



The Telethon Institute for Child Health Research

Consumer and Community Participation Policy

Aim

The Telethon Institute for Child Health Research (TICHR) recognises the central role of health consumers and community members in its research. Our aim is to develop partnerships in which consumers, community members and researchers work together to make decisions about research priorities, goals, methodologies, questions, and dissemination of results.

This aim is aligned with the National Health and Medical Research Council (NHMRC) and Consumers' Health Forum of Australia (CHF) joint Statement on Consumer and Community Participation in Health and Medical Research.

Scope

This policy covers all research undertaken at TICHR. It is acknowledged that each research project is unique and there will be varying levels of consumer and community participation depending on the research project.

This policy is complementary to the policy on Participating in Research at the Institute.

Definitions

The NHMRC / CHF Statement define consumers as:

- Patients and potential patients
- Carers
- Organisations representing consumers' interests
- Members of the public who are targets of health promotion programs
- Groups asking for research because they believe that they have been exposed to potentially harmful circumstances, products or services.

The NHMRC / CHF Statement define community as:

- a group of people sharing a common interest – for example, cultural, social, political, health, economic interests – but not necessarily a particular geographical association.

Principles

- Consumers and the community will be acknowledged as a key stakeholder in all research undertaken at TICHR.
- Consumers, the community and researchers will work together to add value to research at TICHR.
- Partnerships between consumers, the community and researchers will be based on mutual respect for one another's different knowledge and experience.
- Partnership roles will be decided by consultation between consumers, community and researchers.
- Consumers and community members will be provided with all information related to fulfilling these roles.
- Consumers and community members will be required to comply with TICHR's policies on Privacy and Intellectual Property.
- Consumers and community members will be remunerated for the contributions they make to the partnership.
- Consumer and community participation, and TICHR's support for participation will be evaluated in consultation with consumers, community members and researchers, and made available to the public

Governance and Ethics

- A Consumer and Community Advisory Council will be established and supported by the Consumer Research Liaison Officer.
- The Consumer Research Liaison Officer will provide regular reports on the activities of the Council to the Director and the Board of TICHHR.
- Consumer and Community Advisory Council Membership and Terms of Reference will be decided by consultation between consumer and community representatives and TICHHR.

Benefits

The establishment of effective partnerships between consumers, the community and researchers will:

- Add value to evidence based research at TICHHR.
- Facilitate and enhance understanding of consumer and community priorities, perspectives and issues.
- Enhance the planning, conduct and analysis of TICHHR's research programs.
- Enhance the dissemination of research findings and increase translation into policy and practice.
- Provide increased opportunities to obtain funding for research which addresses the needs and priorities of the community.

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