



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

CHS Office of Research and Education (ORE)

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## Document version history

Version	Date	Notes
V1 Endorsed	2 March 2026	Endorsed by the CHS Network Partnering with Consumers and Carers Committee



# Introduction

Welcome to the *Partnering with Consumers and Carers in Research Toolkit*, developed by the Canberra Health Services (CHS) Office of Research and Education (ORE).

This toolkit is designed specifically for **you**, our consumers and carers. It provides practical guidance to help you partner confidently and meaningfully with researchers across health research at CHS. It is part of the broader suite of services and resources offered by CHS ORE to support your involvement.

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

## Understanding partnering with consumer and carers in research

Partnering with consumer and carers in research means working together with people like you who have lived experiences of health issues. We also partner with community members to help with health research projects. Your unique views are important in shaping research that truly shows and meets the needs of our community.

Health research, sometimes referred to as medical or clinical research, encompasses studies aimed at gaining more knowledge about human health, finding better ways to prevent and treat diseases, and improving overall healthcare outcomes. Health research can take many forms, including clinical trials, public health studies, epidemiological research, health services research, and more.

## Why should you get involved?

Partnering in research means that our research addresses issues relevant to the ACT and Southern NSW communities. Your involvement provides different viewpoints, making the research more thorough and effective.

## How does the partnership work?

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

## What does this toolkit offer?

- learn about consumer and carer research partnerships at CHS, including their benefits and how to make sure they are successful
- discover how you can engage in research priority setting, design, execution, dissemination, and translation
- tips for starting, planning, and working in a consumer and carer research partnership



# Toolkit background

## Context

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

Our systems at CHS are designed and used to support consumer, carers, and families to be partners in their own care, as well as in organisational governance, healthcare planning, design, measurement, and evaluation.

Consumers, carers, and families are actively supported and encouraged to collaborate in and co-design service improvements where possible and appropriate and contribute their experience and expertise to support the delivery of exceptional care for every consumer and carer, every time.<sup>1</sup>

Our CHS Research Strategy 2021-2025<sup>2</sup> (Strategic Commitment 5 [SC5]) focuses on creating impactful research partnerships with consumer, carers, and communities as a foundation for delivering exceptional care to the ACT and Southern NSW community.

Australian and international health and medical researchers and funding entities are increasingly recognising the role of consumer and carer research partnerships, as they offer many benefits.<sup>3</sup>

## Development

We developed this toolkit through a detailed literature review, which can be found on request by emailing [chs.research@act.gov.au](mailto:chs.research@act.gov.au).

The CHS ORE Consumer, Carer and Community Partnerships Collaborative Working Group (CWG) provided insights and expertise, greatly influencing its structure and content.

We thank the Collaborative Working Group and other CHS consumers, carers and researchers for their essential input. A list of CWG members can be found in Appendix A.

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<sup>1</sup> CHS Exceptional Care Framework

<sup>2</sup> The CHS Research Strategy 2021 to 2025 is currently being updated. A new version is expected by mid-2026.

<sup>3</sup> National health and medical research entities such as the NHMRC recognise the critical contribution that consumers and carers can make to research, as outlined in the Australian Code for the Responsible Conduct of Research and the Statement on consumer and carer and community involvement in health and medical research.



# Toolkit user guide

This toolkit is a practical guide for consumer and carer research partners at all levels of experience when working in partnership with CHS researchers. It can be adapted to suit the goals and challenges of each research project or team.

It is also designed to be a living document, with updates planned to follow evolving guidelines from organisations like the National Health and Medical Research Council (NHMRC), ensuring it remains an up-to-date and useful resource for consumer and carer research partnerships. The most recent version is available at: <https://www.canberrahealthservices.act.gov.au/about-us/research>

## Seeking further advice

While this toolkit gives you a foundation, you are warmly invited to seek support from the CHS ORE team by emailing [chs.research@act.gov.au](mailto:chs.research@act.gov.au). In particular, the CHS ORE Director of Consumer, Carer, and Community Partnerships in Research (Director of CCCPR) is available to support you in a variety of ways.

You can contact the Director of CCCPR at: [chs.research@act.gov.au](mailto:chs.research@act.gov.au)

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

## CHS documents related to this toolkit

CHS Exceptional Care Framework – find [here](#).

CHS Partnering with Consumers and Carers Policy – find [here](#).

CHS Consumer and Carers Reimbursement Procedure – find [here](#).

CHS Consumer and Carer Representatives Welcome Booklet – available on request by emailing [chs.research@act.gov.au](mailto:chs.research@act.gov.au)



## Definitions

The following consumer and carer-related definitions are adapted from the NHMRC's Statement on Consumer and Community Involvement in Health and Medical Research, customised to align with the CHS context.

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

Term	Definition
<b>Carer</b>	A carer is 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.
<b>Community Member</b>	An individual belonging to a community, contributing to its shared interests and activities.
<b>Community</b>	Community defines individuals and groups of people, interest groups and citizen groups. A community may be geographical location, a community of similar interest or a community of affiliation or identity.
<b>Consumer</b>	Consumers are people who use, or are potential users, of health organisations. In this document we use the term “consumers and carers” to refer to people accessing health services at CHS, their carers, families and supporters, as well as the broader community, who are potential users of the health service.
<b>Consumer Advocacy Group</b>	Organisations advocating for health care consumer rights, focusing on access to equitable, high-quality, and safe health care services.
<b>Consumer Representative</b>	An individual representing consumer perspectives in decision-making, possibly nominated by a consumer organisation, trained to advocate for consumer-centred health care.
<b>Research</b>	An original investigation undertaken to gain knowledge, understanding and insight.
<b>Research Process</b>	The planning, funding and conduct of an individual piece of research in addition to implementation of research findings and publication of research findings.
<b>Researcher</b>	A person who conducts research



## Defining partners vs participants

When it comes to research, you can get involved in two main ways: either as part of 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 be able to work with researchers to decide what the research should focus on, how it is done, and how the results are shared. This role gives you a say in the research process itself, making sure the research is relevant, understandable, and helpful to the community.

On the other hand, as a **Research Project Participant**, you are someone who volunteers to take part in a study by providing data, like answering surveys or participating in interviews. Your role here is to give information that researchers will analyse to answer specific questions. Unlike in a partnership, your involvement is usually just during the data collection phase, and you do not have a say in how the research is designed or what happens with the results.

### Compare and contrast table

Aspect	Consumer and Carer Research Partner	Research Project Participant
<b>Role in Research</b>	You actively help shape what the research is about, how it's done, and how the results are shared.	You provide data or answers for the research but don't influence the process.
<b>Engagement Level</b>	You're actively involved, ideally from the planning stages through to the sharing of results.	Your involvement is usually limited to when you provide data during the study.
<b>Influence on Research Decisions</b>	Your insights can influence key research decisions, like the study design and methods used.	You don't have a say in the research decisions; you follow what the researchers have planned.
<b>Purpose of Involvement</b>	To make sure the research is relevant, easy to understand, and beneficial to the community.	To contribute data that helps answer the research question.
<b>Level of Expertise Required</b>	You might need some understanding of research, but your expertise comes from your lived experience. Lived experience is considered a professional asset as it brings a unique data set that often the researcher/research team lacks.	No specific expertise is needed, just the ability to meet the study's criteria.
<b>Ethical Considerations</b>	You don't usually need formal human research ethics committee (HREC) approval since your role is about partnership, not direct research activities involving people.	Formal ethics approval (HREC) is sought by researchers to help ensure your rights are protected, including informed consent, privacy, and minimising harm, as your data will be analysed in the study.
<b>Compensation</b>	You might receive compensation for your time and expertise as a research partner. <i>See the <a href="#">CHS Consumer and Carer Reimbursement Procedure</a> for more information.</i>	You might get compensation or incentives for participating, like reimbursement for travel expenses.



## Guiding principles<sup>4</sup>

### **Partnering happens at all levels of research**

Consumers and carers are involved as research partners in setting priorities, designing studies, shaping methods, interpreting findings, and sharing results. Their experience strengthens research relevance and impact.

### **Consumer and carer input is supported and influential**

We create space and provide support for consumers and carers to contribute meaningfully throughout the research process. Their insights shape how research is designed, conducted and applied.

### **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 or afterthought.

### **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. Likewise, 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 our research.

### **We address barriers to involvement**

We recognise that access to consumer and carer research partnership is not equal. We work to reduce barriers and support the involvement of people who may face structural exclusion.

### **We invest in learning and capability building**

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

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<sup>4</sup> Based on the CHS Partnering with Consumers and Carers Policy – Guiding Principles



### **Diversity strengthens research**

We seek research 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**

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

### **Lived experience is expertise**

We recognise consumer and carer experience as a legitimate and important form of knowledge. It brings insight into what matters, what works, and what change is needed across our research activities.

### **Carers, families and supporters are included**

Consumers define who is important in their lives. This often includes carers, family members or other supporters. We respect and support their involvement in research partnerships. We recognise that carers bring distinct expertise that is different from (not secondary to) consumer perspectives across our research.

### **Cultural safety is essential**

We reflect on our own power, privilege and assumptions across our research activities. 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 in our research, what decisions are open to influence, and how feedback will be used. We always report back on outcomes.

### **We use flexible approaches to involvement**

We adapt our research 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 our research more grounded, inclusive and responsive to community needs.



## Consumer and carer research partnership levels

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

However, your level of involvement and the scope of your role can vary based on your personal circumstances, such as the amount of time you can commit, the type of research being undertaken, and the expected duration of the project.

### Dimension 1: Levels of consumer and carer involvement

We often use a framework similar to the [IAP2](#) to figure out how involved you can or want to be. There are five levels:

1. **Inform:** you will be kept informed with all the necessary information to help you understand the research
2. **Consult:** you will be asked for your feedback, which will be used to guide key decisions in the research
3. **Collaborate:** you will have a strong voice, actively contribute ideas, and play a key role in shaping decisions about a CHS research project
4. **Co-Design:** you will work as equal partners with our researchers in deciding how a CHS research project is designed and run from the start
5. **Empower:** you will be supported by researchers to take the lead, making final decisions and guiding the entire research process.

### Dimension 2: Stages of consumer and carer involvement

You may be involved at different stages of the research process:

1. **Discovery:** research ideas and concepts are developed
2. **Design:** the research methodology and plan are created
3. **Conduct:** the research is conducted, including data collection and analysis
4. **Disseminate:** research findings are shared with others
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 consumer and carer research partnerships that best fits project goals, resources, and the needs of everyone involved.

As such, this toolkit (and broader CHS ORE services) offers flexible support for all levels of consumer and carer partnership and research phases. Further details can be found on the next page.



## Consumer and carer research partnership spectrum *(based on the CHS Partnering with Consumers and Carers Policy Spectrum found [here](#)).*

Research Stage Involvement Level	Inform	Consult	Collaborate	Co-Design	Empower
<b>Discovery</b>	Researchers will share upcoming research themes with you.	You can provide your input on which research priorities matter most to you.	You and the research team will develop these priorities.	Together, you and the research team will co-develop these priorities.	You will take the lead in setting what priorities should be focused on.
<b>Design</b>	Researchers will share detailed research plans and objectives with you.	Your opinions on the research design are sought to understand its impact and relevance.	You and the research team will design the research plans.	You and the research team will co-design the research plans.	You will lead the research design, ensuring it fully represents the community's needs.
<b>Conduct</b>	You are kept updated on the progress of the research.	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 the execution of the research.
<b>Share</b>	Researchers provide you with the results to share within your networks.	You are asked for input on the best ways to disseminate the results.	You present results with the researchers at conferences.	You will co-author and present results with the researchers at conferences.	You lead the sharing of the research results, deciding how and where they are shared.
<b>Translate</b>	You are informed about how the research results are being applied in real-world settings.	Researchers consult with you on potential applications of the results.	You and the research team collaborate on the applications of the research results.	You and the research team co-develop the applications of the research results.	You drive the application of research into practice, ensuring that the results make a tangible impact.



## What does involvement look like in practice?

- **Consult level:** You might receive one or two emails over the course of a 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 will not be expected to commit more time than you are 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 valued and compensated
4. say no, change your mind, or withdraw at any stage
5. to 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 details regarding raising concerns, please see Page 25.



# Setting the scene

## Benefits of partnering with consumer and carers in research

Before understanding how to establish and sustain consumer and carer research partnerships, it is worthwhile understanding the benefits to our research.

### Research that better meets the needs of our community

Consumer and carer research partnerships make sure that research is useful and important to the community. This helps make sure that the research findings can be used effectively in healthcare.

#### Example project:

A research team planned a study on chronic pain in older adults and held workshops with local support groups to understand what services should be offered in the local community. Attendees stressed the importance of non-drug treatments. Based on this feedback, the researchers focused on physical therapy and relaxation classes. This made the study more relevant and useful. The results were quickly used in local clinics, improving patient results.

#### Impact of partnership:

This approach increased the researchers' credibility, helped recruit participants, and provided professional growth. Consumers and carers felt empowered and valued, experienced better health results, and trusted the research process.

### Helps build trust and form long-term relationships

Partnering with consumer and carers in research helps build trust between researchers and our community. This trust is important for doing research ethically and ensuring research projects continue to benefit our community for the long-term.

#### Example project:

In a project on mental health services for young adults, researchers held open forums in community centres with young adults, carers, and mental health professionals to discuss research goals and progress. This open dialogue created a sense of ownership and built trust. Over time, this trust led to more community involvement and support for future studies.

#### Impact of partnership:

This approach ensured the research addressed real community needs and improved the validity of the results. For researchers, it brought innovative ideas, strengthened professional networks, and improved data quality. For consumer and carers, it provided a platform to voice concerns, improved access to mental health services, and fostered a supportive community.



## Improved opportunities for grant funding

Partnering with consumer and carers in research often matches what many funding organisations like NHMRC look for. Partnering with consumer and carers from the start of a research project can make grant applications stronger because it leads to research that is inclusive, relevant, and impactful.

### **Example project:**

A research team submitted a grant proposal to the NHMRC for a project to improve diabetes management in First Nations communities. The proposal highlighted a strong partnership with Indigenous health workers and community members from the start, ensuring the research met community-specific needs. This partnership strengthened the application, aligned with NHMRC's focus on consumer and carer involvement, and helped secure funding.

### **Impact of partnership:**

This approach ensured the study was culturally appropriate and relevant to the community. For researchers, it improved the chances of getting funding and built cultural competencies. For consumer and carers, it addressed their health priorities, gave them a sense of ownership, and built trust and cooperation with the research team.

## Better ways to find participants

Partnering with consumer and carers in research helps create better plans for engaging participants. By understanding what the target group needs and likes, researchers can make recruitment approaches more attractive and easier to join, getting a larger and more diverse group of participants.

### **Example project:**

A study on a new dietary program for heart health struggled to find participants. After consulting with consumer and carer research partners, the team learned their recruitment messages were too clinical. They changed the messaging to identify those with lived experiences, and to highlight personal stories and potential benefits, significantly boosting recruitment and attracting a diverse group of participants.

### **Impact of partnership:**

This approach improved the diversity and representativeness of the sample, leading to more targeted audiences and thus results. For researchers, it enhanced communication skills, recruitment efficiency, and community relationships. For consumers and carers, it made participation more accessible and relatable, and increased awareness of the study's personal relevance.



## Better data quality and interpretation

Consumer and carer research partnerships can greatly improve the quality of the data collected. You can offer unique ideas and perspectives that might otherwise be missed, ensuring the data are complete and accurately reflect the experiences of those affected by the health issue.

### **Example project:**

In research on patient experiences with home dialysis, consumer and carer research partners reviewed early survey results and suggested changes and additional questions about home care support. This input led to more complete data, capturing details about family involvement and personal independence. Their contributions also helped ensure the results reflected patient lived experiences.

### **Impact of partnership:**

This approach added detailed insights and produced more relevant research recommendations. For researchers, it deepened understanding, improved the credibility of results, and encouraged new methods of data collection and analysis. For consumers and carers, it ensured their lived experiences were fully represented, empowered them to shape the research, and made the study's results more useful in daily life.

## Better and broader sharing of results

When consumer and carer research partners are involved in research, the results are more likely to be shared widely and effectively. You can also help turn research results into practical applications by health care professionals and acceptance and adoption by patients, increasing the impact of the research.

### **Example project:**

After completing a study on preventing childhood obesity, the research team collaborated with consumer and carer partners to share the results. They created engaging social media posts, community talks, and school workshops. Guided by the consumer and carer partners' understanding of community concerns, these efforts led to widespread adoption of the recommended practices by local schools and families.

### **Impact of partnership:**

This approach ensured the results reached and connected with a broad audience, increasing the chances of practical application and policy change. For researchers, it raised the visibility of their work, improved outreach plans, and built a stronger community connection. For consumers and carers, it made sharing methods accessible and engaging, empowered them to advocate for health improvements, and highlighted the value of their contributions to the research.



# The five steps of a consumer and carer research partnership

These five steps are designed to give a simple overview of how to create and maintain consumer and carer research partnerships. They are based on several well-established methods for partnerships, projects, and research planning:<sup>5</sup>.

## 1. **PREPARE**

- laying the foundations to your consumer and carer research partnership
- identifying and reaching out to potential research partners

## 2. **PLAN**

- collaboratively drafting a partnership plan detailing goals and roles
- mutually agreeing on methods for collaboration and responsibilities

## 3. **COLLABORATE**

- facilitating inclusive conversations throughout the project's lifecycle
- actively involving all voices in decision-making, addressing barriers to participation

## 4. **ENHANCE**

- reflecting on the partnership's progress to continuously improve
- recognising consumer and carer partners' contributions and championing partnerships

## 5. **CONCLUDE**

- appreciating and communicating the efforts and achievements of all involved
- officially ending the partnership

The specific actions and decisions at each step will vary based on how involved you are, as well as the size and needs of your research project.

Many of the actions can also be included in the overall planning and execution of the research project. This flexible approach ensures that the partnership aligns with both the research project's goals and your preferred level of involvement.

Finally, all steps, and the actions within them, can be supported by the CHS ORE team, including the Director of CCCPR. Support includes in-person help, providing and adapting templates, and connecting with other researchers for peer-to-peer learning.

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<sup>5</sup> [NCCPE Partnership Cycle](#); [CEIH Partnership Cycle](#); [Oxford PPI Research Cycle](#); [Project Life Cycle](#);



## Step 1: Preparing for a consumer and carer research partnership

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

### Exploring previous efforts

It is useful to start by looking into any previous consumer and carer research partnerships that might relate to your area of interest. If you're not sure where to begin, the Director of CCCPR can guide you. They can help you connect with groups like the Health Care Consumers and Carers Association (HCCA) or Carers ACT, which might have ideas or data relevant to your community. Even broader Australian or international research can be a good starting point for discussions that affect the ACT/Southern NSW communities.

### Defining the partnership's purpose and your role

As a potential consumer and carer research partner, it is important to understand why you want to form a partnership. You might want to make research more relevant by including diverse community views, improve research quality with your unique ideas, or help address specific health issues that matter to you. Being involved can also help you build research skills and gain a better understanding of the research process. Knowing your purpose helps ensure your contributions are valuable. Researchers also need to identify the purpose of the partnership to align research project goals.

The Consumer and Carer Research Partnership Spectrum (on Page 14) shows the different levels of consumer and carer involvement. Depending on resources like funding, support, and time, the level of your involvement might vary.

### Finding the right fit in research partnerships

The selection of consumer and carer research partners often depends on the needs of everyone involved. If the research involves conditions or services you are familiar with, your firsthand lived experience can be very valuable. In projects where the aim is to assess informational materials like consent forms, a broad view may be enough to ensure clarity and accessibility for the wider community.

### Initiating 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 do not receive one, you can ask for it. These initial details will help you understand what is expected and how you can contribute. Fact sheets, often provided during these early discussions, can give a concise overview of the project.

If you're interested in taking a more active role, you may need to go through an expression of interest (EOI) and possibly an interview process. The Director of CCCPR can support you through this process, making sure you're well-prepared and informed.



## Step 2: Planning for your consumer and carer research partnership

This step is important for turning the idea of your consumer and carer research partnership into a concrete, actionable plan.

### Setting goals, objectives, and milestones

To make sure the partnership is successful, it is important to clearly define the goals and objectives you and the research team aim to achieve and set milestones to track the progress of both the research project and the partnership itself. This clarity ensures everyone involved is aligned, helping with a more effective partnership.

You can discuss these goals and milestones with the Director of CCCPR, who can offer examples and guidance on common objectives in consumer and carer research partnerships.

### Understanding roles, responsibilities, and support

Knowing exactly what your role involves helps prevent overlaps and ensures no gaps in responsibilities. Your contributions might include decision-making, attending meetings, or providing input on research design. Understanding the support available to you, such as access to ICT resources, emotional support, or administrative help, is also important.

It is also important to discuss how you will be compensated for your time and ideas. The Director of CCCPR can provide you with CHS's policy on compensating consumer, carers, and community representatives<sup>6</sup>, including examples of how others have been compensated in past projects.

### Preparing for introduction, training, and risk management

An introduction will help you understand the specific aspects of the research project, CHS policies, and the broader context of health research. The Director of CCCPR can guide you to both internal and external training resources that could be helpful, such as training in consumer and carer research partnership principles or research methods.

Planning also involves preparing for potential risks, like misunderstandings or disagreements. Creating a risk management plan specifically for the consumer and carer research partnership can help manage these challenges effectively. This might include a risk matrix that outlines potential issues and plans for dealing with them, which the Director of CCCPR can help you and the research team set up.

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<sup>6</sup> [https://www.canberrahealthservices.act.gov.au/data/assets/word\\_doc/0007/1981249/Consumer,-Carer-and-Community-Representative-Reimbursement.docx](https://www.canberrahealthservices.act.gov.au/data/assets/word_doc/0007/1981249/Consumer,-Carer-and-Community-Representative-Reimbursement.docx)



## Setting up communication, feedback, and assessment processes

Creating a communication plan is vital to maintain open and consistent dialogue between all team members. This plan should include how and when updates and meetings will happen and how feedback will be gathered and used. Being actively involved in the feedback process ensures your ideas are considered in the research.

Regular assessments of the partnership by all involved can also help assess its effectiveness and identify areas for improvement. These assessments might look at the impact of your involvement on the research results, your satisfaction with the partnership, and whether the set goals are being met. The CCCPR Director can show you and your researcher examples of communication and assessment plans to help you get started.

### Step 3: Working together in partnership

This step is all about working together effectively by focusing on clear communication, mutual respect, and shared goals. These elements help use the diverse strengths of your team, creating a partnership that's both effective and sustainable.

#### Initial team meeting and project introduction

The initial meeting with all project team members, including you as a consumer and carer research partner, is important for setting the tone of the working together. This meeting is your chance to meet everyone involved, which helps create a sense of unity and shared purpose.

During this meeting, the research team will walk you through the research idea or plan. This presentation is designed to ensure everyone understands the project's scope and significance right from the start.

You can share questions or feedback at any time. The initial meeting is a good place to start. This is your chance to make clear expectations and ensure your views are included in the research from the beginning.

#### Collaboration and meeting logistics

To keep the collaboration effective, plan regular meetings that fit with the overall project plan. Consistent meetings help maintain steady progress and keep all team members, including you, engaged and informed.

It is important that meeting logistics accommodate everyone's needs, such as choosing accessible locations and ensuring the right technology is available for effective communication. This is especially important if you or other consumer and carer research partners have specific requirements or preferences.



## **Role clarification, team expectations, and conflict resolution**

As the project progresses, it is important to keep clarifying the roles and responsibilities of each team member, including yours. Clear roles help prevent overlaps and confusion, making the teamwork smoother.

It is also important to be open about time commitments, communication methods, and preferred ways to solve disagreements. Regular reviews of confidentiality agreements and ethical rules are needed to ensure everyone understands and follows these rules. The Director of CCCPR can help with these tasks and connect you with others who can provide more support. Likewise, if you feel your role and / or expertise is being dismissed or tokenised, we can support you and also link you up with external advocacy groups. For more information regarding raising concerns, please see Page 25.

Additionally, you may withdraw from the project at any time and for any reason. Choosing to withdraw will not affect your current or future eligibility to partner with CHS on other projects, nor will it impact any current or future care you receive from CHS.

## **Step 4: Enhancing your consumer and carer research partnership**

Enhancing your involvement in the consumer and carer research partnership involves ongoing reflection, learning, and advocacy. This step focuses on improving the partnership's effectiveness and increasing its impact through regular reviews and sharing successes.

### **Regular review on progress and improvement**

Taking part in regular reflection sessions with the whole research team, including other consumer and carer research partners, is worthwhile. These sessions are a chance to see how well the partnership is meeting its goals for both the project and the partnership itself.

Use these sessions to review progress, deal with challenges, and celebrate successes. They are also useful for finding areas where the partnership could be improved, such as better communication plans or more inclusive decision-making processes. The Director of CCCPR can help organise these reviews and collaboratively design solutions.

### **Maintain a 'live' partnership reflection log**

Consider helping with a central, accessible log that records the ongoing progress and experiences of the consumer and carer research partnership. This 'live' document should be available to all team members as a transparent record of the partnership's journey.

In this log, write down successful plans and practices that positively impact the partnership, as well as any issues or challenges encountered, and the strategies used to deal with them. This living document should help with ongoing improvements and serve as a resource for continuous learning. The Director of CCCPR can show you examples and guide you on how to effectively contribute to this log.



## Expand consumer and carer research partnership networks

It is important to engage with broader networks to share and learn from the experiences of other consumer and carer research partners and researchers. You can participate in knowledge-sharing sessions, such as workshops where people present case studies, share best practices, and discuss both the challenges and successes they've encountered in their consumer and carer research partnerships.

CHS ORE will provide details of relevant events and projects through platforms like the CHS HealthHub and the CHS ORE Research Newsletter, helping you stay informed and connected. Engaging in these networks not only improves your own understanding but also contributes to the wider community's learning and improvement in consumer and carer research partnerships.

## Step 5: Concluding your consumer and carer research partnership

The end of your involvement in a consumer and carer research partnership is an important time. It is when contributions are recognised, results are shared, and future collaborations are considered. This phase is a chance to celebrate the achievements of the partnership and the valuable ideas you have provided.

### Formal acknowledgment of contributions

As the project or its phase winds down, it is important to ensure that your contributions are formally recognised. This might involve including your name in interim or final project reports, presentations, or publications, according to any prior agreements on credit and recognition. Likewise, you can seek assistance from the project lead to record your details in a public researcher ID system such as [ORCID](#). Such acknowledgments should respect and highlight your important role in the project's success.

Even if a partner needs to step back before the project ends, or if the project ends early, it is important to appreciate their efforts. Your input should be valued regardless of the project's duration or outcome.

### Sharing research results

Sharing the research results, as well as potential uses of the results, is important. You have the right to receive updates on new developments, follow-up projects, or future uses of the research. Keeping you informed shows the lasting value of your contributions. The Director of CCCPR can help you access communication channels at CHS ORE for this purpose.



## Planning for future collaboration

As the current project ends, discussions about future collaborations should start. This is your opportunity to explore how you want to stay involved. Explore upcoming projects or areas of mutual interest and think about how you might like to continue your involvement. This encourages ongoing involvement and helps you see where you can effectively contribute to future projects.

## Formal closure (planned and unplanned)

Whether the partnership ends as planned or unexpectedly, having a formal celebration or meeting is a good practice. This event recognises the partnership's achievements and the collective efforts of the project team. During this closure, reflect on what has been accomplished and the positive impacts of the partnership. Sharing these reflections can provide valuable ideas for future collaborations. The Director of CCCPR can offer examples and guidance on organising a meaningful closure event or meeting.



# 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. This section explains what to do, who to contact, and what protections are in place for you.

## Your right to raise concerns

You can raise a concern at any time during your research partnership. You do not need to wait until the project ends. You do not need permission from the researcher or anyone else.

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

## What kind of concerns can you raise?

You can raise any concern about your experience in the research partnership. This includes concerns about:

- 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 does not feel right

You do not need to be certain that something is wrong before raising it. If something feels off, that is enough reason to talk to someone.



## Who to contact

There are several ways to raise a concern. You can choose the pathway that feels most comfortable for you.

Who	When to contact them	How to contact them
<b>Your research team lead</b>	For day-to-day issues about the project, your role, communication, or scheduling.	Contact details will be provided when your partnership begins.
<b>Director of Consumer, Carer, and Community Partnerships in Research (Director of CCCPR)</b>	For concerns about the partnership itself, including feeling unheard, tokenised, or unsupported. Also for guidance on your rights or next steps.	Email: <a href="mailto:chs.research@act.gov.au">chs.research@act.gov.au</a>
<b>Executive Director, Research and Academic Partnerships</b>	If your concern involves the Director of CCCPR, or if you have raised a concern and feel it has not been resolved.	Email: <a href="mailto:chs.research@act.gov.au">chs.research@act.gov.au</a> (mark your email to the attention of the Executive Director)
<b>CHS Consumer Feedback</b>	If you want to provide formal feedback about your experience or make a complaint through the CHS feedback system.	<a href="https://www.canberrahealthservices.act.gov.au/before,-during-and-after-your-care/outpatients/after-you-leave/give-feedback-or-volunteer/feedback">https://www.canberrahealthservices.act.gov.au/before,-during-and-after-your-care/outpatients/after-you-leave/give-feedback-or-volunteer/feedback</a>
<b>External Consumer and Carer Advocacy Groups</b>	If you want independent support or advice from a consumer advocacy organisation outside of CHS.	<a href="#">Health Care Consumers Association (HCCA)</a> <a href="#">Carers ACT</a> <a href="#">ADACAS</a> <a href="#">ACT Mental Health Consumer Network</a>
<b>ACT Human Rights Commission</b>	If you believe your rights have been breached or you want to make a formal complaint to an independent body.	<a href="https://www.hrc.act.gov.au/complaints">https://www.hrc.act.gov.au/complaints</a>

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 the HCCA.



## What happens when you raise a concern

When you raise a concern with someone at CHS, they should:

- listen to you and take your concern seriously
- explain what they can and cannot do to help
- tell you what the next steps are and when you can expect to hear back
- follow up with you within an agreed timeframe
- keep your concern confidential, unless there is a safety or legal reason to share it, in which case they will tell you

If you are not satisfied with the response, you can escalate your concern to the next level in the contact table above. You can also ask the Director of CCCPR to help you navigate the process.

## Emotional and psychological safety

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

This does not mean something has gone wrong. But it does mean that support should be available to you.

If you feel distressed during your involvement in a research partnership, you can:

- let your research team lead or the Director of CCCPR know, so they can adjust how you are 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
<b>Lifeline</b>	13 11 14	24 hours, 7 days
<b>Beyond Blue</b>	1300 22 4636	24 hours, 7 days
<b>Carer Gateway</b>	1800 422 737	8am–5pm weekdays
<b>13YARN (Aboriginal and Torres Strait Islander crisis support)</b>	13 92 76	24 hours, 7 days

You do not need to be in crisis to use these services. They are 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 on page 26.

Culturally unsafe behaviour includes (but is not 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 ORE 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 do not need to give a reason.

Withdrawing will not affect:

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

If you are thinking about withdrawing, you are welcome to talk it through with the Director of CCCPR first. They can help you explore options, such as adjusting your role or level of involvement, before you make a final decision. But you do not have to. The decision is yours.

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



# Additional tips and hints

## Ethics and partnering with consumer and carers in research

When engaging as a consumer and carer research partner in projects, the ethical considerations are important even though your involvement generally does not require an ethical review. Here is how these considerations play out in your role and what they mean for you:

### Human research ethics application (HREA) considerations

Even though the project might not need an ethical review just because you are involved, your roles and contributions still need to be carefully detailed in the Human Research Ethics Application (HREA). Whether you're taking part as a co-investigator or a member of a working group, it is important that your involvement is clearly outlined:

- clearly describe what you will be doing in the project, how you will be helping, and the expected impact of your contributions on the research
- if you're a key part of the research team, you might be listed as a co-investigator in the HREA. This means your roles, responsibilities, and contributions will be clearly described to show your importance to the project
- if your contributions are less frequent or specific to certain tasks, like giving feedback on design or checking materials, you may not be listed as a co-investigator. However, your input should still be acknowledged in the project documentation as a best practice
- it is important that you, as a consumer and carer included in the research team, are not also a research participant. This helps avoid potential disagreements of interest. If your participation is essential, clear processes should be established to reduce any potential disagreements and biases
- measures to protect your privacy and confidentiality should be noted, especially when you are sharing sensitive information
- the HREA should detail any training and support you receive to ensure you have the necessary skills and knowledge for effective and ethical participation. It should also mention any ongoing support, mentorship, and resources available to you for continued involvement



# Grant applications and partnering with consumer and carers in research

Being involved in grant applications as a consumer and carer research partner is a significant way to ensure that consumer and carer views are integrated right from the start of a project, strengthening the application and confirming that your involvement is meaningful and not merely tokenistic.

## Key considerations for your inclusion in grant applications

- if your involvement in the research project is continuous and integral, you should be listed as a co-investigator in the grant application. This formal recognition highlights your important role and contributions to the research
- if your involvement is more occasional, such as providing feedback on specific aspects of the project, your contributions should still be detailed in the appropriate sections of the application to acknowledge your input

## Detailing consumer and carer research partnerships in applications

- it is important that the grant application clearly describes your role and contributions. It should explain how your involvement will enrich the research and contribute to its success
- the application should detail any support or training you receive to enable effective participation in both the research project and the grant application process
- the application should also highlight the unique expertise and views you bring, reinforcing the value of your involvement

## Tips for engaging in grant applications

- to ensure your views are thoroughly integrated, it is important to be involved from the early stages of designing of the project and then preparing the grant application
- if there's an urgent need for your input, make sure you understand why your contribution is needed quickly and that you receive adequate support to meet any deadlines
- maintain open communication with the rest of the research team to ensure you understand the grant application process and your role within it
- the application process should include a mechanism for ongoing feedback and refinement, allowing you to collaborate actively in shaping the grant proposal



## Authorship and partnering with consumer and carers in research

When you participate as a consumer and carer research partner in a project, acknowledging your role isn't limited just to the research process; it also extends to the potential authorship of resulting publications. Here's how you can be integrated as an author, if eligible:

### Defining consumer and carer-authorship in research

- as a consumer and carer author, you are someone with personal experiences related to the research topic who meets specific authorship criteria, allowing you to be listed as a co-author on publications
- these are publications where you, as a consumer and carer research partner, co-author the piece, showcasing your contributions and unique views

### Authorship criteria for consumer and carer research partners

- to qualify for authorship, you must make an intellectual or scholarly contribution to the research and its output. This could involve contributions to the conception or design of the work, or the acquisition, analysis, or interpretation of data
- while the specific requirements for what constitutes a significant contribution can vary across disciplines, generally, you should meet one and preferably a combination of the following criteria:
  - conception and design of the project or output
  - acquisition of research data where the acquisition has required significant intellectual judgment, planning, design, or input
  - contribution of unique knowledge, which could include First Nations' knowledge, where justified
  - analysis or interpretation of research data
  - drafting significant parts of the research output or critically revising it in ways that contribute to its interpretation
- You must approve the final manuscript version before publication and agree to be listed as an author. It is important to note that all listed authors, including yourself, are collectively accountable for the integrity and accuracy of the whole research output.



## Tips to incorporating consumer and carer research partners as authors (general advice)

- start conversations about authorship with the research team at the beginning of the project. This early dialogue helps ensure that your contributions are recognised from the start and considered throughout the project
- make sure your roles and contributions align with the established authorship criteria in research. This includes significant involvement in the conception, design, data collection, analysis, and interpretation of the research
- keep clear and transparent documentation of your contributions throughout the project. This should cover all relevant aspects such as study design, data collection, analysis, and any other significant input you provide
- recognise that the publication process might be unfamiliar to you. The research team should provide guidance and support to help you navigate this process effectively. This includes explaining the peer review process, assisting with manuscript preparation, and addressing any questions or concerns you might have
- your unique views, shaped by personal experiences and ideas, improve the study's results and relevance. These should be acknowledged as adding substantial value to the research

## Recognition beyond authorship

Even if your contributions do not meet the formal criteria for authorship, it is important that they are acknowledged. Contributions by consumer and carer research partners like you can offer valuable ideas and views that enrich the research process. These should be recognised in a way that shows your impact on the project

## Special considerations for first nations knowledge

When publishing knowledge from First Nations consumer and carers, researchers must get consent from both the individuals involved and the community where the knowledge comes from. This ensures that both individual and collective contributors are appropriately recognised. Before naming contributors, consent should be secured to ensure it does not imply their endorsement of the research results.



# Appendices

## Appendix A: Collaborative Working Group (CWG) membership

The Collaborative Working Group (CWG) was formed to support the design of the CHS ORE Consumer, Carer, and Community Partnerships initiative by providing practical advice and expertise. The aim was to create an innovative, effective, and sustainable consumer and carer research partnership initiative, benefiting consumers, carers, community members, and clinicians/researchers.

Over the course of six workshops (June to November 2023), the CWG fostered a collaborative and inclusive atmosphere, encouraging open discussion and ensuring equal opportunities for all contributors.

The workshops focused on key aspects of the initiative, such as its guiding principles, structure, evaluation methods, accessibility, and continuous improvement, while also celebrating cultural and contextual diversity to ensure inclusivity and relevance.

While the group had core members, the CWG remained open to all interested stakeholders, allowing for flexible participation. Attendees were not required to attend every workshop and had the opportunity to provide feedback asynchronously.

Below is a list of people involved in the CWG (as of December 2023):

<b>Name</b>	<b>Affiliation/Title</b>
Dr Brett Scholz	Senior Research Fellow / Senior Lecturer, ANU Medical School
Shivana Chandra	Research Officer, Health Care Consumers and carers' Association Inc
Darlene Cox	Executive Director, Health Care Consumers Association Inc
Terri Warner	PhD Scholar, ANU Medical School
Dr Alyssa Morse	ANU College of Health and Medicine
Dr Ramila Varendran	Staff Specialist, CHS Hospital in the Home program
Dr Michael Chapman	Director of Palliative Care
Hailey Hoolihan	CHS Aboriginal and Torres Strait Islander Consumer Reference Group
Reagan Taylor	ACTHD Centre for Health and Medical Research
Bailey De Paiva	CHS Director of Consumer Experience, QSII
Rowan McIntyre	CHS Director of Consumer Experience, QSII
Kylie Lewis	CHS Consumer Experience Survey Manager, QSII
Chandra Yerrappa	CHS Diversity and Inclusion Manager
Jesse Newman	CHS Systemic Design, Participatory Design, and Interaction Design
Heidi Prowse OAM	Executive Manager, Capital Region Community Services
Karen O'Brien	Director of Nursing, Prof Practice, CHS Nursing, Midwifery & Patient Support



Genevieve Whitlam	Director of Lived-Experience, CHS MHJHADS
Ping Tan	Project Manager, CHS Palliative Care
Dr Margaret Broom	Associate Professor, University of Canberra; SYNERGY: Nursing and Midwifery Research Centre, UC and ACT Health
Kamla Brisbane	Policy Manager, Carers ACT
Jutta Thwaites	Senior Director, Research Strategy and Capability, CHS ORE
Dr Pia Rowe	Assistant Director, Content, CHS Strategic Communications and Engagement
Dr Ros Stanton	Director Research Mentorship, Supervision, and Education, CHS ORE
Dr Prakash Poudel	Research Manager, CHS ORE
Leah Mathews	Director, Consumer, Carer and Community Partnerships, CHS ORE
Prof Imogen Mitchell	Executive Director, Research and Academic Partnerships

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Information about the directorate can be found on the website:  
[www.canberrahealthservices.act.gov.au](http://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.

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