Ethics:
Aboriginal & Torres Strait Islander Communities

Gail Garvey
The overall objective of the Road Map is to support the NHMRC to advise Aboriginal and Torres Strait Islander communities throughout Australia, on the achievement and maintenance of the highest practicable standards of individual and public health, and to foster research in the interests of improving those standards.

ACTION AREAS

- Improving the participation of Indigenous people in NHMRC programs
- Capacity exchange
- Promotion of NHMRC’s role in Indigenous research
- Close the Gap
- Evaluation / Intervention & Priority-driven research

Endorsed NHMRC Dec 2009
Criteria for Health and Medical Research of Indigenous Australians

All NHRMC Grant applicants where there is an Indigenous component to their research are required to address the extent to which their applications fulfil these criteria including documentation and other relevant written evidence where appropriate.
The Criteria

- Community engagement
- Benefit of the research to Aboriginal and Torres Strait Island peoples
- Sustainability and transferability
- Building capability
- Priority of the research for Aboriginal and Torres Strait Island peoples
- Significance of the research for Aboriginal and Torres Strait Island peoples
1. Community Engagement

• The proposal must demonstrate that there has been and will be adequate and appropriate community engagement involving individuals, communities and/or organisations in the conceptualisation, development, management, data collection, analysis, report writing and dissemination of results.
2. Benefit

• The proposal must demonstrate the potential health and wellbeing benefit for Aboriginal and Torres Strait Islander peoples.

• Benefits need not necessarily be direct or immediate but short term and long term benefits need to be identified.
3. Sustainability & Transferability

- The proposal needs to *demonstrate* how the *results* of the project have the potential to *lead to achievable and effective contributions to health gain* for Aboriginal and Torres Strait Islander people, beyond the life of the project.

- This may be through *sustainability* in the project setting and/or *transferability to other settings*. In considering this issue the proposal should address the *relationship between costs and benefits*. 
4. Building Capacity

• The proposal *must demonstrate* how Aboriginal and Torres Strait communities, researchers and others will *develop relevant capabilities* through:
  – Participation in the project
  – Information and education
  – Contribution to community development
  – Employment and training
  – Qualifications
  – Publications
5. Priority
• The *research and potential outcomes are a priority for Aboriginal and Torres Strait Islander communities* either at community, regional or national levels.

6. Significance
• The *research addresses an important public health issue for Aboriginal and Torres Strait Islander people.*
Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research

These guidelines were formally endorsed in 2003, and replaced the 1991 “Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research”.

The document focuses on six value principles.
The values that are documented as the basis for ethical conduct in Aboriginal and Torres Strait Islander health research include:

Diagram 1: Aboriginal and Torres Strait Islander Peoples values relevant to health research ethics
These values are:

• **Reciprocity** - inclusion of; recognition of contributions from; and meaningful and equitable benefits to Aboriginal and Torres Strait Islander peoples and communities (NS 1.14; 1.4)

• **Respect** – acknowledgement and affirmation of the right of Aboriginal and Torres Strait Islander people and communities to have different values, norms and aspirations (elimination of difference). (NS 1.2; 1.7; 1.8; 1.9; 1.10; 1.12)
Values …

• **Equality** – commitment to distributive fairness and justice for Aboriginal and Torres Strait Islander people, with recognition of our rights to be different (NS 1.5; 1.6)

• **Responsibility** – acknowledge commitment to promoting and protecting individual and collective responsibilities of Aboriginal and Torres Strait Islander people, through the establishment of transparent, timely and appropriate accountability regimes for all partners and stakeholders (NS1.1;1.3;1.13;1.18;1.19)
Values …

- **Survival and Protection** – recognition, respect and maintenance of the underlying tenets of solidarity, social cohesion and cultural distinctiveness within Aboriginal and Torres Strait Islander collectives.

- **Spirit & Integrity** – where spirit is evidence of Aboriginal and Torres Strait Islander people’s continuity between past, present and future, and integrity recognizes the need for uncompromising behaviour that upholds the other values.
The Values & Ethics document

These guidelines provide guidance to researchers in the conception, design, and conduct of research, as well as to HRECs, including Aboriginal specific HRECs or sub-committees.

Researchers, communities, other stakeholders and HRECs should consider proposals for research in the light of the proposal’s attention to the values and requirements.
The synergies of the RoadMap, the Criteria and the Values and Ethics Principles strengthen the capacity of the NHRMC to foster high quality and relevant research in partnership with Aboriginal and Torres Strait Islander people.
Research merit and integrity

(4.7.1) The researcher should ensure that research methods are respectful and acknowledge the cultural distinctiveness of discrete Aboriginal and Torres Strait Islander communities or groups participating in the research – including national or multi-centre research.

(4.7.2) There should be evidence of support for the research project from relevant Aboriginal and Torres Strait Islander communities or groups and the research methodology should engage with their social and cultural practices.

(4.7.3) The researcher should ensure that research methods provide for mutually agreed mechanisms for such matters as:
(a) appropriate recruitment techniques;
(b) suitable information about the research;
(c) notification of participants’ consent and of research progress; and
(d) final reporting.

(4.7.4) The researcher should seek to identify any potential negative consequences of the proposed research, to design processes to monitor them, and to advise steps for minimising them.
(4.7.5) The research methods and processes should provide opportunities to develop trust and a sense of equal research partnerships.

(4.7.6) Where:
(a) the geographic location of the research is such that a significant number of the population are likely to be Aboriginal and Torres Strait Islander, and/or
(b) the research is focused on a topic or disease/health burden identified as being of specific concern to Aboriginal and Torres Strait Islander Peoples and the population base has a significant proportion of Aboriginal and Torres Strait Islander people, the research should provide fair opportunity for involvement of Aboriginal and Torres Strait Islander Peoples, and the guidelines in this chapter apply to those participants.
**Beneficence**

(4.7.7) The benefits from research should include the enhancement or establishment of capabilities, opportunities or research outcomes that advance the interests of Aboriginal and Torres Strait Islander Peoples.

(4.7.8) The described benefits from research should have been discussed with and agreed to by the Aboriginal or Torres Strait Islander research stakeholders.

(4.7.9) The realisable benefits for Aboriginal and Torres Strait Islander participants from the research processes, outcomes and outputs should be distributed in a way that is agreed to and considered fair by these participants.
Respect

(4.7.10) The research proposal should demonstrate evidence of respectful engagement with Aboriginal and Torres Strait Islander Peoples. Depending on the circumstances, this might require letters of support from Aboriginal and/or Torres Strait Islander community Councils or other organisations accepted by the participating communities (see Chapter 2.1: Risk and benefit and Chapter 2.2: General requirements for consent, especially paragraph 2.2.13, page 21).

The research processes should foster respectful, ethical research relationships that affirm the right of people to have different values, norms and aspirations.

(4.7.11) The research approach should value and create opportunities to draw on the knowledge and wisdom of Aboriginal and Torres Strait Islander Peoples by their active engagement in the research processes, including the interpretation of the research data.

(4.7.12) National or multi-centre researchers should take care to gain local level support for research methods that risk not respecting cultural and language protocols.
Targeting Aboriginal and Torres Strait Islander People:

• Indigenous status is a key determinant;
• Data collection is explicitly directed;
• Aboriginal and/or Torres Strait Islander peoples, as a group, will be examined in the results;
• The information has an impact on one or more Aboriginal and/or Torres Strait Islander communities;
• Indigenous health funds are a source of funding.