

A stylized illustration of a diverse group of people in various poses and outfits, rendered in shades of orange and brown. The people are arranged in several rows, with some waving or gesturing. The background is white.

The National Health and Medical Research Council & Consumers Health Forum of Australia

Review of the Statement on Consumer and Community Involvement in Health and Medical Research (2016)

**Anne McKenzie AM
November 2022**

1999: Wills Strategic Review of Health & Medical Research



2002: Joint NHMRC/CHF Statement published



2005: Joint NHMRC/CHF Framework published



2016: Joint NHMRC/CHF reviewed and published

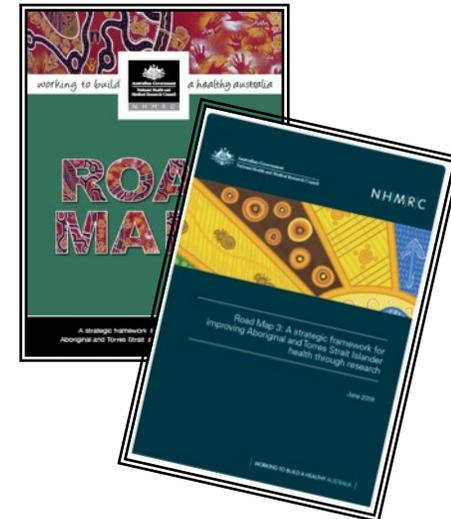
My journey with the NHMRC / CHF 'Statement'

2004: UWA & Telethon Kids Institute Involvement Program



2007-2009: Training developed for consumers & researchers

2002-2018: NHMRC Road Maps 11 & 111



Principles, Guidelines, Position Statements, Frameworks, Core Values



- National Health and Medical Research Council & Consumers Health Forum
- Medical Research Futures Fund (under development)
- Cancer Australia's Framework
- WA Health Translation Network
- Australian Health research Alliance & Consumers Health forum
- Australian Clinical Trials Alliance
- Victorian Comprehensive Cancer Centre Alliance
- Australian Genomics (under development)
- +++++



- World Health Organisation
- International Association for Public Participation
- National Institute for Health Research (UK)
- Canadian Institute for Health Research Research
- Patient Centered Outcome Research Institute (USA)

Conclusion: we are great at 'Reinventing Wheels'



Value Partnerships Feedback Trust
Accountability Plain stages Training Involved Equal
Information all Honesty Inclusion
together sharing Valued Responsible
Equitable organisations accessible outcomes Emotional
influences Transparency decision self
Impact Clear Cultural Right Respect Active
decision-making contribution Seeks Attitudes affected Recognises
Clarity perspectives action Sustainability
making Inclusive
Confirmed building start Diverse commitment language decisions
input learning Contributions Included needs consumers flexibility
Resourced Diversity equity Democratic Adds beginning Working
Meaningful Skill relationships roles Mutual
Values involvement Capacity Governance
Acknowledged Power Accomplished
determination Communication Leadership
Resources Recognition

A changing landscape

What's working well

Increased commitment from funding bodies

More awareness of the value of involvement

Greater opportunities for consumers / community members

Organisations established to support increased involvement

Increased positions to support involvement

What's not working so well

Lack of single statement / guidance from funders

No criteria to assess involvement activities in grant applications

Lack of guidance on budgets for involvement

No single place to access support or training

Remains an 'optional extra' for some

My thoughts on what is needed next

- Wide consultation with consumers, community members, researchers, research organisations, funders, ethics committees to ensure diverse views are captured
- A national statement of core high-level principles to include:
 - Principles
 - Expectations / requirements from funders
 - Roles and responsibility statements for all
- Principles to be underpinned with a commitment to:
 - Supporting effective partnerships between the community and researchers
 - Requiring involvement activities being planned and implemented in all types research

Suggested elements for principles

- **Effective involvement** of consumer and community members in decision-making
- **Trust and respect** for all parties
- **Equitable partnerships** where consumer/community expertise is included and valued
- **Communication and information** that is easily accessible and understandable
- **Accountability and transparency** with research outcomes reported to community
- **Adding value** to research with consumer and community involvement
- **Diversity** of consumers and community members being involved
- **Involvement** of consumers/community members from the start

Implementation – have a plan

- Address support/training needs for consumers/community members and researchers
- Consumer / community members to become full members of grant review panels
- Criteria for assessment of involvement activities in grant review panels
- Consumer / community involvement activities to be included in overall score for grant applications
- Question in HREC applications about how the consumers and community members have been/will be involved in the research in
- Provide guidance and line-item in grant applications for involvement budgets

Other important points to consider

- Implement good practice examples already established i.e., Aboriginal and Torres Strait Islander communities, Cancer Australia
- Look to other countries where consumer and community involvement is integrated into normal practice and a requirement of funding i.e., the UK and Canada

Limit the wheels



The elephant in the (virtual) room

‘Terminology’ - consumers, community members, clients, patients, members of the public, citizens, survivors, people with lived experience

How to address people - requires respectful, mutual decisions between consumers, community members researchers, research organisations and funding bodies

Terminology should not ‘highjack’ the aim of increasing the consumer/community ‘voice’ in research. We all need to stay on message - ‘consumers add value to research’

Thank You