Partnering with consumers and carers in research:

Quick Start

Researcher Toolkit

CHS Office of Research and Education (ORE)

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Why this matters to your research

Partnering with consumers and carers means involving people with lived experience of health conditions in your research. Not as participants providing data, but as partners shaping the research itself.

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, and produces more relevant findings.

This guide gives you the practical steps. The full toolkit has more detail, examples, and alignment tables. Both are available on the CHS Research HealthHub.

You do not have to do this alone.

The Director of Consumer, Carer, and Community Partnerships in Research (Director of CCCPR) 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

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

	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.
Payment	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, 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 are new to this, the Collaborate level is a good entry point. It lets you build rapport, develop your partnership skills, and learn the process. You can increase depth over time. The Director of CCCPR can help you work out what fits your project.

Five steps to get started

These steps apply whether you are starting a new project or adding consumer and carer partnership to an existing one. The Director of CCCPR can support you at every step.

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 of CCCPR 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 is working? What needs to change? ☐ Keep a partnership reflection log accessible to all team members. ☐ Share what you learn with peers through CHS ORE 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 do not need HREC approval. However, 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 also not be research participants (conflict of interest).

Payment

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

- **Reimbursement** covers out-of-pocket costs: travel, parking, childcare, communication.
- Build this into your budget from the start. Rates should match the type and depth of involvement.
- If funding is not 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 do not meet authorship criteria, acknowledge them in other ways. Always 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 about a Year 9 reading level. The full toolkit has more guidance on this.

Get started

Email chs.research@act.gov.au to connect with the Director of CCCPR. They can help you find partners, plan your approach, provide templates, and link you with experienced researchers. The full Researcher Toolkit is available at: https://www.canberrahealthservices.act.gov.au/about-us/canberra-health-services-research

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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.

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