Partnering with consumers and carers in research: Researcher Toolkit

CHS Office of Research

August 2026

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

Contents

Document version

Version	Date endorsed	Notes
V1	16 July 2025	Endorsed by the CHS Network Partnering with Consumers and Carers Committee
V2	15 October 2025	Added National Clinical Trials Governance Framework (NCTGF) details; reimbursement guidance; writing in plain English guidance.
V3	11 August 2026	Toolkit content's inserted into the new CHS Research template and edits related to the establishment of the CHS Office of Research.

Introduction

This toolkit helps CHS researchers build and sustain partnerships with consumers, carers and community members across research activities. It sits within the CHS Office of Research suite of resources and services.

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.

Partnering with consumers and carers in research at CHS

What is partnering with consumers and carers in research?

Partnering with consumers and carers means collaborating with people who have personal experience of health conditions, their carers and community members. These partners contribute insights and expertise that can shape research at every stage.

Why partner with consumers and carers in research?

Consumer and carer partnerships help make sure research responds directly to community priorities across the ACT and Southern NSW. They bring diverse viewpoints and produce more inclusive research outcomes.

As an organisation, we recognise that consumers and carers bring perspectives that differ from, and add to, clinical and research expertise. When we work alongside consumers and carers, and learn from their lived experience, we gain a fuller picture of what safe, high-quality care looks like.

How does it work?

Build your partnership on mutual respect and active collaboration, with researchers, consumers and carers working toward shared goals.

When these partnerships align with the National Safety and Quality Health Service (NSQHS) and National Clinical Trials Governance Framework (NCTGF) Partnering with Consumers Standards, they grow into genuine collaborations with shared decision-making. This goes beyond token involvement; it creates real co-ownership of the research process and its outcomes.

You can bring consumer and carer partners in at any point, from priority setting and design through to dissemination and implementation. Different methods suit different levels of expertise, project types and available resources.

What can you expect from this toolkit?

- The essentials of consumer and carer research partnerships at CHS, including their benefits and what makes them work
- How consumer and carer partners can work with you to set research priorities and design, conduct, disseminate and translate your research
- Practical tips for starting, structuring and evaluating partnerships, and for concluding them constructively

Toolkit background

Context

Our 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.

CHS's approach aligns with national safety and quality expectations under the NSQHS Standards and the NCTGF.

The NSQHS Standards embed consumer and carer partnering across all eight standards. NSQHS Standard 2, Action 2.11 requires CHS to:

1. involve consumers and carers as partners in the governance of, and in designing, measuring and evaluating, health care; and
2. have processes so that the consumers and carers involved in these partnerships reflect the diversity of consumers who use the service or, where relevant, the local community.

The NCTGF, developed by the Australian Commission on Safety and Quality in Health Care, applies these same principles to hospital-based clinical trials. It aligns with the NSQHS Standards and outlines requirements for governance, workforce, risk management and consumer and carer partnering across the research lifecycle.

Strategic Commitment 5 (SC5) 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.

Australian and international researchers and funding bodies are increasingly recognising the value of consumer research partnerships (also known as consumer and community involvement) and the wide range of benefits they offer.

Development

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

The review drew on over 10 meta-analyses, more than 50 peer-reviewed papers, over 30 frameworks, statements and toolkits, and 23 programs and initiatives. Managers of local and national consumer research partnership programs shared their insights in semi-structured interviews.

The CHS Office of Research Consumer, Carer, and Community Research Partnerships Collaborative Working Group (CWG) provided insights and expertise that shaped the toolkit's structure and content. We extend our appreciation to the CWG and other CHS consumers and carers, consumer advocacy organisations and researchers for their input.

Toolkit user guide

This toolkit is a practical guide for CHS researchers at all levels of experience. You can adapt it to suit the objectives and context of each project and team.

Throughout this toolkit, "consumer and carer" includes consumers, carers, families, supporters and relevant community members who contribute to research.

It is a living document. We will update it as guidelines from bodies like the National Health and Medical Research Council (NHMRC) evolve.

Seeking further advice

While this toolkit provides a foundation, the CHS Office of Research team can offer further support. Email 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.

Email chs.research@act.gov.au to contact the Director for templates, fact sheet examples, reflection logs, reimbursement procedures and evaluation plans.

Area	What the Director can do
Finding partners	Connect you with consumer and carer advocacy organisations (HCCA, Carers ACT, Mental Health Consumer Network) and individuals aligned with your project.
Partner selection	Advise on expression of interest and interview processes. Support partner selection decisions.
Planning	Advise on partnership goals, roles and scope. Help you work out what level of partnership fits your project and resources.
Remuneration	Advise on CHS remuneration and reimbursement rates and processes. Contact the CHS Office of Research team for templates and examples.
Training	Advise on internal and external training resources for researchers and consumer and carer partners, including cultural competency training.

Risk and conflict	Help identify common partnership risks and mitigations. Provide conflict resolution support.
Meetings	Help plan initial team meetings and ongoing collaboration logistics, including accessible venues and technology.
Evaluation	Advise on partnership reflection and evaluation approaches. Provide examples of reflection logs and evaluation plans.
Communications	Provide access to CHS Office of Research communication channels for sharing findings and updates.
Networking	Connect you with experienced CHS researchers for peer-to-peer learning.
Closure	Advise on formal acknowledgment, closure events and future collaboration planning.

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

Definitions

The following definitions are adapted from the CHS Partnering with Consumers and Carers Policy and the NHMRC's statement on consumer and community involvement in health and medical research.

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 who are potential users of the health service.
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.
Researcher	A person who conducts research.

Partner vs participant

In research, people may engage in two distinct roles: as a consumer and carer research partner, or as a research project participant.

A consumer and carer research partner provides insights, guidance and lived experience to shape research direction and outcomes. Their role may span the entire research process, from planning to dissemination.

A research project participant contributes data to a research study through methods like surveys or interviews. Their involvement is typically limited to data collection, with no role in shaping the study's design or outcomes.

Comparison

	Consumer and carer research partner	Research project participant
Role	Actively shapes the research agenda, design and dissemination.	Provides data or responses for research.
Engagement	High engagement, often involved throughout the research lifecycle.	Limited engagement, usually during data collection only.
Influence	Influences decisions on study design, methodologies and dissemination strategies.	Follows protocols set by researchers; no influence on research decisions.
Ethics	Does not usually require HREC approval, but involves best practices for respectful and meaningful engagement.	Requires HREC approval to protect participants' rights, privacy and safety.
Remuneration and reimbursement	Should receive remuneration for time, expertise and contributions. See the CHS Consumer, Carer, and Community Representative Reimbursement Procedure.	May receive reimbursement or incentives for expenses incurred.

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. 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 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.

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. This often includes carers, family members or other supporters. We respect and support their involvement in research partnerships. 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 level and scope

Consumer and carer research partnerships are about working with consumers and carers in the research process. These partnerships are grounded in mutual respect and should be built in from the start of any CHS research project.

The level and scope of any partnership will vary depending on the needs and preferences of everyone involved, available resources, and the project context.

Dimension 1: Levels of consumer and carer research partnerships

The IAP2 framework is commonly used to identify feasible levels of consumer and carer involvement in government contexts. This version, adapted from the CHS Partnering with Consumers and Carers Policy, has five levels:

1. **Inform:** consumers and carers receive accurate, timely and clear information about a CHS research project.
2. **Consult:** consumers and carers share their feedback on a CHS research project.
3. **Collaborate:** consumers and carers have a strong voice, actively contribute ideas, and play a key role in shaping decisions.
4. **Co-Design:** consumers and carers work as equal partners in deciding how a CHS research project is designed and run from the start.
5. **Empower:** consumers and carers take the lead in deciding how a CHS research project is designed and/or run.

Dimension 2: Research phases

The scope of a partnership can be mapped across five research phases:

1. **Discovery:** initial development of research ideas, themes and concepts.
2. **Design:** designing the research methodology.
3. **Conduct:** undertaking the research, such as data collection or analysis.
4. **Disseminate:** sharing research findings.
5. **Translate:** applying research findings into practice, policy or further research.

Applying both dimensions

Using these two dimensions together helps you determine the right partnership approach for your project. The key is to align the approach with the project's goals, resources and the needs of everyone involved.

A two-dimensional Consumer and Carer Research Partnership Spectrum follows on the next page. This toolkit (and broader CHS Office of Research services) offers flexible support for partnerships at all levels and scales.

Consumer and Carer Research Partnership Spectrum

Research phase	Inform	Consult	Collaborate	Co-Design	Empower
Discovery	Share upcoming research themes with consumers and carers.	Gather consumer and carer input on research priorities.	Determine research priorities together with consumers and carers.	Consumers and carers co-produce research priorities.	Consumers and carers lead the setting of research priorities.
Design	Share research plans and objectives with consumers and carers.	Seek consumers' and carers' opinions on research design.	Design research plans with consumers and carers.	Consumers and carers co-design research plans.	Consumers and carers lead the research design.
Conduct	Keep consumers and carers updated on research progress.	Consult consumers and carers on research activities.	Undertake research with consumers and carers.	Consumers and carers co-produce research.	Consumers and carers have the leading role in conducting the research.
Disseminate	Provide consumers and carers with findings to share in their networks.	Request consumer and carer input on how best to disseminate findings.	Author and present findings with consumers and carers at conferences.	Consumers and carers co-author and present findings at conferences.	Consumers and carers lead the dissemination of research findings.
Translate	Inform consumers and carers how research findings are being applied.	Consult with consumers and carers on applications of results.	Design applications of research findings with consumers and carers.	Consumers and carers co-design applications of research findings.	Consumers and carers drive the application of research into practice.

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.

Co-designed research embedded in care: Good Omen Goodeze, CHS

Good Omen Goodeze (GOG) is a Canberra charity that provides handcrafted comfort items, including sensory toys, blankets, eye masks and comfort pillows, to patients and families across Canberra Health Services (CHS) and the ACT Ambulance Service. A co-designed study (ETH00074) led by Kim Crook (University of Canberra), Mary Liondi-Barlow (GOG founder) and Leah Mathews (CHS Director of Consumer, Carer, and Community Partnerships in Research) is evaluating how consumers, carers and staff experience these non-pharmacological comfort interventions.

GOG worked as part of the research team to develop the research questions, recruitment approach and survey content. QR code tags attached to the comfort items allow consumers and staff to complete the survey at the point of care, providing real-time feedback about their experience. GOG champions across CHS services and ACT Ambulance support item distribution, creating around 5,000 opportunities each year for consumers and staff to engage with the study across Canberra Hospital, North Canberra Hospital, University of Canberra Hospital, Clare Holland House, all five Walk-in Centres and ACT Ambulance.

Consumer-led research priorities: ACACIA, ANU

ACACIA (the ACT Consumer and Carer Mental Health Research Unit at ANU) is led by researchers with lived experience as mental health consumers or carers. In 2018, the unit worked with consumers and carers to identify its research priorities through a face-to-face forum involving 25 participants, which generated 79 research topics grouped into 14 themes. These priorities were then validated and ranked through a national online survey completed by 70 respondents.

The consultation identified trauma-informed care as the highest-priority research area, despite it not being a major focus for researchers beforehand. By setting the agenda based on consumer and carer priorities, ACACIA established a clear and credible direction for its research program, leading to peer-reviewed publications and strengthening its ability to secure and maintain research funding.

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

Culturally governed clinical trial: INFERR

The INFERR trial (intravenous iron for First Nations haemodialysis patients) established two Indigenous Reference Groups (IRGs) of dialysis patients in the Top End and Central Australia. Communities advised that local cultural differences required two separate groups, not one. Supported by First Nations Research Officers, the IRGs shaped study materials, ensured culturally safe trial conduct and translated findings into culturally appropriate messages.

The partnership improved recruitment and retention among a population that standard trial approaches struggle to reach. First Nations consumers engaged because they felt respected, listened to and empowered to achieve change. The model demonstrated that culturally governed clinical trials produce better science and stronger community relationships.

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

Evaluated co-design in a cancer trial: RECAP, WEHI

The RECAP study (registry-generated personalised care plans for rectal cancer patients) involved six consumers working with four researchers to co-design a care plan giving patients accessible information about their diagnosis, treatment and follow-up. The partnership was formally evaluated using the Australian Clinical Trials Alliance (ACTA) consumer-involvement tool across seven domains.

The evaluation found consumer involvement was meaningful, respectful, inclusive and impactful. It also identified practical improvements needed around workload, communication and remuneration. One of the few formal Australian evaluations to both demonstrate and measure the value of consumer co-design in a clinical trial.

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

Community-led co-design: Nra:gi Ya:yun, Flinders University

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

The co-design produced a culturally grounded 28-week pilot (fresh meal boxes, continuous glucose monitoring, group yarning) that a researcher-designed study would not have achieved. The first co-designed, targeted diabetes remission program for Indigenous peoples on Ngarrindjeri Country. Published in Nature Medicine and BMJ Open; funded by NHMRC and MRFF.

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

These five steps give a high-level overview of how to establish and sustain consumer and carer research partnerships:

1. PREPARE

- Lay the foundations for partnering with consumers and carers in your research
- Identify and reach out to potential consumer and carer research partners

2. PLAN

- Collaboratively draft a partnership plan detailing goals and roles
- Agree on methods for collaboration and responsibilities

3. COLLABORATE

- Facilitate inclusive conversations throughout the project's lifecycle
- Actively involve all voices in decision-making; address barriers to participation

4. ENHANCE

- Reflect on the partnership's progress and improve continuously
- Recognise consumer and carer partners' contributions and champion partnerships

5. CONCLUDE

- Appreciate and communicate the efforts and achievements of everyone involved
- Officially end the partnership

The specific actions at each step will vary based on the level of consumer and carer engagement and the scope and requirements of your project. Many of the actions can be built into broader project planning activities.

The CHS Office of Research team can support all steps.

Step 1: Preparing for a consumer and carer research partnership

Preparation is the first step toward a successful partnership. This step focuses on building a strong foundation by reviewing past collaborations, defining objectives and identifying suitable consumer and carer partners.

Explore past efforts

Start by finding out whether there have been any previous consumer and carer research partnerships in your research area. Published literature on consumer and carer research priorities may also be available in your field. These can be a starting point for local discussions, even if they don't directly match your project.

Recognising and valuing past research engagement:

- shows commitment to learning from past experiences, which builds trust and respect
- provides continuity in community engagement by building on existing relationships and knowledge
- helps identify areas that may have been overlooked or need further exploration

Determine purpose, level and available resources

When starting a partnership, define its purpose. Consumer and carer partnerships can serve many purposes: making studies more relevant by bringing in diverse perspectives, improving research quality through consumer and carer input, or strengthening ethics and governance. Your specific purpose will guide partner selection and the level of their involvement.

Consider why consumers and carers want to partner with you. They might want to influence research that affects their communities, make sure the research addresses issues they care about, gain a sense of involvement in the scientific process, or improve personal and community health outcomes. Recognising these motivations helps build stronger partnerships.

The Consumer and Carer Research Partnership Spectrum (page 14) provides a framework for categorising the extent and nature of partnerships. At CHS, different projects will naturally align with different levels. When determining the level, consider available resources: funding for engagement activities, access to consumer and carer support services, and any time constraints.

There is no one-size-fits-all approach. If you're starting out, beginning at the 'Collaborate' level can feel more manageable. This lets you build rapport, develop your partnership skills, and become familiar with the process.

Determining consumer and carer research partners

Who you approach depends on the research topic and the partnership's intended goals. For research requiring extensive collaboration, you may want people with personal experience of the health condition under study or who frequently use the health service being examined.

If the goal is to gather feedback on informational materials such as consent forms, specific health condition experience may be less critical. A broader consumer and carer perspective might be sufficient to make sure materials are clear and understandable.

Consider the barriers consumers and carers face. People living with mobility difficulties may encounter logistical challenges such as transport issues and personal health impacts. Many carers face time constraints due to care responsibilities, financial limitations and limited access to respite, as well as privacy concerns and lack of clarity about their role. Discuss how you can support partners to overcome these barriers with consumer and carer advocacy organisations or the CHS Office of Research team (chs.research@act.gov.au).

Approaching and interviewing consumer and carer research partners

When reaching out to potential partners, provide details of the research project. Offer a plain English draft of the research questions or project description, objectives and timelines. This helps prospective partners understand the scope. Project 'fact sheets' can be particularly effective for conveying this information accessibly. The CHS Office of Research team has examples of previous research project fact sheets (chs.research@act.gov.au).

For some projects, you may want to run a formal expression of interest (EOI) and interview process.

Selecting your consumer and carer research partner(s)

Selecting your partner(s) is about forming a respectful, equal relationship, not filling a role. Lived and living experience brings valuable insights, and partners should feel supported, heard and included from the beginning.

When deciding, consider:

- whose experience best connects with the focus of your research
- who shows interest and confidence in contributing
- whether the partnership feels like a good fit for open, honest, two-way communication
- what support your team can offer to help the partner feel safe, valued and involved

If more than one person is suitable, you might involve others in different ways now or in future projects. Let all applicants know the outcome. Thank them for their time and offer to stay connected.

Step 2: Planning for your consumer and carer research partnership

The planning stage turns the concept of a partnership into a detailed and practical plan. This step covers partnership goals, roles, training for you and your partners, and communication. You can do this planning as part of the overarching project plan.

Partnership goals, objectives and milestones

Define specific partnership goals and objectives and set milestones to track both the research project and the partnership itself. This keeps everyone aligned and connects individual efforts to the project's overall aims.

You can integrate this into the overarching project plan or create a standalone document.

Roles, responsibilities, support and remuneration

Define the roles and responsibilities of everyone involved: researchers, consumer and carer partners, and supporting CHS staff and advocacy organisations. Clear role definitions prevent overlaps and gaps. Each role should be covered in the project plan, including contribution to decision-making, participation in meetings and shared decision-making, participation in meetings, and contributions to research design and delivery.

Identify and provide access to support structures for your consumer and carer partners. This includes ICT resources, emotional and cultural support, administrative support, and referrals to consumer and carer support organisations.

Establish a remuneration and reimbursement schedule for the project. This recognises the value of consumer and carer partners' contributions. The CHS Consumer, Carer, and Community Representative Reimbursement Procedure is available from the CHS Office of Research team.

Orientation and training

A well-planned orientation helps create a safe, accessible and inclusive partnership where researchers and consumer and carer partners can contribute equally. The orientation should cover CHS policies, specific aspects of the research project and the broader context of health research.

Internal and external training resources are available from the CHS Office of Research team. For some projects, consider relevant cultural competency training to help all team members understand diverse cultural and contextual backgrounds.

Risk management

Develop a consumer and carer research partnership risk matrix that identifies potential challenges (such as misunderstandings, delays or conflicts) and strategies for managing them. You can integrate this into the project's risk matrix or create a standalone document. The Director can help identify common challenges and mitigations to get you started.

Communication, feedback and evaluation

Create a communication plan to maintain open and consistent channels between all team members. Include regular updates, meetings and feedback mechanisms. Actively engage consumer and carer partners in the feedback process so their insights influence decisions and project direction. CHS Office of Research has a communications expert who can assist.

Plan for periodic evaluations of the partnership. These might consider the impact of consumer and carer involvement on research outcomes, partner satisfaction and progress toward goals. Evaluations help you make adjustments and improve the overall collaboration. The CHS Office of Research team has examples of partnership communication and evaluation plans (chs.research@act.gov.au).

Step 3: Working together in partnership

This step focuses on collaboration through clear communication, mutual respect and shared objectives. This approach lets your team draw on each member's strengths and sustain an effective partnership.

Initial team meeting and project introduction

Host an initial meeting with all project team members, including consumer and carer partners, to set the tone for collaboration. Introduce everyone and build a sense of unity and shared purpose.

Present the research idea or plan, outlining aims, goals and expected impacts. This aligns everyone's understanding of the project's scope and significance.

Invite consumer and carer partners to ask questions and provide feedback and ask how they'd like to offer ongoing feedback. This clarifies expectations and brings consumer and carer perspectives into the research from the outset.

Collaboration and meeting logistics

Set up a regular schedule for collaborative sessions that aligns with the project plan. Consistency keeps all team members engaged and informed.

Make logistical arrangements considerate of everyone's needs. Choose accessible locations and make sure the necessary technology is available for effective communication, especially for consumer and carer partners who may have different requirements or preferences. The Director can share resources to assist.

Role clarification, expectations and conflict resolution

As the project progresses, continue to clarify roles and responsibilities for each team member, including consumer and carer partners. Clear roles prevent overlaps and confusion.

Promote transparency around time commitments, preferred communication methods and options for resolving conflicts. Regularly review confidentiality agreements and ethical guidelines so all team members remain informed and compliant.

Step 4: Enhancing your consumer and carer research partnership

Enhancement requires ongoing reflection, learning and advocacy. This step focuses on refining the partnership's effectiveness and expanding its impact through regular reviews and sharing successes.

Reflect on progress regularly

Organise periodic reflection sessions with the entire team, including consumer and carer partners. During these sessions, evaluate how effectively the partnership is meeting its goals.

Use these sessions to review progress, discuss challenges and celebrate successes. Identify where the partnership could improve, whether that's communication strategies or more inclusive decision-making.

Keep a 'live' partnership reflection log

Develop a centralised, accessible log to document the partnership's ongoing progress and experiences. All team members should be able to access it, and it should serve as a transparent record of the partnership's journey.

Use the log to record successful strategies, document issues or challenges encountered, and note the strategies used to address them. It should be a living document that informs ongoing improvements and supports continuous learning.

Expand partnership networks

CHS researchers are encouraged to seek out opportunities to share and learn from peers. This could start with knowledge-sharing sessions such as workshops where researchers present case studies, share best practices and discuss challenges and successes. CHS Office of Research will provide details of relevant events and initiatives via the CHS Office of Research Newsletter and chs.research@act.gov.au.

Step 5: Concluding your consumer and carer research partnership

The conclusion of a partnership is a chance to recognise contributions, share findings and consider future partnerships. It is also a chance to celebrate what was achieved.

Formal acknowledgment of contributions

As your project or project phase reaches its conclusion, recognise the impact consumer and carer partners have had on the project's success. This may include acknowledging them in interim or final project reports, presentations or publications, in line with authorship guidelines and any prior agreements.

If a consumer or carer partner decides to step back before the project ends, or if a project concludes prematurely, still acknowledge their contributions. Express appreciation for their involvement regardless of the project's duration or outcome.

Share research findings and outcomes

Share the project's initial findings, outcomes and the potential applications of results with consumer and carer partners. Continue to provide updates on any developments, follow-up projects or subsequent applications of the research. Keeping partners informed reinforces the ongoing value of their contributions.

Plan for future collaboration

Discuss potential future collaborations and opportunities for consumer and carer partners to stay involved in research or in an advisory capacity. Talk about upcoming projects or areas of mutual interest. Encourage partners to stay engaged and consider their potential role in future work.

Formal closure (planned and unplanned)

Whether the conclusion is planned or unplanned, consider marking the end with a formal meeting or celebration. This serves as recognition of the partnership's achievements and the collective effort of the team.

Take the opportunity to reflect on accomplishments and the positive impact the partnership brought to the research. Sharing these reflections can offer useful insights for both ongoing and future collaborations. The CHS Office of Research team has examples of project closure activities (chs.research@act.gov.au).

Additional tips and hints

Ethics and partnering with consumers and carers in research

Engaging consumer and carer partners in projects does not usually require an ethical review, but it does require careful consideration in the Human Research Ethics Application (HREA). Detail consumers' and carers' roles, whether as co-investigators or working group members, within the HREA.

The National Statement on Ethical Conduct in Human Research advises undertaking and documenting evidence of consumer consultation during the discovery, planning and design stages of research projects.

Completing the HREA (general advice)

- Define the partnership's scope, detailing consumer and carer contributions and their expected impact on the research.
- For consumer and carer partners who are integral to the research team, list them as co-investigators in the HREA. Describe their roles, responsibilities and contributions explicitly.
- For less frequent or task-specific contributions (such as input on design), consumers and carers might not be listed as co-investigators. Acknowledge their input in the project's documentation as best practice.
- Consumers and carers on the research team typically should not be research participants, to avoid conflicts of interest. If their participation is vital, establish clear processes to mitigate potential conflicts and biases.
- Reference the measures in place to protect the privacy and confidentiality of consumer and carer partners, especially when they share sensitive information.
- Outline the training and support provided to consumer and carer partners, and mention any ongoing support, mentorship and resources available.

Grant applications and partnering with consumers and carers in research

Including consumers and carers as partners in grant applications strengthens the application and makes sure consumer perspectives are integrated from the start.

Key considerations

If consumers and carers are integral to the research team and involved throughout the project, list them as co-investigators in the grant application. This acknowledges their role and contribution.

If consumer and carer involvement is more ad-hoc (such as providing feedback on certain aspects), list their contributions in the relevant sections of the application.

Detailing partnerships in applications

- Outline the role and contributions of consumer and carer partners clearly. Explain how their involvement will enrich the research.
- Detail any support or training provided to enable their effective participation.
- Highlight the expertise and perspectives that consumers and carers bring to the project.

Tips for grant applications (general advice)

- Involve consumer and carer partners from the early stages of preparing the application to integrate their input throughout.
- If consumer and carer input is urgent, make sure partners understand the reason for the urgency and are well supported to meet the deadline.
- Maintain open communication so partners understand the grant application process and their role in it.
- Build in a mechanism for ongoing feedback and refinement of the application in collaboration with consumer and carer partners.

Authorship and partnering with consumers and carers in research

When collaborating with consumer and carer partners, acknowledge their significant role in the research process and the potential authorship of resulting publications (if they meet the criteria below).

Defining consumer and carer authorship in research

Consumer authors are people with personal experience related to your 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 for consumer and carer research partners

Consumer and carer partners should make an intellectual or scholarly contribution to the research and its output. This includes contributions to the conception or design of the work, or the acquisition, analysis, or interpretation of data.

While authorship conventions vary across disciplines, a significant intellectual or scholarly contribution must include one, and should include a combination of two or more, of the following:

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

They 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 incorporating consumer and carer partners as authors

- Start discussions about authorship at the project's outset so contributions are considered from the beginning.
- Follow established authorship criteria: substantial involvement in conception, design, data collection, analysis and interpretation. Align consumer and carer partners' roles with these standards.
- Maintain transparent documentation of consumer and carer partners' contributions throughout the project: study design, data collection, analysis and other relevant activities.
- Recognise that consumer and carer partners may not be familiar with the publication process. Offer guidance on peer review, manuscript preparation and any questions they may have.

- Acknowledge the perspectives that consumer and carer partners bring, shaped by personal experience and insights, which can strengthen the study's outcomes and relevance.

Acknowledge contributions other than authorship

Recognising consumer and carer contributions to research, even when these don't meet formal authorship criteria, matters. Consumer and carer contributions can offer insights and perspectives that enrich the research process. Acknowledge their input in a way that reflects their impact on the project.

When publishing knowledge of First Nations consumers and carers, researchers should ideally obtain consent from both the consumers and carers involved and the community of origin. Both individual and collective contributors should receive appropriate recognition. Researchers should secure consent from named contributors before acknowledging them in research outputs, as acknowledgements might imply endorsement of the findings.

Reimbursement and/or remuneration

Recognising the time, expertise and lived experience that consumers and carers bring to research is central to ethical and respectful partnering. At CHS, the CHS Consumer, Carer, and Community Representative Reimbursement Procedure is the primary guide. Read this section alongside that Procedure.

Key points

- Reimbursement covers out-of-pocket costs such as travel, parking, childcare or communication expenses. No consumer or carer should be financially disadvantaged by contributing.
- Remuneration acknowledges the value of a consumer or carer's contribution: payment for time in meetings, reviewing documents or co-designing aspects of the research.
- Some grant schemes (such as NHMRC, MRFF) expect consumer and carer involvement to be funded at transparent and fair rates. Check specific funding body requirements.
- Rates should reflect the type and depth of involvement. Attending a single consultation may be remunerated differently to ongoing advisory or governance roles.

When budgets are limited

- Early involvement may occur before funding is secured. Be transparent with consumer and carer partners about what is possible.
- Consider non-financial recognition: authorship, professional development opportunities, letters of appreciation or invitations to events.
- Some advocacy groups (such as HCCA, Carers ACT, Health Consumers NSW/Queensland) can provide support or advice on acknowledging contributions fairly in low-resource contexts.
- Once funding is obtained, include consumer and carer partners in the budget as a priority item. Where possible, consider back-pay arrangements if agreed upfront.

Practical advice

- Build reimbursement and/or remuneration into all project budgets from the beginning, even small amounts.
- Provide clear and accessible information about when and how payments will occur.
- Offer multiple payment methods to reduce barriers (such as EFT, vouchers).
- Be mindful that some payments may affect income support entitlements. Provide partners with information so they can make informed choices.

Writing plain English health research materials

Writing health research materials in plain English makes sure that research information is clear, accessible and understandable for all readers, including consumers, families, carers and the broader community.

Plain English: governing principles

ISO 24495-1:2023 sets four principles for creating plain language documents. It applies to a wide range of documents including research materials (excluding consent documents). It is relevant for most written languages but provides examples only in English.

Principle	Practice
Relevance	Understand your readers' needs before drafting. Identify their characteristics (literacy, language skills, cultural background), purpose (following instructions, making decisions, learning), and reading context (where, how, under what conditions). Select the document type that best fits readers' needs. Make sure content is relevant, accurate and not misleading.
Findability	Structure the document so readers can quickly determine its purpose. Group related information together and order it logically. Use visual cues to make important elements prominent. Use clear headings to help readers predict what comes next.
Understandability	Use familiar words and clear, concise sentences. Avoid jargon and complex words; use active language and simple sentence structures. Write concise sentences and focused paragraphs. Include images and multimedia to aid understanding. Maintain a respectful and appropriate tone.
Usability	Evaluate the document continuously during development. Test it with actual readers. Review and update regularly based on feedback.

Misconceptions about plain English

- It doesn't mean patronising language or writing like 'cat sat on the mat'.
- It doesn't mean reducing message length or altering meanings. Complex documents can still be clear.
- It isn't easy. It requires effort to avoid bureaucratic, inefficient and unfriendly writing.

Techniques for writing in plain English

- Keep sentences short: aim for 15–20 words. This makes information easier to process.
- Use everyday language. For example, use 'doctor' instead of 'physician' and 'start' instead of 'commence'.
- Use pronouns like 'you' and 'we' to make the text more relatable.
- Use positive language where possible. Instead of 'Do not forget', say 'Remember'.
- Use examples and analogies to explain complex ideas.
- Include charts, diagrams and images to support the text.

Steps to implement plain English

- Understand who will read the information. Tailor the language and content to their needs and knowledge level.
- Write the first draft focusing on clarity and simplicity. Don't worry about length at this stage.
- Review the draft against plain English principles. Edit for clarity, conciseness and readability.
- Use readability tools to check the reading level. Aim for around grade 8 or 9.
- Test the material with a sample of the target audience. Gather feedback and make adjustments.