## **Clinical Research Rehabilitation and Translation Research Group**

## **Community Partnership Group**

# ****Terms of Reference 5 February 2024****

**Clinical Research Rehabilitation and Translation Research Group is a group of UC academics who team-up with communities, clinical partners and health providers to improve health outcomes for people in the Canberra region and beyond. This group is endorsed 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.**

**Our first theme is Clinical Research, and settings for the research may be acute care, rehabilitation or primary care. Our second theme is Rehabilitation from illness and injury and living better with chronic illness and emerging new challenges like Long COVID. Rehabilitation is defined as “a set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment” (WHO). Our third theme is Translation, which is making sure best evidence is provided in care.**

Our people: our core members are 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 and Tayne Ryall. 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 (CHS) and Long Covid group (UCH). Soon Rehabilitation Robotics (UCH) will launch as a fourth. These have attracted funding, successfully supervised students and been published in high impact journals. We have a strong track record supervising students and generating research outputs from the Student Led Clinic, for example in Parkinson’s Disease.

## 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. We know when we design studies together that the 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.

**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.

The Community Partnership Group will be chaired by a community member and include 3-6 community members and two research group members. Support will be provided by the research group. Members of the research group will be called upon to provide training, information, present research projects and ask questions of the Community Partnership Group.

**Role of members**

Members will be active in two 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).

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

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

**Terms of membership:** up to Dec 2024, but may be extended.

**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 [(1 March 2024),](https://www.hcca.org.au/events-and-training/events/) 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>

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