Partnering with consumers and carers in research: Quick Read

Consumer and Carer Research Partner Toolkit

CHS Office of Research and Education (ORE)

This is a summary of the full Consumer and Carer Research Partner Toolkit.
For complete details, templates, and appendices, please refer to the full toolkit available at:

www.canberrahealthservices.act.gov.au/about-us/research

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About this toolkit

This toolkit helps you partner confidently and meaningfully with researchers across health research at Canberra Health Services (CHS).

It was developed by the CHS Office of Research and Education (ORE) with input from consumers, carers, and researchers through a Collaborative Working Group.

What is partnering in research?

Partnering with consumers and carers in research means working together with people who have lived experiences of health issues to help shape health research. Your unique views are important in making research relevant to our community.

How does the partnership work?

A consumer and carer research partnership is based on mutual respect. You and researchers work together towards shared research goals. You can get involved at any stage, from the initial idea through to sharing results with the community.

What does this toolkit cover?

- what consumer and carer research partnerships are and their benefits
- how you can engage in research priority setting, design, execution, dissemination, and translation
- tips for starting, planning, and working in a research partnership
- your rights and how to raise concerns

Key contact

For questions or support, contact the CHS ORE team:

Email: chs.research@act.gov.au

The Director of Consumer, Carer, and Community Partnerships in Research (Director of CCCPR) is available to support you throughout your partnership.

Key definitions

These definitions are adapted from the NHMRC Statement on Consumer and Community Involvement in Health and Medical Research.

Term	Definition
Consumer	People who use, or may use, health services at CHS. This includes their carers, families, supporters, and the broader community.
Carer	A person who provides unpaid support to a family member or friend with a disability, illness, ongoing condition, or age-related frailty, or who is a kinship or foster carer.
Research	An original investigation undertaken to gain knowledge, understanding and insight.
Researcher	A person who conducts research.

Partner vs participant

There are two main ways you can be involved in research:

Aspect	Research Partner	Research Participant
Your role	You help shape the research: what it focuses on, how it is done, and how results are shared.	You provide data or answers (e.g. surveys, interviews) but do not influence the research process.
When involved	Ideally from planning through to sharing results.	Usually only during data collection.
Expertise	Your lived experience is your expertise. It brings unique insight that the research team may lack.	No specific expertise needed. You meet the study criteria.
Ethics approval	Generally not required for your partnership role.	Formal HREC approval is sought by researchers to protect your rights.
Compensation	You may receive compensation for your time and expertise. See the CHS Reimbursement Procedure.	You may receive incentives such as travel reimbursement.

Guiding principles

These principles guide how CHS approaches consumer and carer research partnerships.

Our guiding principles
Partnering happens at all levels of research.
Consumer and carer input is supported and influential.
Partnerships are built on trust, respect and shared purpose.
Consumer and carer involvement is embedded, not symbolic.
Aboriginal and Torres Strait Islander voices are prioritised.
We uphold rights-based approaches.
We address barriers to involvement.
We invest in learning and capability building.
Diversity strengthens research.
Trauma-aware approaches improve how we work.
Lived experience is expertise.
Carers, families and supporters are included.
Cultural safety is essential.
Roles and expectations are clear.
We use flexible approaches to involvement.
Shared decision-making is part of how we do research.

Levels of involvement

Your level of involvement can vary based on your circumstances, the type of research, and the time you can commit.

Five levels of involvement

Level	What it means
1. Inform	You are kept informed with information to help you understand the research.
2. Consult	You are asked for feedback, which is used to guide key decisions.
3. Collaborate	You actively contribute ideas and play a key role in shaping decisions.
4. Co-Design	You work as equal partners with researchers from the start.
5. Empower	You take the lead, making final decisions and guiding the research process.

What does involvement look like in practice?

Level	Typical time commitment
Consult	1 to 2 hours total. You might review a short document or respond to one or two emails.
Collaborate	2 to 4 hours per month for 6 to 12 months. You might attend monthly meetings and review documents.
Co-Design / Empower	4 to 8 hours per month for 12+ months. You might attend fortnightly meetings, contribute to research design, and help write or review outputs.

> Your time commitment will be discussed and agreed before you begin.
>
> You will not be expected to commit more time than you are comfortable with.

The five steps of a research partnership

These steps give a simple overview of how to create and maintain consumer and carer research partnerships. The Director of CCCPR can support you at every step.

Step	What happens
1. Prepare	Learn about previous research partnerships in your area of interest. Understand the purpose of the partnership and how you can contribute. Receive a plain-English summary of the research from the researcher. Discuss your preferred level of involvement.
2. Plan	Set goals, objectives, and milestones with the research team. Clarify your role, responsibilities, and available support. Discuss compensation for your time and ideas. Set up communication and feedback processes.
3. Collaborate	Attend an initial team meeting to meet all project members. Share questions and feedback throughout the project. Attend regular meetings with logistics that suit your needs. Clarify roles as the project progresses.
4. Enhance	Take part in regular reflection sessions with the research team. Contribute to a partnership reflection log. Engage with broader consumer and carer research networks. Celebrate successes and identify areas for improvement.
5. Conclude	Ensure your contributions are formally acknowledged. Receive updates on research results and how they are being used. Discuss future collaboration opportunities. Take part in a formal closure meeting or event.

> You can withdraw from a research partnership at any time and for any reason.
>
> Withdrawing will not affect your care at CHS or your eligibility for future partnerships.

Your rights

As a consumer and carer research partner, you have the right to:

1. understand the research before you agree to be involved
2. ask questions at any time
3. know how your time will be valued and compensated
4. say no, change your mind, or withdraw at any stage
5. raise concerns without it affecting your care or future involvement
6. be acknowledged for your contributions
7. receive information in a format you can understand

Raising concerns and staying safe

You can raise a concern at any time. You do not need to wait until the project ends. You do not need permission from the researcher.

Raising a concern will not affect your care at CHS or your eligibility for future research partnerships.

Who to contact

Who	When to contact them	How
Your research team lead	Day-to-day issues about the project, your role, or scheduling.	Details provided when your partnership begins.
Director of CCCPR	Concerns about the partnership itself, including feeling unheard or unsupported.	chs.research@act.gov.au
Executive Director, Research and Academic Partnerships	If your concern involves the Director of CCCPR, or has not been resolved.	chs.research@act.gov.au (attention: Executive Director)
CHS Consumer Feedback	Formal feedback or complaint through the CHS system.	canberrahealthservices.act.gov.au (feedback page)
External advocacy groups	Independent support or advice.	HCCA, Carers ACT, ADACAS, ACT Mental Health Consumer Network

Emotional and cultural safety

Research partnerships can sometimes involve topics that are emotionally difficult, especially if the research relates to your own health experiences.

If you feel distressed during your involvement, you can let your research team lead or the Director of CCCPR know, take a break at any time, or access the support services below.

Service	Contact	Available
Lifeline	13 11 14	24 hours, 7 days
Beyond Blue	1300 22 4636	24 hours, 7 days
Carer Gateway	1800 422 737	8am to 5pm weekdays
13YARN (Aboriginal and Torres Strait Islander crisis support)	13 92 76	24 hours, 7 days

If you experience culturally unsafe behaviour during your research partnership, you have every right to name it and have it addressed through the feedback pathways listed on the previous page.

Related CHS documents

- CHS Exceptional Care Framework
- CHS Partnering with Consumers and Carers Policy
- CHS Consumer and Carers Reimbursement Procedure
- CHS Consumer and Carer Representatives Welcome Booklet (available on request)

For more information

Contact the CHS ORE team: chs.research@act.gov.au

Visit: www.canberrahealthservices.act.gov.au/about-us/research

This quick read is a summary only. Please refer to the full toolkit for complete guidance.

Information about the directorate can be found on the website:
www.canberrahealthservices.act.gov.au

Acknowledgement of Country

Canberra Health Services acknowledges the Ngunnawal people as traditional custodians of the ACT and recognises any other people or families with connection to the lands of the ACT and region. We acknowledge and respect their continuing culture and contribution to the life of this region.

Accessibility call (02) 5124 0000

Interpreter call 131 450

canberrahealthservices.act.gov.au/accessibility