



Consumer & Community Involvement in Health Research

POSITION STATEMENT



Consumer and Community Involvement in Health Research

The Australian Health Research Alliance (AHRA) comprises seven Advanced Health Research and Translation Centres (AHRTCs) and three Centres for Innovation in Regional Health (CIRHs), accredited by Australia's National Health and Medical Research Council (NHMRC) as leaders in translating research for better health outcomes.

The Consumers Health Forum (CHF) is the national peak body representing the interests of Australian healthcare consumers, working to achieve safe, quality, timely healthcare for all Australians supported by accessible health information and systems.

AHRA commits to strengthening consumer and community involvement (CCI) in health research across Australia.

AHRA acknowledges the leadership of the NHMRC and CHF in promoting consumer and community involvement in health research. We share the vision set out in the *NHMRC Statement on Consumer and Community Involvement in Health and Medical Research*:

Consumers, community members, researchers and research organisations working in partnerships, to improve the health and well-being of all Australians through health and medical research.¹

AHRA and CHF recognise that consumers and community members have an inherent right to be informed and included in decisions affecting health research.

As highlighted in a recent review², we recognise that the design, conduct, benefits and translation of health research are significantly improved by the involvement of consumers and community members throughout the research process.

We also recognise that researchers and consumers must be supported through policy, information and resources in order to achieve optimal outcomes.

AHRA and CHF promote the involvement of consumers and community members in health research, not only as participants, but also in:

- generating research ideas
- working with researchers to design projects
- developing research resources such as information sheets and consent forms
- being involved in conducting research activities
- being involved in interpreting and analysing results and their implications for policy and practice
- helping to promote the use of research to inform improvement in health care and health outcomes, especially research that suggests a change in public awareness or behaviour.³

AHRA and CHF advocate for a consistent approach to embedding consumer and community involvement in health research across Australia, guided by best practice, ongoing evaluation and continuous improvement. The collective and accumulated expertise of AHRA members and consumer advocates will be complemented by local and international experience, tools and resources.

AHRA and CHF encourage AHRA member organisations to build capacity and infrastructure in collaboration with researchers, consumers and community members to develop the capacity to enhance research, its outputs, and its impacts on health services and health outcomes.

Guiding Principles

AHRA and CHF endorse the following guiding principles for involving consumers and community members in health research.

- Consumer and community involvement in research relies on an equal commitment to partnership based on mutual trust with a shared belief in the value of research.
- Involving consumers and community members in research should be planned from the beginning of the project, resourced, monitored and acknowledged appropriately in reporting.
- The roles and responsibilities of consumers and community members should be understood and agreed. Such involvement should be meaningful, rigorous and genuinely contribute to the research process.
- Training and support should be provided to consumers, community members and researchers to work together effectively.
- The contributions made by consumers and community members should be fairly and appropriately recognised and acknowledged.

What is AHRA Doing?

In 2018 AHRA launched its national CCI Initiative (Phase 1), conducting a baseline survey and environmental scan of current activities and resources to support consumer and community involvement in research. Four priority areas were identified for further development in Phase 2, which is now underway and is expected to be completed by June 2022:

1. Develop minimum standards for good practice in consumer and community involvement in translational health research
2. Facilitate access to, and sharing of, resources and expertise to support consumer and community involvement in translational health research
3. Develop a framework for measuring the impact of consumer and community involvement in translational health research
4. Establish formal alliances with leading international agencies promoting consumer and community involvement in health research.

This position statement was endorsed by AHRA and CHF in September 2020.

¹National Health and Medical Research Council, Consumers Health Forum of Australia, 2016. Statement on Consumer and Community Involvement in Health and Medical Research. Accessed 19 May 2020: <https://www.nhmrc.gov.au/about-us/publications/statement-consumer-and-community-involvement-health-and-medical-research>

²Miller C, Caruso J, Gancia A, Michelmore A, Keech W, Overton J, Kerrins E. The Value of Consumer and Community Involvement in Health and Medical Research - A Narrative Review. Adelaide: South Australian Health and Medical Research Institute and Health Translation SA. November 2020: <https://healthtranslationsa.org.au/our-work/platforms/consumer-and-community-engagement/>

³Consumers Health Forum of Australia, 2018. Shifting Gears—Consumers Transforming Health. A White Paper. Accessed 19 May 2020: https://chf.org.au/sites/default/files/181125_shifting_gears_-_consumers_transforming_health.pdf



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