Partnering with consumers and carers in research: Consumer and Carer Research Partner Toolkit

CHS Office of Research

August 2026

This work is subject to copyright. Apart from any use permitted under the Copyright Act 1968, no part may be reproduced by any process without written permission from the Territory Records Office, GPO Box 158 Canberra ACT 2601.

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

© Australian Capital Territory, Canberra 2026 | canberrahealthservices.act.gov.au

Contents

Introduction

This toolkit is for you, our consumers and carers research partners. It gives you practical guidance so you can partner confidently and meaningfully with CHS researchers across health research. It sits within the broader suite of services and resources from the CHS Office of Research.

Our goal is to build a strong, well-supported community of informed consumer and carer research partners across the ACT region and surrounding NSW.

Understanding partnering with consumers and carers in research

Partnering with consumers and carers in research means working with people like you who have lived experience of health issues. This may include consumers, carers, family members, supporters and community members who bring relevant lived experience and perspectives to research. Your perspectives shape research so it reflects and meets community needs.

Health research (sometimes called medical or clinical research) covers studies aimed at understanding human health, preventing and treating diseases, and improving healthcare outcomes. It includes clinical trials, public health studies, epidemiological research, health services research and more.

Why should you get involved?

Your involvement helps make sure CHS research addresses issues that matter to the ACT and Southern NSW communities. You bring viewpoints that make research more relevant and effective.

How does the partnership work?

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

What does this toolkit offer?

- An introduction to consumer and carer research partnerships at CHS, including their benefits and what makes them work
- How you can engage in research priority setting, design, conduct, dissemination and translation
- Tips for starting, planning and working in a consumer and carer research partnership

Toolkit background

Context

CHS's vision is 'creating exceptional health care together'.

CHS designs its systems to support consumers, carers and families as partners in their own care and in organisational governance, healthcare planning, design, measurement and evaluation. Consumers, carers and families are actively supported to collaborate in co-designing service improvements and to contribute their experience to the delivery of exceptional care.

Strategic Commitment 5 of the *CHS Research Strategy 2021–2025* focuses on creating impactful research partnerships with consumers, carers and communities as a foundation for delivering exceptional care to the ACT and Southern NSW community. (The Strategy is currently being updated; a new version is expected by mid-2026.)

Australian and international researchers and funding bodies are increasingly recognising the value of consumer and carer research partnerships and the many benefits they bring.

Development

We developed this toolkit through a detailed literature review, available on request by emailing chs.research@act.gov.au.

The CHS Office of Research Consumer, Carer and Community Partnerships Collaborative Working Group (CWG) provided insights and expertise that shaped the toolkit's structure and content.

Toolkit user guide

This toolkit is a practical guide for consumer and carer research partners at all levels of experience. You can adapt it to suit the goals and context of each research project or team.

It is a living document. We will update it as guidelines from organisations like the NHMRC evolve. The most recent version is available at: canberrahealthservices.act.gov.au/about-us/research

Seeking further advice

While this toolkit gives you a foundation, you are welcome to seek support from the CHS Office of Research team by emailing chs.research@act.gov.au. The Director of Consumer, Carer, and Community Partnerships in Research (Director) can help with the areas listed in the support table below.

Local and national entities, including the ACT Health Directorate (ACTHD) and the NHMRC, can provide additional support on consumer and carer research partnership guidelines and best practices.

Email chs.research@act.gov.au to contact the Director for templates, reimbursement procedures and other resources.

Area	What the Director can do
Getting started	Help you understand what's involved and what level of partnership suits you.
Finding a project	Connect you with research teams looking for consumer and carer partners.
Planning	Help you and the research team set goals, clarify roles and agree on how you'll work together.
Remuneration	Explain CHS remuneration and reimbursement rates and processes. Provide the CHS Reimbursement Procedure and advise on rates and processes.
Training	Point you to training resources on research partnerships, methodology and your rights as a partner.

Risk and conflict	Help you and the research team plan for disagreements or other challenges.
Meetings	Help plan meetings in accessible locations and formats that work for you.
Evaluation	Help set up partnership reflection sessions. Provide examples of reflection logs and evaluation approaches.
Raising concerns	Receive and respond to concerns about the partnership. See also the contact table on page 25.
Withdrawal	Talk through your options if you're thinking about stepping back.
Results and closure	Help you access research results. Advise on formal acknowledgment and closure events.

CHS documents related to this toolkit

- CHS Exceptional Care Framework
- CHS Partnering with Consumers and Carers Policy
- CHS Consumer and Carers Reimbursement Procedure
- CHS Consumer and Carer Representatives Welcome Booklet

Definitions

The following definitions are adapted from the NHMRC's Statement on Consumer and Community Involvement in Health and Medical Research, customised for the CHS context.

CHS uses the term 'consumer' in line with national health frameworks. We recognise that some people prefer 'patient', 'person' or 'community member'. Whatever term you prefer, this toolkit is for you.

Term	Definition
Carer	An individual who provides unpaid support to a family member or friend with a disability, mental illness, ongoing medical condition, age-related frailty, or who is a kinship or foster carer for a child or young person.
Community member	An individual belonging to a community, contributing to its shared interests and activities.
Community	Individuals and groups of people, interest groups and citizen groups. A community may be defined by geographical location, shared interest, or affiliation and identity.
Consumer	People who use, or are potential users of, health organisations. In this document, "consumers and carers" refers to people accessing health services at CHS, their carers, families and supporters, and the broader community.
Consumer advocacy group	An organisation that advocates for health care consumer rights, focusing on access to equitable, high-quality and safe health care services.
Consumer representative	An individual who represents consumer perspectives in decision-making, possibly nominated by a consumer organisation, trained to advocate for consumer-centred health care.
Research	An original investigation undertaken to gain knowledge, understanding and insight.
Research process	The planning, funding and conduct of a piece of research, plus implementation and publication of findings.

Defining partners vs participants

You can get involved in research in two main ways: as a consumer and carer research partner or as a research project participant.

As a consumer and carer research partner, your insights and lived experience help shape the research from start to finish. You may work with researchers to decide what the research should focus on, how it's done, and how results are shared. This role gives you a say in the research process itself.

As a research project participant, you volunteer to take part in a study by providing data (for example, answering surveys or participating in interviews). Your involvement is usually limited to the data collection phase, and you don't have a say in the research design or what happens with the results.

Comparison

	Consumer and carer research partner	Research project participant
Role	You actively help shape what the research is about, how it's done, and how results are shared.	You provide data or answers for the research but don't influence the process.
Engagement	You're involved from planning through to the sharing of results.	Your involvement is usually limited to the data collection phase.
Influence	Your insights influence key research decisions, such as study design and methods.	You follow what the researchers have planned; you don't shape the decisions.
Ethics	HREC approval is not usually required since your role is about partnership, not direct research activities.	Researchers seek HREC approval to protect your rights, including informed consent, privacy and minimising harm.

Guiding principles

Based on the CHS Partnering with Consumers and Carers Policy.

Partnering happens at all levels of research

Consumers and carers partner in setting priorities, designing studies, shaping methods, interpreting findings and sharing results. Your experience strengthens research relevance and impact.

Consumer and carer input is supported and influential

We create space and provide support for you to contribute meaningfully throughout the research process. Your insights shape how we design, conduct and apply research.

Partnerships are built on trust, respect and shared purpose

We value long-term, respectful relationships grounded in honesty, clear communication and mutual learning. We are upfront about roles, expectations and how input will influence decisions.

Consumer and carer involvement is embedded, not symbolic

We embed consumer and carer partnership into research governance, systems, strategies and funding applications. It is part of how we do research, not an add-on.

Aboriginal and Torres Strait Islander voices are prioritised

We uphold the sovereignty, knowledge systems and leadership of Aboriginal and Torres Strait Islander peoples in research. We support culturally governed research that reflects community priorities. CHS acknowledges Indigenous Data Sovereignty and governance principles.

We uphold rights-based approaches

We work in line with the Australian Charter of Healthcare Rights, the ACT Carers Recognition Act 2021 and other rights-based frameworks that affirm the role of consumers and carers in shaping research.

We address barriers to involvement

Access to consumer and carer research partnership is not equal. We work to reduce barriers and support people who face structural exclusion.

We invest in learning and capability building

We offer training, resources and mentoring so researchers and consumer and carer partners can collaborate effectively. We build shared understanding, not just skills.

Diversity strengthens research

We seek partnerships with people from different backgrounds, communities and experiences. Diverse perspectives improve the relevance and quality of research.

Trauma-aware approaches improve how we work

Many people have experienced trauma. We work in ways that promote emotional and cultural safety, build trust, and support choice.

Lived experience is expertise

We recognise consumer and carer experience as a legitimate and important form of knowledge. It tells us what matters, what works and what change is needed.

Carers, families and supporters are included

Consumers define who matters in their lives. We respect and support the involvement of carers, family members and other supporters. Carers bring distinct expertise that is different from (not secondary to) consumer perspectives.

Cultural safety is essential

We reflect on our own power, privilege and assumptions. We work in culturally safe ways and build respectful, accountable partnerships with people from all backgrounds and identities.

Roles and expectations are clear

We clearly explain why we are seeking consumer and carer input, what decisions are open to influence, and how we will use feedback. We report back on outcomes.

We use flexible approaches to involvement

We adapt our ways of working to suit different people, projects and contexts. We use a range of partnership models, from informal advice to shared governance or co-leadership.

Shared decision-making is part of how we do research

We involve consumers and carers in decisions about how research is designed, conducted, governed and used.

We collaborate with community and advocacy organisations

We build strong connections with consumer, carer and community organisations. These partnerships help make research more grounded, inclusive and responsive to community needs.

Consumer and carer research partnership levels

Consumer and carer research partnerships are about working with you to make research better. They are built on mutual respect and should be part of any CHS research project from the start.

Your level of involvement and the scope of your role can vary based on your circumstances: the time you can commit, the type of research, and how long the project will run.

Dimension 1: Levels of involvement

We often use a framework similar to IAP2 to work out how involved you can or want to be. There are five levels:

1. **Inform:** you receive accurate, timely and clear information about the research.
2. **Consult:** you share feedback that guides key decisions in the research.
3. **Collaborate:** you have a strong voice, actively contribute ideas, and play a key role in shaping decisions.
4. **Co-Design:** you work as an equal partner with researchers in deciding how the project is designed and run from the start.
5. **Empower:** you take the lead, making final decisions and guiding the research process. Researchers support you.

Dimension 2: Stages of involvement

You may be involved at different stages:

1. **Discovery:** research ideas and concepts are developed.
2. **Design:** the research methodology and plan are created.
3. **Conduct:** the research is carried out, including data collection and analysis.
4. **Disseminate:** research findings are shared.
5. **Translate:** research results are applied in practice, policy or further research.

Bringing it all together

By considering both the level and stage of involvement, we can create partnerships that fit the project's goals, resources and the needs of everyone involved.

This toolkit (and broader CHS Office of Research services) offers flexible support for all levels of partnership and research phases. A spectrum showing how these dimensions work together is on the next page.

Consumer and Carer Research Partnership Spectrum

Based on the CHS Partnering with Consumers and Carers Policy Spectrum.

Research stage	Inform	Consult	Collaborate	Co-Design	Empower
Discovery	Researchers share upcoming research themes with you.	You provide input on which priorities matter most to you.	You and the research team develop priorities together.	Together, you and the research team co-develop priorities.	You take the lead in setting priorities.
Design	Researchers share research plans and objectives with you.	Your opinions on research design are sought.	You and the research team design research plans together.	You and the research team co-design research plans.	You lead the research design.
Conduct	You are kept updated on research progress.	Your feedback on specific research activities is requested.	You and the researchers conduct the research together.	You and the researchers co-produce the research.	You take a leading role in conducting the research.
Disseminate	Researchers provide you with results to share in your networks.	You are asked for input on the best ways to share results.	You present results with the researchers at conferences.	You co-author and present results with the researchers at conferences.	You lead the sharing of research results.
Translate	You are informed about how results are being applied.	Researchers consult with you on potential applications.	You and the research team collaborate on applications of results.	You and the research team co-develop applications of results.	You drive the application of research into practice.

What does involvement look like in practice?

- **Consult level:** You might receive one or two emails over the project and be asked to review a short document. Time: 1–2 hours total.
- **Collaborate level:** You might attend a monthly meeting and review documents between meetings. Time: 2–4 hours per month for 6–12 months.
- **Co-Design or Empower level:** You might attend fortnightly meetings, contribute to research design, and help write or review outputs. Time: 4–8 hours per month for 12+ months.

Your time commitment will be discussed and agreed before you begin. You won't be expected to commit more time than you're comfortable with.

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 recognised, remunerated and reimbursed
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

For more detail on raising concerns, see the section on page 25.

Setting the scene

Benefits of partnering with consumers and carers in research

These examples show what consumer and carer research partnerships look like in practice and what they produce for the research, for researchers and for consumer and carer partners.

Shaping research from the ground up: Good Omen Goodeze, CHS

Good Omen Goodeze (GOG) is a Canberra charity whose volunteers make handcrafted comfort items (sensory toys, blankets, eye masks, comfort pillows) for patients across CHS and the ACT Ambulance Service. When GOG wanted to study the impact of these items, GOG's founder Mary Liondi-Barlow didn't just advise on the study. She shaped the research questions, the recruitment method and the survey content as a co-designer.

The result: QR code tags on the items themselves, so patients and families can share their experience at the point of care. The study (ETH00074) gives GOG's volunteers evidence that their work has measurable impact on patient care, something the organisation had long observed but never formally documented. Mary moved from charity founder to named research partner in an ethics-approved study.

Setting the research agenda: ACACIA, ANU

ACACIA (the ACT Consumer and Carer Mental Health Research Unit at ANU) is led and staffed by researchers who themselves have lived experience as consumers or carers. In 2018, consumers and carers set the unit's research agenda by ranking 79 research topics across 14 themes in a face-to-face forum and national survey.

Consumer and carer partners didn't just give feedback on someone else's priorities. They identified trauma-informed care as the most important research area, shifting the unit's direction. Partners held genuine leadership roles and saw their lived experience recognised as expertise that shaped a national research agenda.

Source: Banfield et al., Health Research Policy and Systems, 2018.
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6292010/

Guiding a clinical trial: INFERR

The INFERR trial (intravenous iron for First Nations haemodialysis patients) established two Indigenous Reference Groups of dialysis patients. Communities advised that local cultural differences required two separate groups, and the research team listened. Supported by First Nations Research Officers, reference group members shaped study materials, ensured culturally safe trial conduct and developed feedback processes.

Consumer research partners engaged because they felt respected, listened to and empowered to achieve change. The partnership gave First Nations consumers a direct role in ensuring clinical research affecting their communities was conducted on their terms.

Source: Long et al., Research Involvement and Engagement, 2024.
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC11250943/

Co-designing a cancer care plan: RECAP, WEHI

Six consumers worked with four researchers to co-design personalised care plans for people newly diagnosed with rectal cancer. The care plans gave patients accessible information about their diagnosis, treatment and follow-up schedule.

The partnership was formally evaluated and found to be meaningful, respectful and inclusive. The evaluation also led to practical improvements in how the team managed workload, communication and remuneration for consumer partners. Consumer partners had genuine influence over a clinical trial and saw their input change how patients received information about their care.

Source: Gard, Gibbs et al., Research Involvement and Engagement, 2025.
https://link.springer.com/article/10.1186/s40900-025-00716-0

Community ownership of health research: Nra:gi Ya:yun

Nra:gi Ya:yun ("very good foods") is a type 2 diabetes and metabolic syndrome program co-designed with Aboriginal people on Ngarrindjeri Ruwe (Country) in South Australia. Ngarrindjeri Elders and senior community representatives initiated the program and shaped it through yarning sessions and ten workshops over six months. Aboriginal governance and leadership were central, with an Aboriginal project manager and multiple Aboriginal investigators.

Community members owned the design. They chose a low-carbohydrate approach centring Indigenous dietary knowledge, and the program ran on Country with fresh meal boxes, continuous glucose monitoring and group yarning. Community partners had control, reciprocity and cultural safety, and they shaped a program that researchers could not have designed without them.

Source: Ryder et al.; Omodei-James et al., BMJ Open, 2024.
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC11047281/

The five steps of a consumer and carer research partnership

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.

Step 1: Preparing for a consumer and carer research partnership

This step is about building a strong foundation. You'll start by learning from previous collaborations, understanding the partnership's goals and identifying how you can best contribute.

Exploring previous efforts

Start by looking into any previous consumer and carer research partnerships in your area of interest. If you're not sure where to begin, broader Australian and international examples can also be a useful starting point for discussions.

Defining the partnership's purpose and your role

Think about why you want to be involved. You might want to make research more relevant by bringing community perspectives, improve research quality with your insights, or help address specific health issues that matter to you. Being involved can also help you build research skills.

The Consumer and Carer Research Partnership Spectrum (page 13) shows the different levels of involvement. Depending on resources like funding, support and time, the level of your involvement may vary.

Finding the right fit

The selection of consumer and carer partners often depends on everyone's needs. If the research involves conditions or services you're familiar with, your firsthand lived experience can be very valuable. For projects aimed at assessing informational materials like consent forms, a broad perspective may be enough.

Making initial contact and setting expectations

When looking into a potential partnership, you should receive a plain-English summary of the research from the researcher. If you don't receive one, ask for it. Fact sheets, often provided during early discussions, give a concise overview of the project.

If you want to take a more active role, you may need to go through an expression of interest (EOI) and possibly an interview process.

Step 2: Planning for your consumer and carer research partnership

This step turns the idea of your partnership into a clear and practical plan.

Setting goals, objectives and milestones

Define the goals and objectives you and the research team aim to achieve and set milestones to track progress. This keeps everyone aligned and makes the partnership more effective.

Understanding roles, responsibilities and support

Knowing exactly what your role involves prevents overlaps and gaps. Your contributions might include decision-making, attending meetings or providing input on research design. Also find out what support is available: ICT resources, emotional support or administrative help.

Discuss how you'll be compensated for your time and expertise. The CHS Consumer and Carer Reimbursement Procedure and examples from past projects are available from the CHS Office of Research team (chs.research@act.gov.au).

Orientation, training and risk management

An orientation will help you understand the research project, CHS policies and the broader context of health research.

Planning also involves preparing for potential challenges like misunderstandings or disagreements. A risk management plan for the partnership can help manage these.

Communication, feedback and evaluation

A communication plan keeps dialogue open and consistent. It should cover how and when updates and meetings will happen, and how feedback will be gathered and used. Your active involvement in the feedback process makes sure your ideas are considered.

Regular evaluations help assess the partnership's effectiveness and identify areas for improvement. The CHS Office of Research team has examples of communication and evaluation plans (chs.research@act.gov.au).

Step 3: Working together in partnership

This step is about working together effectively through clear communication, mutual respect and shared goals.

Initial team meeting and project introduction

The initial meeting with all project team members, including you, sets the tone for collaboration. The research team will walk you through the research idea or plan. You can share questions or feedback at any time.

Collaboration and meeting logistics

Regular meetings that fit with the project plan keep everyone engaged and informed. Meeting logistics should accommodate everyone's needs: accessible locations, the right technology, and flexibility for consumer and carer partners who may have specific requirements.

Role clarification, expectations and conflict resolution

As the project progresses, keep clarifying roles and responsibilities. Clear roles prevent overlaps and confusion. You and the research team should be open about time commitments, communication methods and preferred ways to resolve disagreements.

If you feel your role or expertise is being dismissed, we can support you and link you with external advocacy groups. For more on raising concerns, see page 25.

You may withdraw from the project at any time and for any reason. Withdrawing won't affect your eligibility to partner with CHS on other projects, or any care you receive from CHS.

Step 4: Enhancing your consumer and carer research partnership

Enhancement involves ongoing reflection, learning and advocacy.

Reflect on progress regularly

Take part in regular reflection sessions with the whole research team. These sessions are a chance to see how well the partnership is meeting its goals, address challenges and celebrate successes.

Keep a ‘live’ partnership reflection log

Help maintain a central, accessible log that records the partnership’s ongoing progress and experiences. Record successful strategies, issues encountered, and solutions used. Contact the CHS Office of Research team for examples (chs.research@act.gov.au).

Expand partnership networks

Engage with broader networks to share and learn from other consumer and carer partners and researchers. CHS Office of Research will provide details of relevant events through the CHS Office of Research Newsletter and chs.research@act.gov.au.

Step 5: Concluding your consumer and carer research partnership

The end of your involvement is a chance to recognise contributions, share results and consider future collaborations.

Formal acknowledgment of contributions

As the project concludes, make sure your contributions are formally recognised. This might include your name in reports, presentations or publications. You can also seek help from the project lead to record your details in a public researcher ID system such as ORCID.

If a partner steps back before the project ends, or the project ends early, their efforts should still be valued.

Sharing research results

You have the right to receive the research results and updates on new developments or future uses of the research.

Planning for future collaboration

As the current project ends, discuss future collaborations. Explore upcoming projects or areas of mutual interest.

Formal closure (planned and unplanned)

Whether the partnership ends as planned or unexpectedly, a formal meeting or celebration is good practice. Reflect on what was accomplished and the positive impacts.

Raising concerns and staying safe in your research partnership

Your safety and wellbeing matter. If something goes wrong during your research partnership, you have the right to raise it.

Your right to raise concerns

You can raise a concern at any time. You don’t need to wait until the project ends. You don’t need permission from the researcher or anyone else.

Raising a concern won’t affect your current or future care at CHS. It won’t affect your eligibility to partner with CHS on other projects. You won’t be treated differently because you spoke up.

What kind of concerns can you raise?

You can raise any concern about your experience, including:

- feeling unheard, dismissed or not taken seriously
- your role being different from what was agreed
- not receiving information you were promised
- communication problems within the research team
- feeling unsafe, uncomfortable or distressed
- behaviour that feels disrespectful, discriminatory or culturally unsafe
- concerns about how the research is being conducted
- problems with compensation or reimbursement
- anything else that doesn’t feel right

You don’t need to be certain something is wrong. If something feels off, that’s enough reason to talk to someone.

Who to contact

Choose the pathway that feels most comfortable for you:

Who	When to contact them	How to contact them
Your research team lead	For day-to-day issues about the project, your role, communication or scheduling.	Contact details provided when your partnership begins.
Director of CCCPR	For concerns about the partnership itself, including feeling unheard or unsupported. Also for guidance on your rights or next steps.	chs.research@act.gov.au
Executive Director, Research and Academic Partnerships	If your concern involves the Director of CCCPR, or if you've raised a concern and feel it hasn't been resolved.	chs.research@act.gov.au (mark to the attention of the Executive Director)
CHS Consumer Feedback	If you want to provide formal feedback or make a complaint through the CHS feedback system.	canberrahealthservices.act.gov.au/feedback
External consumer and carer advocacy groups	If you want independent support or advice from an organisation outside CHS.	HCCA: hcca.org.au Carers ACT: carersact.org.au ADACAS: adacas.org.au ACT Mental Health Consumer Network: actmhcn.org.au
ACT Human Rights Commission	If you believe your rights have been breached or you want to make a formal complaint to an independent body.	hrc.act.gov.au/complaints

You can use more than one pathway. For example, you might raise a concern with your research team lead and also seek independent advice from local consumer and carer advocacy groups like HCCA and Carers ACT.

Emotional and psychological safety

Research partnerships can sometimes involve topics that are emotionally difficult, especially if the research relates to your own health experiences or those of someone you care for.

That doesn't mean something has gone wrong. But it does mean support should be available to you. If you feel distressed, you can:

- let your research team lead or the Director know, so they can adjust how you're involved
- take a break from the partnership at any time without needing to explain why
- access support through the services listed 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–5pm weekdays
13YARN (Aboriginal and Torres Strait Islander crisis support)	13 92 76	24 hours, 7 days

You don't need to be in crisis to use these services. They're also available if you need someone to talk to after a difficult meeting or conversation.

Cultural safety concerns

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

Culturally unsafe behaviour includes (but isn't limited to) comments or actions that are racist, dismissive of your cultural identity, disrespectful of your knowledge systems, or that make assumptions about you based on your background.

The research team and CHS Office of Research are committed to creating research partnerships that are culturally safe for everyone. If we get it wrong, we want to know so we can learn and do better.

Withdrawing from a research partnership

You can withdraw from a research partnership at any time and for any reason. You don’t need to give a reason.

Withdrawing won’t affect:

- your current or future care at CHS
- your eligibility to partner with CHS on other research projects
- any agreed remuneration or reimbursement you’ve already been promised for work completed

If you’re thinking about withdrawing, you’re welcome to talk it through with the Director first. They can help you explore options. But you don’t have to. The decision is yours.

If you do withdraw, the research team should acknowledge the contributions you made.

Additional tips and hints

Ethics and partnering with consumers and carers in research

When you engage as a consumer and carer research partner, your role as a research partner generally does not require ethical review. But your roles and contributions still need to be detailed in the Human Research Ethics Application (HREA).

HREA considerations

- The HREA should describe what you'll be doing in the project, how you'll be helping, and the expected impact of your contributions.
- If you're a key part of the research team, you might be listed as a co-investigator. Your roles, responsibilities and contributions will be described to show your importance to the project.
- If your contributions are less frequent or task-specific, you may not be listed as a co-investigator. Your input should still be acknowledged in the project documentation.
- As a consumer and carer on the research team, you should not also be a research participant. This avoids potential conflicts of interest.
- The HREA should note measures to protect your privacy and confidentiality.
- The HREA should detail any training and support you receive, plus ongoing support and resources available to you.

Grant applications and partnering with consumers and carers in research

Being involved in grant applications makes sure consumer and carer perspectives are integrated from the start, strengthening the application.

Key considerations

- If your involvement is continuous, you should be listed as a co-investigator in the grant application.
- If your involvement is more occasional, your contributions should still be detailed in the appropriate sections.

Detailing partnerships in applications

- The application should clearly describe your role, contributions and how your involvement will enrich the research.
- It should detail any support or training you receive.
- It should highlight the expertise and perspectives you bring.

Tips for engaging in grant applications

- Get involved from the early stages so your perspectives are integrated throughout.
- If there's an urgent need for your input, make sure you understand why and that you receive adequate support.
- Maintain open communication with the research team about the grant process and your role.
- The process should include a mechanism for ongoing feedback and refinement.

Authorship and partnering with consumers and carers in research

Your role as a consumer and carer research partner can extend to authorship of resulting publications, if you're eligible.

Defining consumer and carer authorship

Consumer and carer authors are people with personal experience related to the research topic who meet authorship criteria and are listed as co-authors.

Consumer-authored publications are publications co-authored by consumer and carer partners, incorporating their contributions and perspectives.

Authorship criteria

- To qualify, you must make an intellectual or scholarly contribution to the research. This could involve contributions to the conception or design, or the acquisition, analysis or interpretation of data.

A significant contribution should include one, and preferably a combination of:

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

You must approve the final manuscript version and agree to be listed as an author. All listed authors are collectively accountable for the whole research output.

Tips for consumer and carer authors

- Start conversations about authorship at the beginning of the project.
- Make sure your contributions align with established authorship criteria.
- Keep clear documentation of your contributions throughout the project.
- The research team should provide guidance on peer review, manuscript preparation and any questions you have.

Recognition beyond authorship

If your contributions don’t meet formal authorship criteria, they should still be acknowledged in a way that shows your impact on the project.

Special considerations for First Nations knowledge

When publishing knowledge from First Nations consumers and carers, researchers must get consent from both the individuals involved and the community of origin. Consent should be secured before naming contributors.