

Consumer and community involvement in COVID-19 research

Ben Horgan and Briony Williams
HCC Consumer Representative Drop in | Friday 17th April 2020

Acknowledgement of Country

I would like to acknowledge the traditional custodians throughout Western Australian and their continuing connection to the land, water and community.

I would like to pay my respects to all members of the Aboriginal communities and their culture, and to Elders past and present.

Outline

- About us
- What is involvement
- Why it's important
- COVID-19 Research Grants Program
- CCHRN's response
- Community training

The Western Australian Health Translation Network (WAHTN)

- A state-wide collaborative network of WA's universities, medical research institutes, health care service providers and the Health Department.
 - Allied Health Enabling Platform
 - Australian National Phenome Centre (ANPC)
 - Biobanking
 - Clinical Trials & Data Management Centre (CTDMC)
 - **Consumer & Community Health Research Network (CCHRN)**
 - Health Economics
 - Research Education & Training (RET) Program



<https://www.wahtn.org/>

Consumer and Community Health Research Network (CCHRN)

CCHRN supports consumers, community members and researchers to work in partnership to make decisions about health research priorities, policy and practice.

We improve lives by ensuring the community's voice is heard and understood in health research

We enable involvement in health research by supporting and connecting community with researchers, partners and policy makers

<https://www.youtube.com/watch?v=oaACJ1nL6Yo&feature=youtu.be>

Definitions¹

- **Consumer** – patients and potential patients, carers and people who use health care services.
- **Consumer representative** – someone who voices consumer perspectives and takes part in the decision-making process on behalf of consumers.
- **Community** – a group of people sharing a common interest (e.g. cultural, social, political, health, economic interests) but not necessarily a particular geographic association.
- **Community member** – a member of a community

1. Statement on Consumer and Community involvement in Health and Medical Research, National Health and Medical Research Council (2016), Consumers Health Forum of Australia.

What is involvement?

- Consumer and community involvement is about research being carried out **with or by** consumers and community members rather than to, about or for them.
- Involvement is where consumers and community members actively work with researchers and research organisations to help shape decision about health research, priorities, policy and practice.



Why it's important²

Consumers and community members:

- Have a lived experience of what it's like to have a particular disease, illness or health condition
- Have the knowledge and experience of living in a particular community
- Provide researchers with an alternative view
- Have an interest in turning research findings into improved policy and practice
- Have a right to be involved in the research process

Why it's important²

Involving consumers and community members can:

- Research that is relevant to the needs of consumers and community
- Improve health outcomes by fast tracking research findings



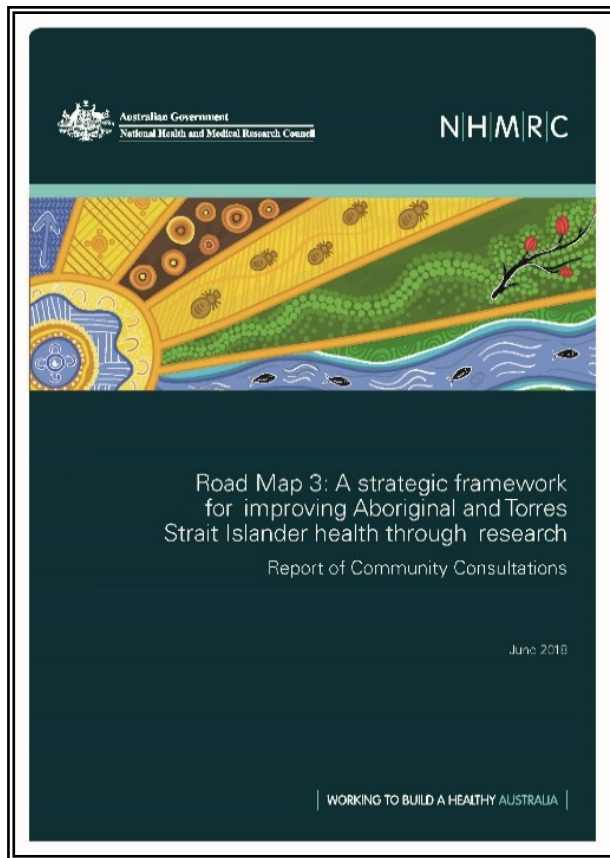
2. Consumer Involvement & Engagement Toolkit, Australian Clinical Trials Alliance (2019)

Human Research Ethics Committees

- It is a requirement for Human Research Ethics Committees to include 'lay' people
 - One male and one female, who have no affiliation with the institution and do not engage in medical, scientific, legal or academic work
- It is a requirement for Animal Research Ethics Committees to include 'lay' people
 - Some one who has never engaged in animal experimentation



Aboriginal and Torres Strait Islander research



Funding requirement



Government of **Western Australia**
Department of **Health**



Australian Government
Cancer Australia

COVID-19 Research Grants Program

- Established by the WA Department of Health (in conjunction with WAHTN)
- Funding high-quality COVID-19 related research projects that have the potential to be translated into improved policy and/or practice across the WA public health system
 - Impact 40% (Significance, Partnerships, Research Translation)
 - Methods 30% (Innovation, Research Plan)
 - Capability 30% (Budget, Capacity, Consumer Involvement)

Describe how consumers have been involved in the development of the research proposal and the plan for ongoing engagement during the study.

- The WA Health Department, through the guidance of CCHRN, has included questions in their recent \$3million research fund around how the research will include the Community to inform their work
- Successful grants expected to be announced end of April

CCHRN's response

- Call out for community members to join a COVID-19 Community Representative Pool – ready to assist with requests for support from researchers applying to for the Research Grant Program

75+ applications from community members to join the Pool

20+ research projects linked with community members – watch this space!

- CCHRN is leading WA's COVID-19 research Consumer and Community Involvement strategy
- Our website is updated regularly with the latest information and opportunities to be involved:

<https://www.involvingpeopleinresearch.org.au/>

Community training workshop

- Will run in early May via Zoom
 - Introduction to consumer and community involvement
 - COVID-19 research update – successful projects
 - Tools and tips to be an effective Community Representative
 - Other opportunities to be involved

Join our Network!

<https://www.involvingpeopleinresearch.org.au/join-our-network/>

Questions?



Contact information

Consumer and Community Involvement (CCI) Program Coordinator:

Briony Williams

0428 967 833

briony.Williams@uwa.edu.au



www.InvolvingPeopleInResearch.org.au



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