

CHAPTER 4.7: ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLES

INTRODUCTION

Research with Aboriginal and Torres Strait Islander Peoples spans many methodologies and disciplines. There are wide variations in the ways in which Aboriginal and Torres Strait Islander individuals, communities or groups are involved in or affected by research to which this chapter applies. The variations depend on the scope of the project, the demographics of participants, the illnesses or social phenomena under study, and their historical, social and cultural context and connections.

Researchers should address relevant issues of research design, ethics, culture and language. Depending on the field of study and complexity of the proposed research, these issues might be addressed in numerous ways. A cornerstone of an ethical research relationship with Aboriginal and Torres Strait Islander Peoples is respect for and valuing of cultural and language diversity.

For health research fitting the above description, researchers must consult *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* (NHMRC 2003) ('Values and Ethics').

Other documents that might provide useful guidance for researchers are *Keeping research on track: A guide for Aboriginal and Torres Strait Islander peoples about health research ethics* (NHMRC 2005) and the *Guidelines for Ethical Research in Indigenous Studies* (Australian Institute of Aboriginal and Torres Strait Islander Studies 2002).

Human Research Ethics Committees (HRECs) are also required to apply the Values and Ethics guidelines as the basis for assessing proposals for health research with Aboriginal and Torres Strait Islander participation.

In applying Sections 1 and 2 of this National Statement, researchers from other disciplines, HRECs and other ethical review bodies may also find the Values and Ethics guidelines informative.

The Values and Ethics guidelines are based on six core values identified as being important to Aboriginal and Torres Strait Islander Peoples. The message for researchers is that there is great diversity across the many Aboriginal and Torres Strait Islander cultures and societies. Application of these core values, and of additional cultural and local-language protocols, should be determined by the Aboriginal and Torres Strait Islander communities or groups involved in the research. The six core values are:

- Reciprocity
- Respect
- Equality
- Responsibility
- Survival and protection
- Spirit and integrity.

Research to which this chapter applies must be reviewed and approved by a Human Ethics Research Committee (HREC) rather than by one of the other processes of ethical review described in paragraphs 5.1.7 and 5.1.8 (page 78). The HREC process must have included assessment by or advice from:

- **people who have networks with Aboriginal and Torres Strait Islander Peoples and/or knowledge of research with Aboriginal and Torres Strait Islander Peoples; and**

- **people familiar with the culture and practices of the Aboriginal and Torres Strait Islander people with whom participation in the research will be discussed.**

Values, principles and themes that must inform the design, ethical review and conduct of all human research are set out in Sections 1 and 2 of this National Statement. The guidelines and headings below show how those values, principles and themes apply specifically in research that is the subject of this chapter.

GUIDELINES

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.

Justice

- 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.