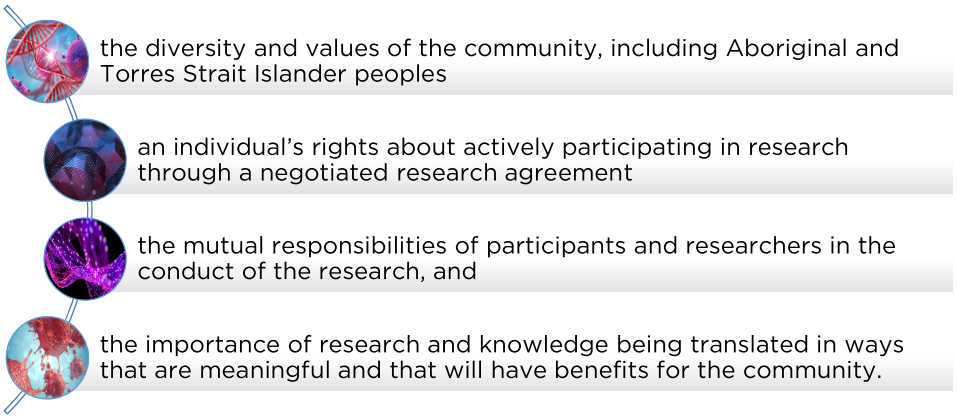
Australian Government
National Health and Medical Research Council

NHMRC

Measuring Alignment with Consumer and Community Expectations in Research

Regardless of who formulates the research idea or who undertakes the research, it is important to consider whether the proposed research is ethical and appropriate for all involved.

This thinking should happen throughout the research journey and should be informed by recognising and understanding:



The following list sets out questions for researchers to ask themselves throughout the research journey to assess alignment of their research with consumer and community expectations:

1. **Does the research project involve consumers and community members in:**

   - research concept/hypothesis/question development
   - research project design including consideration of diversity and values of the community
   - methodology and process development
   - budget development including cost of consumer/community involvement
   - trial participant recruitment
   - research conduct
   - research reporting
   - translation, implementation or identification of subsequent research required?

2. **Underpinning this, researchers should consider how consumers will be involved at each stage of the research project. Options may include:**

   - membership of project oversight, governance and/or ethics committees
   - chief or associate investigator on the research project
   - individual feedback on documents provided
   - completion of a survey
   - participation in an interview
   - participation in a focus group?

3. **Does the research improve the health outcome for 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 knowledge across the health and medical research spectrum?

4. **Are the outcomes of the research expected to:**

   (a) address an area of urgent and/or unmet need

   (b) reduce the frequency of unnecessary or inappropriate treatments or care

   (c) address an existing inequity

   (d) develop a unique treatment for which there are no current alternatives?

5. **What intellectual property or new resources will be produced, who will own it and how will it be used to realise a benefit:**

   - to the community e.g. by improving health outcomes, filling a key knowledge gap
   - to the future sustainability of the research sector in Australia?

6. **Has the researcher/project addressed the following minimum strategic planning elements:**

   - Research objectives (including the problem to be solved and the population group affected) and how they will be achieved
   - Proposed implementation pathway including potential next stages, any implementation barriers and partners who could assist to overcome barrier/s
   - Length of time to benefit being realised and whether strategic partners could assist in faster delivery of benefits?

7. **Does the research project consider and maximise:**

   Safety:

   - Consideration of potential negative impacts on trial participants
   - Risk identification, minimisation and mitigation strategy for participants and researchers
   - Trial participants include gender and age balance where appropriate

   Quality:

   - Best practice, including consumer involvement, accountability, transparency, privacy, complaints handling, adequate and measurable milestones, key performance indicators and periodic review
   - Good track record for researchers
   - Research hypothesis and assumptions well-articulated
   - Respect in all relationships
   - Ethics
   - Highly likely to achieve objectives or answer research question
   - Considers and rewards partnerships, effectiveness of clinical interface and implementation plan
   - Plan for participants post study (e.g. access to trial medication)
   - Meets the needs of Aboriginal and/or Torres Strait Islander people?

Effectiveness:

- Research question is relevant and significant
- Study is necessary (i.e. need is identified and does not duplicate previous research efforts)
- Study methodology is achievable and is most effective
- Considers burden on trial participants
- Findings are implementable
- Time to benefit ratio is reasonable relative to urgency of required outcomes
- Reward leveraging from previous research learnings, resources and infrastructure?

Cost effectiveness:

- Cost is reasonable for study methodology
- Participants do not have to contribute financially?

Access:

- Access to trial (or other research activity) by diverse populations where they are expected to be affected by the health challenge (e.g. gender, cultural and geographic diversity)?