Partnering with consumers and carers in research: Researcher Toolkit – Quick Read

CHS Office of Research

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Partnering with consumers and carers in research

A quick guide for our consumers, carers and community to shape health research.

Working together

By bringing your lived experience and a research team's clinical knowledge together, you create new insights that benefits the community.

Focusing on what matters

Your involvement helps steer research on what matters to the people it's meant to help. It brings views the research team may not have, builds trust between health services and the community, and drives results that are more useful in practice.

Canberra Health Services (CHS)

For more information on partnering with consumers and carers in research, scan the QR code or visit https://qrs.ly/f4hfhqr in your web browser.

chs.research@act.gov.au

A research partnership in 5 steps

1 Prepare
Learn about research in your area of interest. You can get an easy-to-read summary to decide if you want to be involved. Talk about how much time you can give.

2 Plan
Set goals and key dates with the research team. Be clear about your role, what support is available, and how your time will be valued. Agree on where and how often you will meet.

3 Collaborate
From the first meeting, share your questions and feedback. Roles may change as the project moves forward, so check in regularly.

4 Enhance
Celebrate what's going well and talk about what could be better. Connect with other consumer and carer research partners.

5 Conclude
Your contributions are recognised. You receive updates on the results and how they're used and there may also be future opportunities. The partnership ends with a final meeting or event.

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

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Why this matters to your research

Partnering with consumers and carers means involving people with lived experience as partners in your research. Not as participants providing data, but as contributors who help shape decisions throughout the research process.

This is a requirement under the NSQHS Standards (Standard 2, Action 2.11) and the National Clinical Trials Governance Framework (NCTGF). It also strengthens grant applications, improves recruitment, strengthens relevance and produces more useful findings.

This guide gives you the practical steps. The full toolkit has more detail, examples and alignment tables. Both are available from the CHS Office of Research team (chs.research@act.gov.au).

> **You don't have to do this alone.**
>
> The Director of Consumer, Carer and Community Partnerships in Research (Director) can help at every stage. They can connect you with consumer and carer partners, help you plan, and provide templates.
>
> **Email chs.research@act.gov.au**

The key distinction: partner vs participant

A research partner is not the same as a research participant. This is the most important concept to understand.

	Research partner	Research participant
Role	Shapes the research: design, methods, dissemination.	Provides data through surveys, interviews or trials.
Engagement	Ongoing, often across the full research lifecycle.	Limited to data collection.
Influence	Influences decisions on design, methods and outputs.	Follows protocols. No influence on design.
Ethics	Generally does not need HREC approval. Still requires respectful engagement.	Requires HREC approval.
Remuneration and reimbursement	Should be paid for time, expertise and contributions.	May receive reimbursement or incentives.

Choosing your level of partnership

Not every project needs the same depth of consumer and carer involvement. There are five levels of partnership, and each is valid. The right level depends on your project, your resources and where you are in the research process.

Level	What it means in practice
Inform	You share clear, timely information about your research with consumers and carers. One-way communication.
Consult	You ask consumers and carers for their feedback on specific aspects of your research.
Collaborate	Consumers and carers actively contribute ideas and play a key role in shaping decisions. A good starting point for most projects.
Co-Design	Consumers and carers work as equal partners in deciding how the project is designed and run from the start.
Empower	Consumers and carers take the lead in deciding how the project is designed and/or run.

These levels can apply at any phase of research: Discovery, Design, Conduct, Disseminate or Translate. The full toolkit contains a two-dimensional Partnership Spectrum showing how levels and phases work together.

If you’re new to this, The Collaborate level is often a good starting point. It lets you build rapport, develop your partnership skills and learn the process. You can increase depth over time. The Director can help you work out what fits your project.

Five steps to get started

These steps apply whether you're starting a new project or strengthening consumer and carer partnership within an existing project. The Director can support you at every step.

Step	Actions
Step 1: Prepare	• Check if there are prior consumer and carer partnerships in your area. • Define the purpose of the partnership and the level of involvement you need. • Work with the Director to identify potential partners. • Provide a plain English summary of your project to prospective partners. • Select partners based on relevant experience, interest and fit.
Step 2: Plan	• Agree on partnership goals and milestones. Add these to your project plan. • Define roles and responsibilities for everyone, including consumer and carer partners. • Set up reimbursement and/or remuneration early (see payment section below). • Arrange orientation and training, including cultural competency if relevant. • Set up a communication and feedback plan.
Step 3: Collaborate	• Hold an initial meeting to introduce the team and the research plan. • Ask partners how they want to give feedback and raise questions. • Schedule regular meetings at accessible times and locations. • Keep clarifying roles and resolve any issues early.
Step 4: Enhance	• Run periodic reflection sessions. What's working? What needs to change? • Keep a partnership reflection log accessible to all team members. • Share what you learn with peers through CHS Office of Research events and networks.
Step 5: Conclude	• Acknowledge contributions in reports, presentations and publications. • Share findings with partners and keep them informed of future developments. • Discuss future collaboration opportunities. • Hold a formal closure meeting or event.

Things to get right

These are the areas where researchers most often need guidance. Plan for them early.

Ethics applications

- Consumer and carer partnerships generally don't need HREC approval. Describe their role clearly in the Human Research Ethics Application (HREA).
- **Integral partners:** list as co-investigators in the HREA. Describe their roles and contributions.
- **Task-specific input:** acknowledge in project documentation. Does not require co-investigator listing.
- Partners on the research team should not also be research participants (conflict of interest).

Payment

Read this alongside the CHS Consumer and Carer Representative Reimbursement Procedure.

- Reimbursement covers out-of-pocket costs: travel, parking, childcare, communication.
- Build remuneration and reimbursement into your budget from the start.pr Rates should match the type and depth of involvement.
- If funding isn't yet secured, be upfront about what you can offer. Consider non-financial recognition (authorship, professional development, letters of appreciation).
- Some payments may affect a partner's income support. Give them the information they need to decide.

Authorship

Consumer and carer partners can be listed as co-authors if they make a significant intellectual contribution. This means one or more of:

- conception or design of the project
- data acquisition requiring significant intellectual judgement
- contribution of knowledge, including First Nations knowledge
- analysis or interpretation of data
- drafting or critically revising the research output

Discuss authorship expectations at the start of the project. Where contributions don't meet authorship criteria, acknowledge them in other ways. Get consent before naming contributors.

Grant applications

- Involve consumer and carer partners early in grant preparation.
- List integral partners as co-investigators. For ad-hoc input, describe contributions in the relevant sections.
- Funding bodies (NHMRC, MRFF) increasingly expect consumer involvement to be funded at fair rates.

Plain English materials

Any materials shared with consumer and carer partners should be written in plain English. Keep sentences short (15 to 20 words), use everyday language, and test with your audience. Aim for approximately a Year 8 to 9 reading level. The full toolkit has more guidance.

> **Get started**
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> Email: chs.research@act.gov.au to connect with the Director of Consumer, Carer, and Community Partnerships in Research. They can help you find partners, plan your approach, provide templates, and link you with experienced researchers.
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> The full Researcher Toolkit is available at: https://www.canberrahealthservices.act.gov.au/about-us/canberra-health-services-research/partnering-with-our-consumers-in-research