



Expectations and Value - Framework for Effective Consumer and Community Engagement in Research

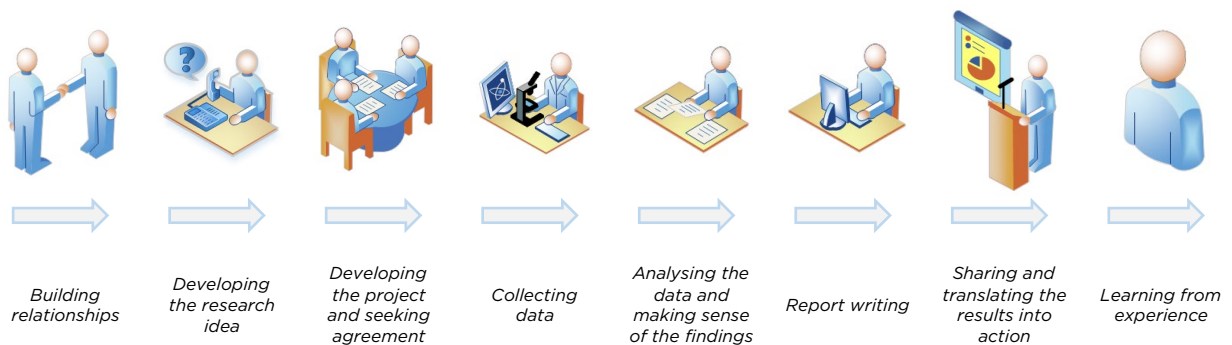
As outlined in the *Statement on Consumer and Community Involvement in Health and Medical Research* (2016) (the Statement), it is now widely accepted that consumers and community members add value to health and medical research and have a right and responsibility to do so.

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.

This overarching document provides researchers with a framework to engage effectively with consumers and community members to deliver high quality and relevant health and medical research.

Research that delivers value to and engages with the community

NHMRC's *Keeping Research on Track II* 2018 identifies eight steps in the research journey:



In order to maximise the value of research, researchers should seek consumer and community involvement in the very early planning stages through building relationships and the identification of community priorities for research.

This involvement needs to be at a level that will have a direct effect on the development of the research project and take into account the following:

- 1. The objective of the research is to improve health outcomes for the community generally, targeted groups within the community and/or people with a specific health challenge by:**
 - (a) Contributing to the prevention of a health condition or the development of a new diagnostic test, treatment or service
 - (b) Improving the safety, quality, effectiveness, cost-effectiveness or access to an existing diagnostic test, treatment or service
 - (c) Facilitating the assessment, modification or deletion of an existing health service
 - (d) Adding to the current knowledge of:
 - i basic science
 - ii healthcare service design, models of care and or services
 - iii public health and illness prevention
 - iv clinical diagnostics, treatments or care



2. Involvement of consumers and community should be in a minimum of four key phases:

- **Determining** research priorities including deciding what to research
- **Development** of research concept/hypothesis/question and design of research project including consideration of partners, methodology and processes and budget development including cost of consumer/community involvement
- **Research** including participant recruitment, consent and responsibility (ethics, governance) and oversight or governance of the conduct of the research
- **Reporting**, communications and publication (including translation). This could include implementation strategies/activities or identification of subsequent research required

3. Research that delivers value to the community requires detailed strategic planning to ensure that the research is fit for purpose and likely to achieve its objectives. The researcher/project is expected to address minimum strategic planning elements including:

- Research objectives (including the problem to be solved and its significance for human health) and how they will be achieved
- Proposed implementation pathway including potential next stages, implementation barriers and partners who could assist in overcoming barrier/s
- Length of time to benefit being realised and whether strategic partners could assist in faster delivery of benefits

4. The benefits of the research are increased because the research project expects to:

- address an area of urgent unmet need
- reduce the frequency of unnecessary or inappropriate treatments or care
- address an existing inequity
- develop a unique treatment for which there are no current alternatives

5. To maximise the cost/benefit ratio for the community and research participants the project should address issues relating to safety, quality, efficacy, cost efficiency and equality.

6. High quality research can deliver valuable products including intellectual property new researcher capability and resources, which can produce benefits extending beyond the research project alone. The products of the research project are expected to contribute to the sustainability and capability of the Australian research sector.

Research specifically related to the health of Aboriginal and/or Torres Strait Islander peoples, or which includes distinct Aboriginal and/or Torres Strait Islander populations, biological samples or data, must consider the following NHMRC documents:

- *Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders 2018*
- *NHMRC Indigenous Research Excellence Criteria* - particularly the community engagement criterion which specifies that the qualifying proposal demonstrates how the research and potential outcomes are a priority for Aboriginal and/or Torres Strait Islander communities with relevant community engagement by individuals, communities and/or organisations in conceptualisation, development and approval, data collection and management, analysis, report writing and dissemination of results.
- *Keeping Research on Track II 2018* - this document provides a summary of the research journey steps including questions to help keep research on track and guidance for community involvement.