



Clinical Research Rehabilitation and Translation Research Group

Community Partnership Group

Terms of Reference 20 February 2025

Purpose of the Community Partnership Group

The purpose of the group is to improve the priorities and the conduct of meaningful, important research, by providing advice as part of the research team. We do better research when we work together. Research is much better at improving outcomes for people with health issues when it is informed by people with lived experience, their families or carers. When we design studies together those studies will be better designed and translate better into practice and better outcomes. When research tools and core domains for clinical trials research are co-designed with our community partners they better capture aspects of key concerns to community.

To quote the NHMRC “Consumers and community members can be actively involved throughout the research journey, and this can lead to quality research that meets the needs of the community and promotes the translation of research into improved policy and practice. However, it is important that involvement of consumers and community is not done in a way that is tokenistic but rather is an active partnership that benefits all.

NHMRC: Involvement of consumers and community should be in a minimum of four key phases:

1. Determining research priorities including deciding what to research
2. Development of research concept or question and design of research projects including consideration of partners, methodology and processes and budget development including cost of consumer/community involvement
3. Research including participant recruitment, consent and responsibility (ethics, governance) and oversight or governance of the conduct of the research
4. Reporting, communications and publication (including translation). This could include implementation strategies/activities or identification of subsequent research required.” NHMRC 2016

In this way our Community Partnership Group will advise on 1) what is important, 2) improvements to studies, 3) how best to work with participants, 4) how best to communicate our research and findings.

The Community Partnership Group formed in 2024 to co-design research with the Clinical Research Rehabilitation and Translation group, and is now funded for two more years (2025, 2026).

“Clinical Research Rehabilitation and Translation Research Group” is a group of academic researchers at University of Canberra. This research group has sponsors the Community Partnerships group.

The Clinical Research Rehabilitation and Translation Research group is supported by the Faculty of Health Research Committee, of University of Canberra. We aim to improve clinical care and health outcomes, to work

with clinical partners on matters of importance, to work with community members for setting priorities and for consumer co-design of research activities. We will walk with First Nations people to assist them in their research priority areas. We will conduct research that is clinician, community, academic or co-initiated where it investigates improving health outcomes, improving health services or improving translation of evidence into practice.

Clinical Research may take place in acute care, rehabilitation or primary care. Rehabilitation from illness and injury helps people live better with chronic illness and emerging new challenges like Long COVID. Translation is making sure the best evidence translates into the best care.

Researchers: Professors Jennie Scarvell and Bernie Bissett, Associate Professors Mei Ying Boon, Elisabeth Preston, Faran Sabeti and Jeroen van Boxtel and Assistant Professors Irmina Nahon, Mary Bushell, Allyson Flynn, Tayne Ryall, Macey Barratt, Jaya Sidareddy. Our affiliates include academic staff Phil Kavanagh, Angie Fearon, Jaqueline Bousie, Vicki Evans, clinical partners and carers.

Collaborations: we have established productive collaborations with UC Student-Led Clinic, Vision ACTION, Trauma and Orthopaedics Research Unit at Canberra Hospital and Long Covid group, Vision testing implementation and Rehabilitation Robotics at University of Canberra Hospital.

Members

Members of the Community Partnership Group may have lived experience of a health issue or be family or a carer of someone with lived experience of a health issue. The health issue may have been short-term and managed quickly or be an ongoing health issue that has been more 'living my best life with this condition'. Members may live in Canberra or the surrounds. They will be over 18 years of age. People with lived experience may be invited to participate for the discussion of particular health issues as requested by the community group.

In 2025-6 the group will be co-chaired by an academic member (Dr Vicki Evans) and a community member. The Community Partnership Group will include 5-8 community members and two research group members. Support will be provided by the academic research group. Members of the academic research group will be called upon to provide training, information, present research projects and ask questions of the Community Partnership Group.

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Role of members

Members will be active in three ways

1. Participating in three Community Partnership Group meetings per year and the activities related to the group, for example read papers before meetings and attend training provided (all)
2. Participating in providing advice or joining research teams to plan, design, or conduct projects (on an individual basis, by negotiation).
3. In evaluation of the work of the community group.

Members will be provided with a mentor, training, and reimbursement.

Remuneration of members: according to ACT Health Schedule for consumer reimbursement

Terms of membership: January 2025 to December 2026, with an opportunity to renew.

Conflicts of Interest (COI): will be recorded when members join and mentioned when COI arise during activities. How the COI is managed depends on the nature of the conflict (financial, privacy, relationships).

Mentoring and training for members

Part of each meeting will be developing the group members' knowledge, skills, and understanding of members roles and research itself. There will be a mentor research academic for each community member.

In addition, if needed, there is training provided online via the following groups:

- Health Care Consumers Association NSW Health Consumers online and face to face,
- Cancer Council. Consumers in Research training. 4 online modules. <https://www.cancer.org.au/online-resources/elearning/consumers-in-research-training>
- Health Consumers NSW Consumer training events mid 2024. <https://hcnsw.org.au/training-resources/training-courses/training-researchers-and-consumers-in-research/>
- West Australian Consumer Involvement Network <https://cciprogram.org/community-involvement/#training>
- Dr Mary Dahm, ANU Introduction to Consumers participating in research. <https://www.youtube.com/watch?v=HFna8SWTYoA>

Review plan for Terms of Reference. The group will have three meetings in 2024, and the group may reflect on the start of the group, or review the Terms of Reference in 2025, if the Academic research group is endorsed to continue 2025-2026.

Further information:

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References

NHMRC. Expectations and Value - Framework for Effective Consumer and Community Engagement in Research. 2016.

<https://www.nhmrc.gov.au/sites/default/files/documents/attachments/Consumer%20Community%20Engagement/Expectations-and-Value.pdf>