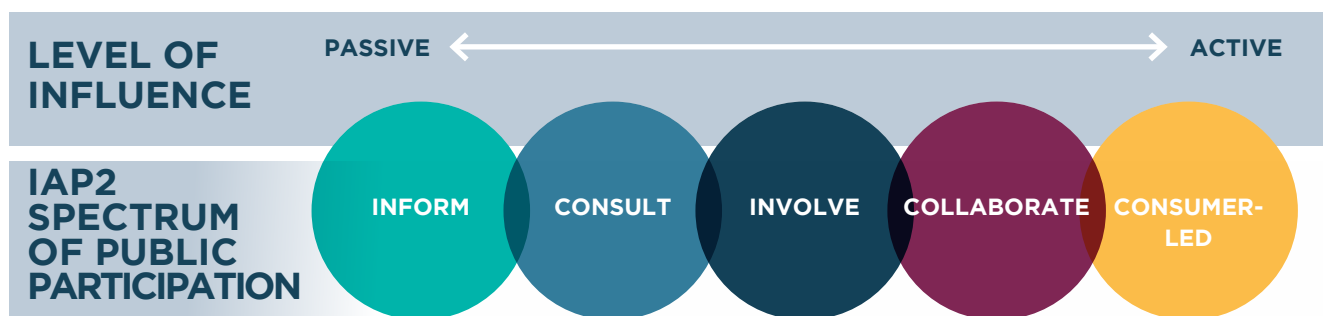
Good partnering takes place **early in any decision-making process** and should incorporate all aspects of a project or program, from initial planning, implementation, and monitoring, through to evaluation and review.

Consumers can be involved in many kinds of health service partnerships from strategic planning for a service, to developing health literate information, to monitoring safety and quality, and to making decisions about their own care.

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 collaborative and consumer-led level. It is expected that health organisations will be very clear about what level of influence you 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.

CONSUMER ENGAGEMENT SPECTRUM



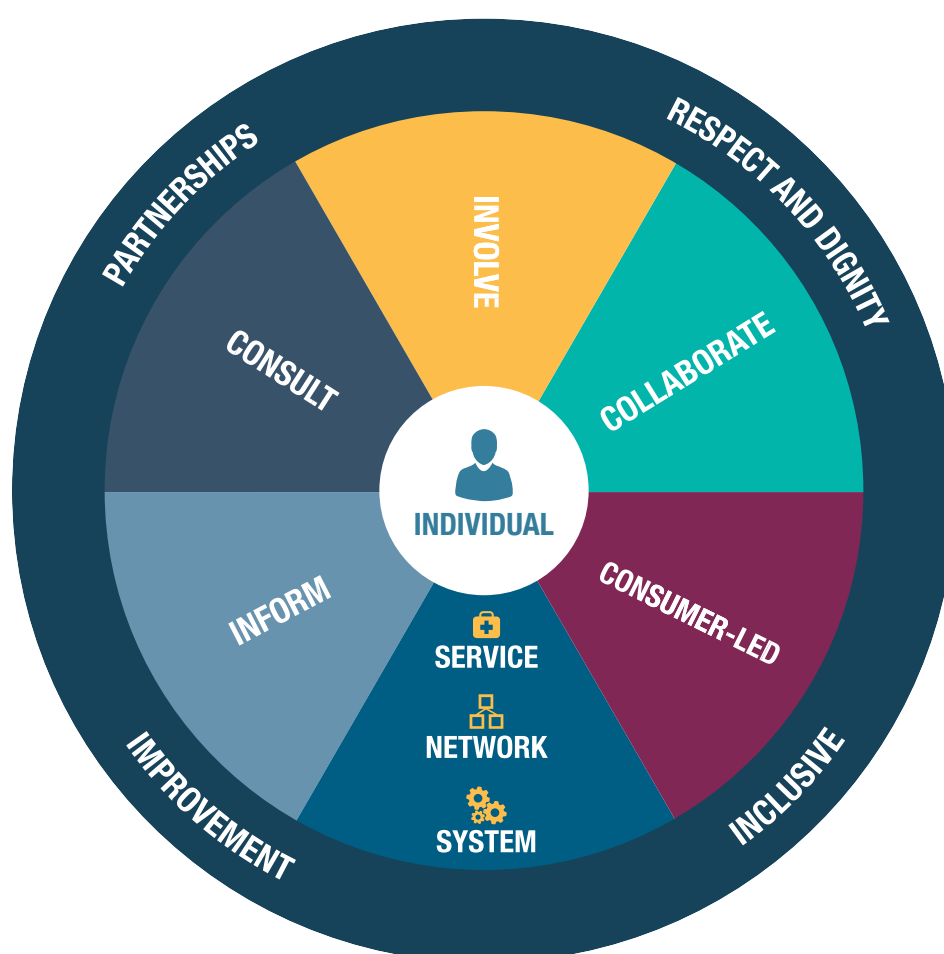
Reference: International Association of Public Participation (IAP2)



Where partnering can happen

It's important to understand the level you are partnering at to understand your role well and how much influence you will be able to have. This understanding can then help you to frame your ideas and suggestions based on the purpose of the committee or project.

Ask about the level you are partnering at in your induction meeting (or in a conversation with the chair) and how the work of your committee fits into the bigger picture.



CONSIDER...

Think about where 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?

Why are Consumer Partnerships Valuable?

Through consumer partnerships, organisations can ensure they meet the health care needs of the community. Partnering 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



CONSIDER...

- How can you be part of creating a culture of partnering in health organisations?
- Speaking up about what is **working well** for consumers can help motivate and provide direction for more positive change

National Safety and Quality Health Service Standards

Australian hospitals and health services, including day hospitals and dental clinics, are accredited against the National Safety and Quality Health Service Standards, which were first introduced in 2011. *Standard 1: Clinical Governance* and *Standard 2: Partnering with Consumers*, set out the requirements for the effective implementation of all the other standards. *Partnering with Consumers* aims to ensure that consumers are partners in the design, delivery and evaluation of healthcare systems and services, and that patients have the opportunity to be partners in their own care. This Standard, together with the Clinical Governance Standard, is the main standard which underpins the other seven standards. The remaining standards cover a wide range of quality and safety factors including medication safety, falls and pressure injuries, healthcare acquired infections, coordination of care, patient identification, and deterioration of mental and physical health.

“

I've been a consumer rep for about two and a half to three years.... In my role currently I'm with the committee known as the Canberra Hospital Expansion Program Committee, which gives suggestions and feedback to the government and Canberra Health Services as to what we need in this brand new building which we are building – not from the architect's and the designer's perspective but from the consumer's point of view, which is totally different. The architects and designers plan it on the basis of what they feel our design should include. But there are many ...things from the consumer's point of view which are missed out by them because they have probably not gone through the system and they are not aware of it.

So, whenever we attend these meetings, we take the opportunity to give the consumer perspective. And very often it seems like it's an “aha” moment for them, or “Okay, sorry. We didn't think of that. Okay. We'll include this in our design.” And that's very important to make the whole expense and the whole effort of a new building really worth its while, because if it's just a building and no consumer participation or partnership is involved, it'd be like another structure and nothing new will come out of it. So it's very important that consumers can have input to make it better for patients and their families.

– *Gev Khambata, Consumer Representative*

The Role of a Consumer Representative

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

While anyone can be considered a consumer through their use of health services, **there are additional expectations and responsibilities when you take on a consumer representative role.** You are there to provide the perspective of someone who uses (or may use) the services, and to consider the issues from that perspective. But it is not just your own perspective you need- it is a broad knowledge of the kinds of issues that matter most to health care consumers. It is your lived experience and personal insights – including those you have gathered from your own networks and research – that make the consumer 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 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 consumer's perspective.

“

It's been really insightful to just see the difference it makes having a consumer there when everybody else in the room is looking at it from a systems perspective.

- Priyanka Raj, HCCA Consumer Representative

Questions are a powerful tool

Take every opportunity to ask questions. There are no wrong questions.

HERE ARE SOME EXAMPLES OF QUESTIONS YOU COULD ASK IN YOUR ROLE AS A CONSUMER REPRESENTATIVE:

- What if we thought about this in a different way?
- How have other places tackled similar problems?
- Is there evidenced to support this decision?
- Can you explain that term to me please?
- Have you spoken to other consumers about this?
- How will you include consumers in this project?
- 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 personal perspective is important

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.

Don't hesitate to seek the help you need

If you have specific needs – whether they are cultural, 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. HCCA can support you to discuss these needs with the health service you are partnering with, and support the relationship you have with other committee members.



CONSIDER...

- What drives you to want to be a consumer representative?
- What inspires you? What do you want to see change in the health system?

Your Role and Responsibilities

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

As a consumer representative, it is important that you actively inform and educate yourself about your role and the processes you are participating in. The health organisation you are partnering 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 consumer perspective, whether that is your own individual viewpoint, or that of a particular consumer population or community organisation. 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 diverse perspectives are considered.



Consumer representation work is not about solving your own individual issues with health care. It's about bringing a broader view of consumer perspectives to health services. Because of that, it's really important that you are networked with groups of other people so that you have information coming in to you about what other people's experiences and issues in healthcare are.

– Kate Gorman, HCCA staff member

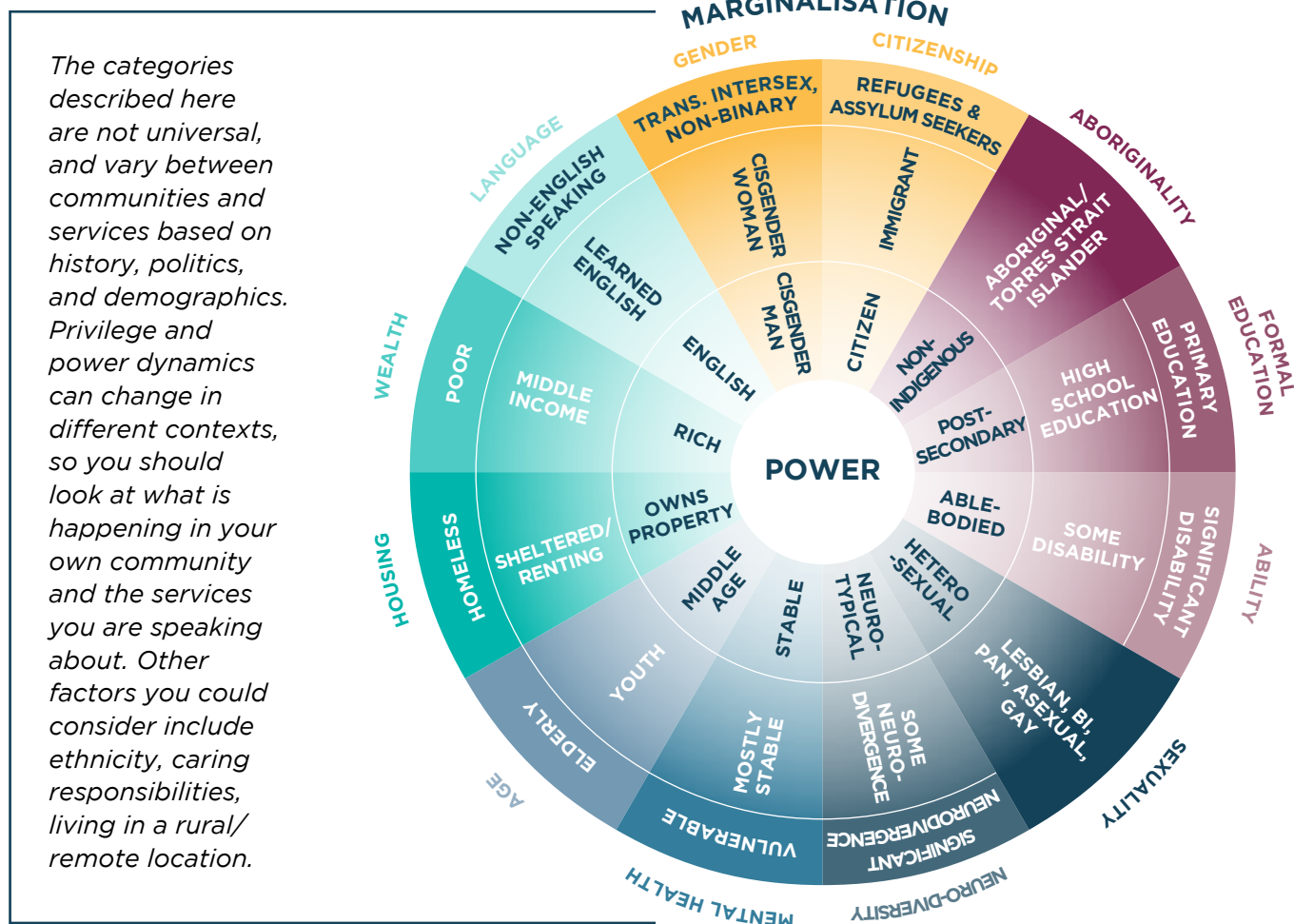
AS A STARTING POINT YOU CAN ASK ABOUT HOW THE HEALTH ORGANISATION IS CONSIDERING THE PERSPECTIVES OF:

- 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

In thinking broadly about different consumer perspectives, remember that consumers have different abilities to access healthcare and get good outcomes from it, depending on many factors in their lives. These factors are called the **social determinants of health**. They include (but are not only) things like

people's background, financial stability, level of education and housing situation. The illustration below shows some of the different factors which influence our ability to seek healthcare and get good outcomes from it.

WHEEL OF POWER / PRIVILEGE



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



ADVOCACY TIP: FOLLOW UP

Unless you have superpowers, it is unlikely you will only have to argue your case once. Advocacy is a process, not an event. You will need to build your case for change over time. Follow up with people. Your priority is not necessarily their priority.

Your responsibilities

As part of your role you will attend meetings, as well as read papers, notes, and other information. You will participate by raising questions and contributing ideas. It is important to remember that you may deal with confidential material at times. You may be asked to sign a **confidentiality agreement**. 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.

Conflict of interest

A conflict of interest can occur when there is a real or perceived conflict between your consumer representative duties and other roles and responsibilities you hold professionally or privately. Sometimes this may simply mean declaring your potential conflict. Other times it may mean you cannot act as a consumer representative on certain matters. If you think you may have a conflict of interest, you should raise this with the chair as soon as possible and be led by their advice. HCCA can also assist with your understanding and decision-making around a conflict of interest.

The Consumers Health Forum of Australia *Guidelines for Consumer Representatives* contains further information about conflicts of information [on their website](#).



What Support Will I Get from the Health Organisation I am Partnering with?

Your time and expertise are valuable. You should expect to:

- Be treated fairly and with respect
- Receive an orientation/induction to your role and the health organisation
- Receive information early so that you can read and prepare for meetings
- Have medical terminology and technical information and acronyms explained in simple language
- Receive information about the terms of your appointment, length of commitment, and the time required for both 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 contact details of committee members and consumer engagement staff
- Understand the organisation's reimbursement policies and processes
- Receive 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 able to speak up about your own specific needs or the needs of the person you care for (if you are a carer) before the meeting, so that you are supported to be able to actively participate.
- Have the same access to information about the work of the committee as the other members

If you feel you are not receiving adequate support or assistance, do not hesitate to speak to the chair of the committee, the committee secretariat, or a consumer engagement staff member. If you are a member of HCCA, you can also be supported by the Consumer Participation team and can contact HCCA at any time for help and advice.



CONSIDER...

Who could you ask for help if you feel disempowered in your role? Reflect on some strategies you could use if you feel like your input is not being heard or valued.

Reimbursement for consumer representatives

Health services vary in the way and the amount they reimburse consumers for the out-of-pocket costs involved in consumer representation roles. In advising health services about this, HCCA recommends that no consumer should be financially disadvantaged as a result of their contribution to a health organisation. The organisation should cover any out-of-pocket expenses such as travel, accommodation, childminding, respite care costs, or printing. Information about reimbursement, how much, what you can claim for and how to claim it, should be provided to you before you start in your role.

The ACT Health Directorate's *Consumer, Carer and Community Representative Reimbursement Policy* outlines their rates for reimbursements for consumer representatives. This is usually based on a flat rate for a two-hour meeting, and a pro-rata rate for meetings longer than two hours. This payment is intended to cover any costs incurred in consumer representative work, such as petrol, parking, printing meeting papers, and childcare. Most health services in the ACT provide a similar rate of reimbursement.

ACT Health's Consumer, Carer and Community Representative Reimbursement Policy is [available on the ACT Health website](#).

Financial implications

If you are employed or receive a pension or benefit you should investigate the impact of any payment or reimbursement for consumer representative roles on your other income. Neither HCCA nor health organisations or services can give financial advice.

The Australian Tax Office can provide advice on tax implications and Services Australia can advise on the impact that reimbursement or remuneration may have on any payments or services you are eligible for.



Your Consumer Representative Partnership Journey

The role of a consumer representative can be challenging but it can also be very rewarding, knowing that you are helping to create positive change in our health system and improving the health care experience for other consumers.

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 provide the questions and not the solutions – your role is to challenge the current system and provide a unique perspective on what is and isn't working for consumers.

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When I first started [as a consumer representative] one of the sage elders from Health Care Consumers would say to me, “drip, drip, drip, Kerry”, because it's systemic advocacy, and so you can't expect a lot of change very quickly. I'm not very good at drip, drip, drip, I'm a spurter, but I think that's probably sage advice – with systemic advocacy, change is going to happen slowly, but I would add that your voice is so important. Lived experience is an incredibly important voice to have around every table.

– Kerry Snell, Consumer Representative

Reflective questions

- Why do I want to do this?
- How much do I want to be involved?
- How might this impact or improve my health and wellbeing?
- How does my family feel about me doing this work?
- What areas of health and health systems do I want to be involved in?
- Where will I get help and support?
- Will there be expenses or time commitments that I cannot meet?
- Would I prefer to give feedback, make a complaint, or give a compliment?
- Am I using partnering to tell my own story, to seek resolution or closure?
- Are the partnership processes going to be culturally appropriate for me?

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Being a consumer rep is really interesting. You learn a lot about the health system, you meet terrific people, and you feel you're doing something for your community.

– Jo Bothroyd, Consumer Representative

How to get your first consumer representation role

There are a number of ways to begin your consumer partnership journey with a health organisation:

You can **become a member of HCCA** and complete the free consumer participation training. You can then nominate yourself for opportunities advertised in HCCA's newsletter, Consumer Bites or via the fortnightly email to members. HCCA offers a variety of roles including health-related committees, reference or working groups, advisory bodies, specific projects, or participation in consumer forums and workshops.

Other consumer organisations such as the [ACT Mental Health Consumer Network](#) may also offer consumer representation opportunities.

You may be **approached by a service** to become a consumer representative if you have an ongoing relationship as a consumer of a health service, and you have shown an interest in providing feedback about the service.

Other ACT opportunities may be **advertised online**. Roles such as Ministerial Advisory Councils are advertised this way and are often seen in the newsletters of community organisations.

National roles are often advertised in the Consumers Health Forum newsletter. You can find this at: www.chf.org.au

Speak with a staff member at any health organisation, hospital, Capital Health Network, or research institute you might be involved with or interested in. Health organisations sometimes have their own network of consumers they call on when there is an opening for consumer involvement. Sometimes these roles are advertised internally, so ask how you can register to receive newsletters or alerts about upcoming consumer opportunities.

However you become a consumer representative, HCCA recommends attending consumer participation training, which will help you to develop an understanding of the role, and a network of other people doing similar work. You can find out about consumer representative training offered by HCCA on our website: www.hcca.org.au



Other ways of participating

While consumers often get involved in committee work, 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
- Participate in focus groups
- Attend forums, symposiums, or public consultation meetings
- Write submissions to reviews
- Review brochures, websites, policy documents, and guidelines
- Seek employment as a peer support worker in a community organisation
- 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.

HCCA can support you to find the right opportunity.

Your Consumer Representative Skills and Experience

When you apply for a job, you usually have a resumé or CV 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 suitable for the role by providing information about yourself. This can include 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.

It's a good idea to keep your own record of your consumer participation in healthcare. Keep track of your skills and experience on committees and groups you have been involved with and what you have achieved or worked on, so you can refer back to it if needed.

Personal qualities

Which of these personal qualities do you have? Which of these qualities would you like to learn and cultivate to be a more effective consumer representative?

Understanding your own strengths and areas for improvement can help you to become a more effective representative.



Ideas to get your application started

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

- 1** To begin, write a brief description or one-line explanation about yourself and why you would make a great health consumer representative.
- 2** Think about those personal qualities listed on the previous page – what best describes you?
- 3** Next, write down your personal healthcare experience. What health-related services have you experienced as a consumer or carer? How did these experiences impact you or develop your advocacy skills? You do not need to go into a great deal of detail about this, either in your application or in your work as a consumer representative. However, it is useful for the committee to have a general idea of what experience of health services you have had.
- 4** Include information about any other boards or committees you are part of, including your memberships of community groups or professional organisations – even if they are not health-related. Your connections or networks can help to show why you would be well-suited to a representative role. They influence your insights or views into issues and provide you with different viewpoints.
- 5** Now you can outline your unique skills, abilities, and achievements. What experiences have you had that have helped shape you and could assist in your representative role? This might include working in successful partnerships or with diverse populations, or any achievements or changes you were able to implement in past committee roles or through self-advocacy. Include any conferences or forums you've attended that would be relevant to the consumer representative role.
- 6** You can also list your qualifications and training. They can help give an insight into your interest, skills, and background knowledge.

Be proud of your unique skills and experience

Do you sometimes feel uncomfortable speaking about yourself? Be proud and identify what you have achieved and what you are capable of.

Remember that being a good consumer representative is not about your level of education or other measurements that might apply in a job situation. It's about being able to use the insights you've gained through your life experience and the experiences of other people, and working collaboratively with others to make improvements to health care.

Already a consumer representative?

If you are already on a committee, it can help to take time to reflect on your consumer partnering journey so far. Are there any gaps in your skills or areas you would like to develop?

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. You may also like to nominate yourself for training or to participate in conferences and workshops related to your role.



Opportunities for development

HCCA PROVIDES MEMBERS AND OUR CONSUMER REPRESENTATIVES WITH OPPORTUNITIES TO DEVELOP THEIR KNOWLEDGE AND SKILLS. THESE INCLUDE:



Sponsorship to attend conferences and workshops to network and gain skills and knowledge



Training opportunities to increase skills and knowledge as a consumer rep



Consumer partnership roles and opportunities advertised on our website (www.hcca.org.au) and in our newsletter, Consumer Bites



Consumer reference groups focused on different topics of interest to healthcare consumers, which can provide consumer representatives with networks and information related to their roles



Member forums, with speakers of broad relevance to healthcare consumers and consumer representatives



Opportunities to provide input into health policy at a local and national level



Opportunities to present consumer perspectives and knowledge at a wide range of forums





Administration and Paperwork

Administration

There can be a large amount of paperwork involved when working with health organisations. You can ask the committee secretariat or HCCA for help in completing any forms or documents.

Many forms are just one-off documents to get you established in the system and ensure that all health and safety and other requirements are met. However, there may be some ongoing paperwork you will need to do, for example, claiming expenses.

Make sure you speak to the consumer engagement staff or the committee secretariat about what is required if you are unsure.

Induction and orientation

Before you begin something new, it is always useful to participate in orientation. An orientation process helps you learn what to expect and how to play your part. When you know where you are and what you have to do, it is easier to contribute and to be constructive and creative.

Every health organisation has their own process for 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.

Before your first meeting

In advance, ask for a map of the venue or access one online.

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 are attending online, make sure you have access to the application the health service will use for the meeting. This may be WebEx, Microsoft Teams, Zoom or another video conferencing program. If you are new to this, you should be able to arrange a practice with the secretariat. HCCA can also help with this.

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

Preparing for a meeting

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, and try to 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?

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Make sure you read your meeting papers thoroughly, and especially at the beginning, it's a good idea to have a few notes about particular things you might intend to comment on or say during the meeting and just be confident and speak up.

– Kathryn Briant, HCCA Staff Member



ADVOCACY TIP: ANSWER THE “SO WHAT” QUESTION

Be able to explain the impacts of what you’re talking about, why it’s important, and why your committee members should care. What’s the win for them?

A QUICK CHECKLIST BEFORE YOU BEGIN YOUR NEW ROLE:

- ☐ Is all required administrative paperwork 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 arranged a 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 and confident.

Your First Meeting

Adapted from work by Health Consumers NSW⁶



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 will be listed on the agenda. It will be hard to remember everyone’s names immediately but keeping some notes will help. You can also suggest that everyone wears name tags. If the meeting is online, most people’s name will be shown on their camera feed, and you can use the chat function to make a point or comment.



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 representative 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. Be sure to share your insights with your fellow consumer representative afterwards.



If you are attending online, make sure your microphone and camera (if you have one) are working and that you know how to mute and unmute yourself. Just like an in-person meeting, it is helpful to join or connect with the meeting a bit before the scheduled start time to make sure all the technology is working and that you are ready to start on time. You can use the ‘raise hand’ function on most online meeting platforms to help give you a turn to talk.



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.

⁶ Health Consumers NSW n.d., *Tips on getting started as a consumer rep*, <<https://www.hcnsw.org.au/consumers-toolkit/tips-on-getting-started-as-a-consumer-rep/>>.



Make the most of any breaks to network and build relationships. This can be harder online, but it can help to join the meeting early to make small talk with committee members while you wait for everyone to join the meeting.



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 [Questions are a powerful tool](#) on page 26 for examples of questions you can ask).



ADVOCACY TIP: KNOW YOUR STAKEHOLDERS

Understand who your stakeholders are and where they stand on your issue. Do they support you? Are they ambivalent and need persuasion? Your allies can open doors for you and help you to understand the context from a different perspective. Other stakeholders may be threatened by what you are proposing, and you need to have a strategy to address their concerns and opposition.

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.



You're probably feeling a little bit nervous if you've never done anything like this before. But I would say "Go for it". It can be very rewarding. And whilst you initially probably feel as though you don't have the skills or the knowledge, you will learn step-by-step and the people that you work with and associate with will be very, very helpful in that regard.

- Karin Calford, Consumer Representative

A word on networking

Networking is important to build relationships with key people who will support your role. Networking with and meeting the chair of your committee is important before your first meeting. Over time you will get to know the other committee members you work with. You can ask to do this outside of meeting times and when it is convenient for them. Let them know of your intention to understand them and their work so you can collaborate and support each other.



Consumer representation work is really all about relationships. So my top tips for consumer representatives are making sure you get to know the people that you're working with and that you do your best to build relationships with them and understand their point of view. It's much more possible to influence decision-making when you've built a healthy, trusting information-sharing relationship with your other committee members.

– Kate Gorman, HCCA Staff Member

Developing and maintaining networks with other consumers and carers is also very important. Not only will it ensure you are aware of experiences of other users of health services, you can share your 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 and enthusiasm to learn about others will set you up as an expert networker.



ADVOCACY TIP: KEEP PEOPLE INFORMED

Share information (that isn't confidential) with your supporting consumer organisation, and other committee members. Communication keeps others engaged in the process, creates excitement, and keeps people informed. This might be sharing updates on research, meetings you have had, commitments you have secured from stakeholders.

How Does a Committee Work?

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So, in terms of consumer representation, it's just making sure that our voices are heard and that changes are made when they're needed.

For me, it's really rewarding because I've been involved in committee work for many years and it's good to now use my skills and experience in consumer representative work at a committee level because often mental health consumers are sidelined because they're not considered, and they don't have value. So it's fantastic that I can actually use my life experience in this role.

What are my tips for new consumer representatives? Firstly, my wife always says you've got two ears and one mouth, so you should listen twice as much as you actually speak. Also, I think it's really important that you take time to learn how the committee works, and get an understanding of the organisation ... before you go jumping in and suggesting changes before you know what services are being provided and how they're being provided.

- Paul Thompson, Consumer Representative

Committee work is based around discussion and debate within a meeting structure. Committees run according to Terms of Reference, which set out the purpose, scope, and authority of the committee. They usually identify what the membership is, how often the committee will meet and any special requirements or procedures that the committee will need to comply with.

Some committees also have strategic plans or work plans to show their agreed purpose, specific outcomes, and timeframes. You can request to view any of these documents before you start or at any time. It is likely you will be the only consumer representative on the committee, or one of only two with the rest of the committee comprised of health professionals or government staff. This can be daunting, but it might also be a stimulating challenge.

Allow yourself time to adjust. Sometimes 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 late payment of your expenses or explain the background to a project.

It is helpful to meet with an experienced consumer representative to get some helpful tips and guidance. For example, you could speak with them before the next meeting to discuss any questions you have about your role. HCCA can help you network with other consumers through their events, and consumer reference groups, or provide a mentor for you.

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, or is not accurate in the minutes, you have a chance 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 or recorded incorrectly, and an amendment can be made.

Most committees require that an agenda, minutes of the last meeting, and any background papers or reports that will be discussed at the upcoming meeting are sent to members of the committee in time for them to read and consider them. In most cases this is a week, but it can be longer. If you are not getting the meeting papers in a reasonable time before the next meeting, you should raise this with the secretariat or the chair of the committee.



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

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

Agenda – is the list of items to be talked about at a meeting.

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

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.

Chair – the person in charge of running the meeting according to the terms of reference.

Minutes – an official record of a meeting.

Motion – the moving (or proposing) of an action or decision. Motion carried means it was passed by the committee.

Moved – proposing an action or decision.

New business – items not on the current agenda.

Present – the names of everyone present.

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.

Quorum – is the minimum number of members who must be present for a meeting to occur.

Seconded – supporting the moving (proposing) of an action or decision.

Secretariat – the person who looks after all the day-to-day actions needed to run the committee and usually takes the minutes.

Tabled papers – documents that are made available for everyone at a meeting to read, but not beforehand.

Terms of Reference (TOR) – the guidelines on the role, responsibilities and operation of a committee.

After a meeting

After a meeting it can be helpful to organise a debrief or an opportunity to catch up with the chairperson of the committee and any other consumer representatives.

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
- Check in with the chairperson to let them know how things are going from your perspective

Remember that anything said in a debrief with the chairperson is not officially recorded so you may want to write some notes to keep accurate records of your conversations.

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 and ask yourself:

- Am I making a difference?
- Is this work making a difference?
- Does the consumer voice need to be supported by an additional consumer representative? 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 representative 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?



ADVOCACY TIP: BE PERSISTENT

It may take months or years for the change you are advocating for to happen. It takes persistence, self-belief, and support to make changes.



ADVOCACY TIP: CELEBRATE SUCCESS

Acknowledge and appreciate the small steps that are made on the way to bigger change.



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, or they may appear resistant to change or still be developing and implementing good partnership principles. If you feel that you are not being respected, that your opinion is not being heard, or that you are unsupported in your role, you should reach out to your committee's key contact or chairperson to raise your concerns. Often the organisation is unaware of how you are feeling and will work to rectify the situation if you bring it to their attention.

- ✓ It may be that things have changed in your own life, and this work is no longer right for you.
- ✓ Self-reflection and -analysis are good habits to get into. It is helpful to reflect on whether there is anything you can do differently.
- ✓ You may want to seek support to improve your communication skills so that your messages are more likely to be heard and understood by health organisation staff.
- ✓ HCCA staff are also available for advice or further assistance to ensure that you feel capable, supported, and valued in your consumer representative role.

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 ongoing attention and effort on both sides.



ADVOCACY TIP: BE OPEN TO COMPROMISE

Sadly, you may not achieve everything you want, and you may have to take a staged approach and lay foundations for future approaches. Think about what you are not prepared to negotiate on— what are your non-negotiable elements? Do not rush into a decision. Take the time to talk to your trusted colleagues.

Leaving your role

Sometimes despite the best efforts of you and the health organisation, you might still decide to leave your representative role. Providing detailed, constructive feedback can help the organisation improve their partnership processes and to assist any future consumer representatives in the role.



CONSIDER...

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

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I just encourage them to not to give up, because I think one of the things, as a consumer representative, change is very slow. And sometimes you might not be able to achieve the things you want as quickly as you think it should be changed. So you do have to have patience and you do have to have stamina to keep going, because sometimes things just take a long time, or you might just have to keep, keep, keep repeating yourself. You might hear yourself saying the same things you've been saying for a few months, maybe even years, but just keep going and remember that at the end of the day, you're trying to improve services, not just for yourself, but for your community and the broader community here in the ACT.

- Purity Goj, Consumer Representative

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.

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 people in 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 participate in a meeting. The health organisation you are working with needs to know if you need additional support or accommodations.

This might include participating in meetings online, or providing your feedback and comments on the meeting papers to the Chairperson prior to the meeting. You can still be involved even if you can't be present.



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 can be very emotionally and mentally draining. Some healthcare topics are very emotive or potentially traumatic, and participation can be a heavy load for committee members.

Think about ways you can manage this emotional load. 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 works for you and make sure that it is part of your 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 other opportunities.

It is important to create a balance in your life that works for you and enables you to contribute without risking your physical or emotional health.



CONSIDER...

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.



ADVOCACY TIP: SELF-CARE

Burnout is real. You need to look after yourself. You will at times feel that you are hitting your head against a wall. That is when you need to stop, reframe the issue, talk to others, and look after yourself. Perhaps even take some time out. Then regroup to continue your advocacy.

Thinking About the Future

Over time in your role as a consumer representative you will build up considerable experience and expertise on how to partner effectively. These valuable learnings and knowledge can be very useful for someone who might be just starting their partnering journey with health organisations.

If you are an experienced consumer representative, have you considered mentoring new and emerging consumer representatives?

Please contact us at HCCA if this is something you have an interest in. Your guidance could support the next generation of consumer representatives to continue the work you started.

Thank you for your dedication and commitment to this work. Always remember you can contact HCCA for support and advice.



Health Care Consumers' Association

The Health Care Consumers' Association (HCCA) is the peak health consumer organisation in the ACT. We work to improve the quality and safety of health services and advocate for health equity for people living in the Canberra region.

We provide a voice for consumers on health issues and provide opportunities for consumers to participate in all levels of health service planning, policy development and decision making.

HCCA INVOLVES CONSUMERS THROUGH:

- Facilitating and supporting consumer representation in health services, infrastructure, policy, and research
- Consumer representative training
- Linking consumer representatives with suitable opportunities with health services
- Consultations and community forums
- Training consumers in healthcare rights and navigating the health system
- Advocating for issues of concern to consumers

As a consumer organisation, HCCA is committed to consumer-led participation and this is reflected in HCCA's governance structures, which place consumer volunteers in decision-making and strategy-setting roles.

HCCA recognises that the capacity of individuals to participate will vary greatly. Time, resources, levels of health literacy and social, economic, and cultural factors all impact on people's ability to participate. The more ways in which HCCA can invite and encourage participation, the richer the picture of consumer experience, values, and views HCCA can bring to its work and to informing health care in the ACT.


HCCA also recognises that different health services may be at different stages in their understanding and practice of consumer participation. HCCA is committed to supporting health services as they evolve towards more impactful consumer participation.


We work closely with our members, local communities, the ACT Government, service providers, media, and non-government and voluntary organisations to provide coordinated action in improving the quality and safety of health services.


The Health Care Consumers' Association is a health promotion charity, registered with the Australian Charities and Not-for-profits Commission.

You can find out more about what we do on our website at
www.hcca.org.au

YOU CAN CONTACT US AT:

 adminofficer@hcca.org.au

 02 6230 7800

 100 Maitland Street, Hackett, ACT 2607

Useful Resources

The **ACT Health** website provides territory-wide information about our health system that may be useful for consumer representatives to understand.

<https://www.health.act.gov.au>

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/>

The **Australian Commission on Safety and Quality in Health Care** has many useful resources. Check out the National Priorities tab for the Atlas of Healthcare Variation.

<https://www.safetyandquality.gov.au/>

Australian Institute of Family Studies produces high quality, responsive and impartial research into 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/>

The **Canberra Health Services** website provides information about acute, sub-acute, primary and community-based health services in the ACT <https://www.canberrahealthservices.act.gov.au/>

HCCA's Consumer and Community Participation Framework aims to guide the work of HCCA, and encourage health organisations to embed consumer and community engagement in their work. The framework describes the principles that underpin partnering 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. The framework can be found on the HCCA website.

<https://www.hcca.org.au>

Consumers Health Forum of Australia (CHF) 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. CHF has an online guide for consumer representatives that might give you more insight into the role.

<https://chf.org.au/guidelines-consumer-representatives>

International Alliance of Patients' Organizations (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) 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>

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.

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

National Standards for Mental Health Services are specific standards 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.

<http://www.health.gov.au/resources/publications/national-standards-for-mental-health-services-2010-and-implementation-guidelines>



Notes

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An electronic version of this document can be found at

hcca.org.au

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