

A Guide for Workers: Partnering with Consumers

Who is a Health Consumer Representative ?

A Health Consumer Representative is a formal, specific role in partnership with a health service to advocate on behalf of other consumers. They can be anyone who has used the health system and have usually received training in advocacy and representation. Although everyone is, at times, a user of the health system, a consumer representative is **not** be a current health service employee. This is because a consumer representative's role is to advocate for the needs of consumers. Current health service employees are required by their employment to bring specific perspectives and priorities which can be a conflict of interest in advocating for consumers.

What is a Consumer Representative's role?

Consumer representatives aim to contribute to health service work, to improve the health system for all consumers who use it. Consumer representatives highlight consumer, carer, and family perspectives. Their role is to voice consumer concerns, identify gaps and help service providers understand different perspectives. They may do this by drawing upon their own experiences, or the wider experiences of other communities and networks across the ACT and their knowledge of the needs and issues consumers face. Their experiences and insights guide positive changes to the design, development, implementation, and governance of health services.

Why are Consumer Representatives important?

The experience of people who use health services is a vital source of knowledge for system improvement. Consumers and their carers have a right to participate in the **creation, implementation, monitoring, and evaluation** of their health care services. More information about this can be found in the Partnering with Consumers Standard of the National Safety and Quality Health Service Standards. Include consumers in the decision-making process from the beginning, as their lived experience means consumers know what would make services more relevant, effective, and respectful. There should be opportunities for consumers to be included in **research, development, improvement, implementation, feedback and evaluation of services, facilities, programs, and policies**. In other words, consumer input should appear in all stages and at all levels of health care services.

How does HCCA coordinate Consumer Representatives?

HCCA's role as the peak body is to help consumers have a say in the design and delivery of health care. We are a valuable source of knowledge for service providers who need advice on how to engage consumers. HCCA's **Consumer Representative Coordinator** is a key point of contact who supports consumers by sharing opportunities with our network of consumer representatives. The coordinator also monitors collaboration between consumers and health service providers to ensure effective consumer involvement and partnership, benefitting both consumer representative and health service providers.

We offer training, support and resource materials to all consumer representatives, covering topics outlined in our [HCCA Guide for Consumers](#). We also support health service staff in finding and supporting consumer representatives in their work. HCCA has an [endorsement process](#) for appointing consumer representatives to committees. Health service providers can request a consumer representative through our [website](#) or by contacting the Consumer Representatives Coordinator at reps@hcca.org.au.



What does a good partnership look like?

Health services and consumer representatives will both benefit when their partnership is well planned, respectful and provides genuine opportunities for change.

Respectful relationships

Information sharing – Provide consumers with an honest overview of projects such as the timeline, your expectations for their input, limitations, and parameters. Make sure there is a good balance between presentation and input. While consumers need to have background information and updates, they are not only there to learn what you are doing, their role is to share their expertise.

Demonstrate trust – It is a consumer representative's responsibility to keep information confidential. You may want to include confidentiality documents when appointing a consumer representative. Sharing information beyond what is already in the public domain will allow consumers to add valuable input. While consumers are there to advocate for improvements, you can also trust consumers to understand why certain decisions have been made. If you are unable to integrate their input, tell

them. This may help build rapport with consumers and avoid wasting consumers time in advocating for change that is not possible.

Celebrate and acknowledge their work – Many consumer representatives have shared experiences with us where they felt they had been “placed off to the side” of projects, dismissed or misunderstood. You can show you value their work in having senior members of staff attend meetings and interact with consumers, publicly thank consumers, publicly acknowledge consumer partnerships and their value, publish outcomes influenced by consumer input, and invite consumers to public celebrations such as milestone events.

Reimburse consumers – if you want to genuinely acknowledge the time and effort people have taken to share stories, give up potential work, commute and prepare, you need to reimburse them in a timely manner. We recommend that reimbursement is in line with [ACT Health’s Consumer, Carer and Community Representative Reimbursement Policy](#) and advise paying consumers within 5 days of their participation.

Privacy and consent – It is crucial to be clear about how you intend to use consumer representatives personal stories and perspectives. Will their conversations stay within committee meetings and emails, or would you like to share their insights more widely through evaluation presentations and media? Sharing someone else’s stories, images, contact information and experiences requires **clear consent**. Confidentiality goes both ways in a consumer/health service partnership.

Remember representation is complicated – Consumers are trying their best to represent their own experiences and give a broader understanding of their communities. However, it is unrealistic and unfair to expect one consumer to speak for an entire community. To avoid tokenistic, tick box style consumer engagement, you may need to do your own research or connect further with communities and organisations to get specific advice on a topic. HCCA and consumers can often point you in the right direction to find the information you need. It is part of our role to identify whose voices are not being heard.

Actively enable people to participate

It’s important to provide a welcoming environment to encourage consumers to share their thoughts and seek their input on topics under discussion. Building rapport and strong relationships with consumers is important in fostering their active involvement.

Understanding – While consumer representatives are passionate about improving the health care system, it is important to understand sometimes circumstances can make participating difficult. This could be a one-off occasion or for extended periods of time. Various circumstances such as carer commitments, becoming unwell or feeling a heavy emotional burden in discussing traumatic experiences can all impact a consumer’s ability to attend and participate.

Be Flexible – Sometimes life does get in the way, but there may still be ways you can be considerate and flexible in involving consumers as much as possible. A flexible approach is also crucial if you are interested in talking to a specific

community or a diverse range of consumers. If you want to hear a range of perspectives from different communities around the ACT, you need to also consider how you will practically support consumers from marginalised backgrounds to provide this information to you.

Demonstrate inclusion – For example, if you would like feedback from a disability lens have you considered your capacity to provide reasonable adjustments to consumers with disability? If you would like to consult a group who may find it difficult to travel, can you visit them? If you would like to hear from multicultural communities, can you translate materials and facilitate sessions in a way that is culturally appropriate? One size does not fit all when it comes to the location, language, format, and needs of consumers. If you truly want to hear from a diverse range of community members, you will need to be adaptive and flexible in your approach. Inclusive participation takes time, so factor this into your planning early. Failure to do so may result in services and facilities that are unsafe or unfit for purpose. It can also lead to broken trust with consumers and the communities they belong to. Consumers may become hesitant to invest their time again.

Make sure consumers can prepare – Often meeting papers are the only form of communication for consumer representatives between meetings. Unfortunately, many consumer representatives receive their meeting papers the day before, or on the day of the meeting. We generally recommend that meeting papers are sent at least a week in advance of the meeting date. If consumers do not have enough time to read the papers, their ability to contribute their thoughts to the committee may be limited or they may abstain from participating in decisions. Late meeting papers also create additional barriers for people from non-English speaking backgrounds, people with disability and others who may need more time to read and understand the paper. Consumer representatives may also need to prepare for in person meeting or site visits. Remember that consumers are likely to be juggling other roles, jobs, and commitments. You can avoid unnecessary preparation for consumers if you provide them with clear maps or instructions about where to go, information on parking and public transport routes.

Communicate in an inclusive way – Only about 40% of Australian adults can understand health information in the way it is presented to them. To help consumers understand, avoid medical jargon, abbreviations, acronyms, or complicated terms. Use Plain English by keeping sentences short, using a conversational tone and an active voice. Inclusive language and communication should be easy to understand, respectful, assumption and judgement free. Everyone processes information in different ways, so verbal instructions or written information may not be accessible for all consumers. Consider using multiple formats to give information to consumers - such as reading aloud, models, pictures, diagrams, videos, or factsheets. To get quality feedback from consumers you may need to provide an option for them to chat through papers and project content before meetings if they need to. Some people may need extra time to process information, so we recommend providing papers at least a week in advance before meetings.

Close the feedback loop!



Too often consumers spend time giving feedback and never hear about the outcomes of their work. Be explicit about how you will inform the consumers about outcomes. Ask consumer representatives how they would like to receive feedback. It could be a standing item on an agenda, a report with infographics, or a direct email. Consumers who have finished partnering with you should still be contacted to close the loop. Inform consumers of project delays or when you have not achieved the outcomes you hoped for. If you do not close the feedback loop, the next time you are recruiting consumers they may be reluctant to invest their time. If you do close the feedback loop this can motivate consumers to join similar projects next time or encourage their communities to.



What does good process look like for committee work?

Recruitment

- **Understand what you need** – Is it a certain group, skill, or experience?
- **What support do you need to provide** for participation (language, location, format)
- **Make sure you have questions** or potential discussion topics prepared when you seek feedback from community groups and organisations. Find out if they have already shared or developed the information you are looking for
- **Provide an orientation and induction** – think about tailoring these (infrastructure knowledge, medical jargon, the roles of different organisations and stakeholders)
- **Clarify how you would like consumers or organisations to contribute to your work.** What are your priorities for feedback?

During projects

- **Clearly communicate** the roles and responsibilities of everyone involved
- **Who can consumers contact** with their questions? Make sure they know

- **Regularly report on success and challenges.** Key learnings must be shared at an organisational level with all stakeholders involved
- **Check in with consumers** and make sure their needs and concerns are met appropriately
- **Establish an issues register** to document and address any problems or challenges that come up during the project
- **Actively involve consumer representatives** in shaping strategies, solutions, or policies during the project

Evaluation

- **Include consumer representatives** in the evaluation process, from design to analysis
- **Consider consumers' feedback and perspectives** during the evaluation process
- **Publish your engagement processes and outcomes**, to contribute to the body of research evidence to support consumer engagement
- **Share results and insights** with all consumer representatives (even those no longer involved) and relevant stakeholders to promote transparency, continuous improvement and close the feedback loop

Where to learn more

- [A Guide for Health Staff: Partnering with Consumers](#)
- [Canberra Health literacy – Community Services and Workers](#)
- [Centre for Culture, Ethnicity and Health - Speaking with Clients who have a Low English Proficiency](#)
- [People With Disabilities Australia Language Guide](#)
- [We Heart Health Literacy – How to write for everyone \(Sort of\)](#)