ETHICAL CONDUCT IN RESEARCH WITH ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLES AND COMMUNITIES: GUIDELINES FOR RESEARCHERS AND STAKEHOLDERS

Public consultation draft
2017
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Key terms

**AIATSIS**
Australian Institute of Aboriginal and Torres Strait Islander Studies; a government agency that promotes knowledge and understanding of Aboriginal and Torres Strait Islander cultures, traditions, languages and stories, past and present. AIATSIS is a research, collections and publishing organisation.

**AHEC**
Australian Health Ethics Committee; one of the principal committees of the NHMRC, responsible for developing ethical research guidelines and providing advice on developments in health ethics issues.

**AHREC**
Aboriginal Human Research Ethics Committee; a Human Research Ethics Committee that specialises in reviewing ethics proposals for research with Aboriginal and Torres Strait Islander Peoples and that has predominantly Aboriginal and Torres Strait Islander members.

**ARC**
Australian Research Council; advises the Australian Government on research matters and administers the National Competitive Grants Programme. It is a Commonwealth Government agency and also has responsibility for Excellence in Research in Australia (ERA).

**HREC**
Human Research Ethics Committee (HREC). HRECs are responsible for the ethical review of research and determine whether research proposals are ethically acceptable. HRECs are generally located within universities, research organisations, hospitals and government departments.

**National Statement**
*National Statement on Ethical Conduct in Human Research 2007*; a guideline that is intended for use by researchers, ethical review bodies such as Human Research Ethics Committees, those involved in research governance and research participants.

**NHMRC**
National Health and Medical Research Council; Australia’s leading expert body for supporting health and medical research; developing health advice for the Australian community, health professionals and governments; and providing advice on ethical behaviour in health care and the conduct of health and medical research.

**UA**
Universities Australia; the peak body representing the Australian university sector.
Acknowledgements
We acknowledge the sovereignty of Aboriginal and Torres Strait Islander Peoples as the original custodians of Australia and acknowledge and pay respects to Elders past, present and future.

We acknowledge all those involved in the development of Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders. The revision of this guideline involved the commitment and contribution of many people.

Description of the artwork
The artwork, as used on the front cover, communicates empowerment of people over their health, the progression of learning and knowledge out from the meeting place (NHMRC – bottom left corner) where many people are gathered. In the streams are the sources of nutrition and health – ants, berry bush and fish, as well as stars which symbolise new ideas.
**Introduction**

The health, wellbeing and experiences of Aboriginal and Torres Strait Islander Peoples continue to be the focus of much research to promote positive outcomes. Over the years, research has contributed to positive outcomes and benefits in, for example, health, medicine and education and in preserving the languages, stories and songs of Aboriginal and Torres Strait Islander Peoples and communities in culturally appropriate ways.

However, not all research has been of benefit for Aboriginal and Torres Strait Islander Peoples and communities. This absence of benefit can often be understood in the context of ethical considerations related to human research involving Aboriginal and Torres Strait Islander Peoples and communities.

Ethical research involving Aboriginal and Torres Strait Islander Peoples and communities should:

- Improve the way all researchers work with Aboriginal and Torres Strait Islander Peoples and their communities.
- Develop and/or strengthen research capabilities of Aboriginal and Torres Strait Islander Peoples and their communities.
- Enhance the rights of Aboriginal and Torres Strait Islander Peoples as participants in research.

There are two recognised Indigenous Peoples in Australia: Aboriginal Peoples and Torres Strait Islander Peoples and the term ‘Indigenous’ is used to describe both Aboriginal and Torres Strait Islander People. Torres Strait Islander People are of Melanesian origin with their own distinct identity, history and cultural traditions.¹ Many Torres Strait Islander People live on mainland Australia. When conducting research which involves both Aboriginal and Torres Strait Islander Peoples researchers must consult and work with relevant stakeholders from both groups. Aboriginal and Torres Strait Islander Peoples and communities each have their own established values and protocols, and their own unique ways of expressing their different values. Recognising and respecting diversity throughout the research journey helps to initiate, develop and sustain partnerships and relationships with Aboriginal and Torres Strait Islander Peoples and communities that are based on trust, mutual responsibility and ethics.

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Role of the Ethical Guidelines

Ethical guidelines are a set of principles to ensure research is safe, respectful, responsible, of high quality and of benefit to both Aboriginal and Torres Strait Islander Peoples and communities and to research. These Ethical Guidelines define six core values – spirit and integrity, cultural continuity, equity, reciprocity, respect, and responsibility. Applying these values will ensure that research conducted with or for Aboriginal and Torres Strait Islander Peoples and communities, or their data or biological samples, is ethically conducted.

These Ethical Guidelines, and an accompanying guide to implementing them (Keeping research on track II), are revisions of two previous guidelines:

- **Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Research 2003**
- **Keeping Research on Track: A guide for Aboriginal and Torres Strait Islander peoples about health research ethics 2005.**

The two previous guidelines were revised based on:

- recommendations from the evaluation of the two previous guidelines (see Further resources in Appendix 1)
- advice from NHMRC’s Indigenous Research Ethics Guidelines Review Working Committee (see Appendix 1 for further information).
Related principles
The principles in these Ethical Guidelines are consistent with the right of Aboriginal and Torres Strait Islander Peoples to be involved in all aspects of research undertaken with individuals and within communities and organisations.

These Ethical Guidelines also acknowledge principles outlined in international agreements, such as the United Nations Declaration on the Rights of Indigenous Peoples, which affirms the minimum standards for the survival, dignity, security and wellbeing of Indigenous people world-wide and enshrines Indigenous people’s right to be different. In particular, these guidelines affirm the right to self-determination that is contained in Article 1 of the International Covenant on Civil and Political Rights (ICCPR) and in Article 1 of the International Covenant on Economic, Social and Cultural Rights.

Related to these principles are the rights Indigenous people have in terms of free, prior and informed consent in all aspects of the research process. Consent assumes that Indigenous people are consulted and participate in an honest and open process of negotiation that ensures that all parties are equal, that is, no one party has more power or strength than any other; Indigenous group decision-making processes are allowed to operate, and Indigenous peoples’ right to choose how they want to live is respected. Critical to the understanding of consent, the terms free, prior and informed are defined as follows:

- **Free:** Implies that participation is voluntary and that no force, bullying, pressure or withholding of services is used or perceived to be used to obtain consent.
- **Prior:** Implies consent is to be sought in plenty of time before any approval or beginning of activities and that respect is shown to time needed for consultation and consensus processes. Voluntary informed consent is a pre-requisite for a person’s participation in research.
- **Informed:** Implies that information is provided that covers a range of aspects, including the nature, size, pace, reversibility and scope of any proposed project or activity; the purpose of the project as well as its duration; locality and areas affected; a preliminary assessment of the likely economic, social, cultural and environmental impact, including potential risks; people likely to be involved in doing the project; and procedures the project may entail. This process may include the option for participants to withhold consent. Participants must be kept fully informed if the project or process changes and in situations when early or interim results are identified. Information must be clear and understandable, and provided in a language or format that is understood by participants; an interpreter may need to be provided to help with this process. If people do not understand this information, then they have not been informed.

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Scope of the Ethical Guidelines

These Ethical Guidelines apply to all research involving Aboriginal and Torres Strait Islander Peoples. The Guidelines should inform all steps in the research process including conception (the initial idea), design (plan of the research), conduct (ways of doing the research), reporting (what happened), and dissemination of findings (circulation to relevant bodies) regarding research involving Aboriginal and Torres Strait Islander Peoples and communities.

These Ethical Guidelines should be used in conjunction with:

- The National Statement on Ethical Conduct in Human Research 2007 (the National Statement). The National Statement is grounded in four main principles: respect; research merit and integrity; justice; and beneficence. A research proposal involving Aboriginal and Torres Strait Islander Peoples must comply with these Ethical Guidelines as well as relevant sections of the National Statement.
- The Australian Code for the Responsible Conduct of Research (the Code), which guides institutions and researchers in responsible research practices. The Code promotes integrity in research and explains what is expected of researchers by the community. The Code assists researchers, administrators and the community with how to manage departures from best research practice.
- Keeping research on track II, which is designed for Aboriginal and Torres Strait Islander communities to use when they are considering conducting or being involved with research.4

Keeping research on track II provides advice about how principles and values expressed in these guidelines can be put into practice in research projects with Aboriginal and Torres Strait Islander Peoples and communities. It is designed primarily for Aboriginal and Torres Strait Islander communities to use when they are considering conducting or being involved with research, but is also a useful resource for researchers and others interested in research with Aboriginal and Torres Strait Islander Peoples and communities. It helps people become familiar with the stages in the research journey and make decisions about research.

In addition to compliance with the National Statement and the Code, research involving human beings is subject to a variety of legislative and other regulatory requirements at Commonwealth, state and territory levels. All activities referred to in these Ethical Guidelines must be carried out in compliance with existing legislative and regulatory frameworks.

Intended audience

These Ethical Guidelines are intended for use by researchers and ethics review bodies, such as Human Research Ethics Committees (HRECs). Aboriginal and Torres Strait Islander People, research participants and the wider community may also find these Ethical Guidelines useful.

Research agreements

It is important for the researcher to have a negotiated formal agreement with the Aboriginal and Torres Strait Islander Peoples and communities so that each party fully understands what is expected from them for the research project. Agreements demonstrate respect for the welfare, beliefs, perceptions, customs and cultural heritage (both individual and collective) of those involved in research. Agreements ensure that participating communities have a full understanding of expectations from the research through a written agreement.

The agreement should be comprehensive and cover all aspects of the research, incorporating ethical standards appropriate when working with Aboriginal and Torres Strait Islander Peoples. A full list of issues to be covered can be found on page 11 in Keeping research on track II (Public consultation draft, 2017).

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**Intellectual property**

Research agreements should cover the management of intellectual property rights. Aboriginal and Torres Strait Islanders Peoples have the right to assert ownership of the intellectual property related to the information that is provided to a research project, and it is important that these rights are respected. Links to other relevant resources are provided in the ‘Further resources’ section of this document and there is more information about intellectual property and copyright issues in *Keeping research on track II* (Public consultation draft, 2017; see page 12).
Structure of the Ethical Guidelines: the six core values

The six core values (see Figure 1) – spirit and integrity, cultural continuity, equity, reciprocity, respect, and responsibility – are important to all Aboriginal and Torres Strait Islander Peoples to ensure all human research undertaken for Aboriginal and Torres Strait Islander Peoples and communities:

- respects the shared values of Aboriginal and Torres Strait Islander Peoples
- is relevant for Aboriginal and Torres Strait Islander priorities, needs and aspirations
- develops long-term ethical relationships among researchers, institutions and sponsors
- develops best practice ethical standards of research.

These values are present through time – past, present and future. There is some overlap between the values and their descriptions and interpretations. Given the diversity of Aboriginal and Torres Strait Islander Peoples and communities, each community and/or organisation has the right to express how these core values, and any other values, will be addressed in research.

Figure 1 – the six core values

The next section focusses on each of the six core values. Each core value starts with a brief introduction, and then moves on to a list of points that describe how to demonstrate the value, followed by links to relevant sections in the National Statement.

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5 Adapted from Keeping Research on Track: A guide for Aboriginal and Torres Strait Islander peoples about health research ethics 2005.
**Spirit and integrity**

Spirit and integrity is the central core value that binds all other values together (see Figure 1).

Spirit and integrity is reflected through:

- Respecting Aboriginal and Torres Strait Islander Peoples’ cultural inheritance of past, current and future generations, and of the links which bind the generations together.
- Credibility of intent and in the process of negotiations with Aboriginal and Torres Strait Islander communities; as demonstrated by the researchers’ adherence to these Ethical Guidelines and the behaviour and perceived integrity of the researchers and other stakeholders.

**Demonstrating spirit and integrity**

Research involving Aboriginal and Torres Strait Islander Peoples and communities should:

- Demonstrate commitment in carrying out all the other five values of cultural continuity, equity, reciprocity, respect, and responsibility. Demonstrating commitment to these five values demonstrates commitment to spirit and integrity.

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**Links to National Statement requirements:**

1.3 Research that is conducted with integrity is carried out by researchers with a commitment to:
   a) searching for knowledge and understanding;
   b) following recognised principles of research conduct;
   c) conducting research honestly; and
   d) disseminating and communicating results, whether favourable or unfavourable, in ways that permit scrutiny and contribute to public knowledge and understanding.

1.10 Respect for human beings is a recognition of their intrinsic value. In human research, this recognition includes abiding by the values of research merit and integrity, justice and beneficence. Respect also requires having due regard for the welfare, beliefs, perceptions, customs and cultural heritage, both individual and collective, of those involved in research.
Cultural continuity
Cultural continuity contributes to a sense of strong, shared and enduring individual and collective identities. Cultural continuity includes maintaining the bonds and relationships between people, and between people and their environment. It also includes responsibilities in respect of spiritual domains. Aboriginal and Torres Strait Islander Peoples continue to protect their cultures and identity by reflecting on and drawing strength from their individual and collective identities.

Cultural continuity is reflected through:
• Understanding Aboriginal and Torres Strait Islander Peoples’ experiences and perception of research as an exploitative exercise and the continuing potential for research to assimilate, integrate or subjugate their values.
• Recognising the importance of the personal and collective bonds within Aboriginal and Torres Strait Islander communities and the critical function of these bonds in their social lives.
• Engaging with Aboriginal and Torres Strait Islander Peoples and communities; sometimes this may be collectively, sometimes this may be with individuals and sometimes it may be both.
• Finding ways of working that do not diminish the right to the assertion or enjoyment of cultural distinctiveness.

Demonstrating cultural continuity
Research involving Aboriginal and Torres Strait Islander Peoples and communities should:
• Ensure there are approaches and strategies to protect cultures, language and identities of Aboriginal and Torres Strait Islander Peoples and communities. This includes addressing and managing sensitivity such as participation in cultural events and the sharing of information more broadly (e.g. sacred sites; women’s business and men’s business).
• Demonstrate respect for the intrinsic values-based expectations and identity of Aboriginal and Torres Strait Islander Peoples and communities including the balance between collective and individual identity.
• Respect that each person has his or her own intrinsic value which must inform all interactions between people. This value would be addressed through establishing a community advisory group and respecting the community’s decisions regarding the way the research is to be conducted from project conception to conclusion.

Links to National Statement requirements:
1.3 Research that is conducted with integrity is carried out by researchers with a commitment to:
   a) searching for knowledge and understanding;
   b) following recognised principles of research conduct;
   c) conducting research honestly; and
   d) disseminating and communicating results, whether favourable or unfavourable, in ways that permit scrutiny and contribute to public knowledge and understanding.

1.10 Respect for human beings is a recognition of their intrinsic value. In human research, this recognition includes abiding by the values of research merit and integrity, justice and beneficence. Respect also requires having due regard for the welfare, beliefs, perceptions, customs and cultural heritage, both individual and collective, of those involved in research.
Equity

Equity is reflected by a commitment to showing fairness and justice. Many instances of discrimination and marginalisation have resulted in multiple inequities for Aboriginal and Torres Strait Islander Peoples and communities. In research, Aboriginal and Torres Strait Islander Peoples have perceived the distribution of benefits from research as flowing mostly to the researchers and research institutions. Aboriginal and Torres Strait Islander Peoples have sought the elimination of ignoring cultural differences so that Aboriginal and Torres Strait Islander cultures, history and status can be appreciated and respected.

Equity is reflected through:
- Recognising and valuing Aboriginal and Torres Strait Islander Peoples’ knowledge and wisdom. Aboriginal and Torres Strait Islander Peoples value their collective memory and shared experience as a resource and inheritance.
- Recognising and valuing Aboriginal and Torres Strait Islander Peoples’ current and historic biological and genetic resources, and ensuring fair recognition of these resources.
- Ensuring the fair and reasonable distribution of benefit for Aboriginal and Torres Strait Islander Peoples and communities to achieve equity in economic, legal, social and health status. The distribution of benefit stands as a fundamental test of equity. The equitable distribution of the benefits of research is also discussed as part of the Reciprocity value (see page 14).

Demonstrating equity

Research involving Aboriginal and Torres Strait Islander Peoples and communities should:
- Ensure participating communities are included in all steps of the research processes and consider how this reflects equity.
- Develop risk management strategies to promote and safeguard equity.
- Actively engage participants and communities in negotiations about the meanings of the research topic and the methods of research.

Links to National Statement requirements

1.4 In research that is just:
   a) taking into account the scope and objectives of the proposed research, the selection, exclusion and inclusion of categories of research participants is fair, and is accurately described in the results of the research;
   b) the process of recruiting participants is fair;
   c) there is no unfair burden of participation in research on particular groups;
   d) there is fair distribution of the benefits of participation in research;
   e) there is no exploitation of participants in the conduct of research; and
   f) there is fair access to the benefits of research.

1.7 Researchers are responsible for:
   a) designing the research to minimise the risks of harm or discomfort to participants;
   b) clarifying for participants the potential benefits and risks of the research; and
   c) the welfare of the participants in the research context.

1.8 Where there are no likely benefits to participants, the risk to participants should be lower than would be ethically acceptable where there are such likely benefits.

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Reciprocity

Aboriginal and Torres Strait Islander Peoples’ way of shared responsibility and obligation is based on their kinship networks. This process keeps Aboriginal and Torres Strait Islander Peoples’ ways of living and family relationships strong. These responsibilities also extend to caring for country, which includes the land, sea, waterways, animals, biodiversity and ecosystems and involves sharing benefits from the land, sea and waterways; redistribution of resources; and sharing food and housing. Reciprocity should enable agreements where all groups or people have equal rights and power in relationships, although in the context of research this often involves unequal power relationships. Reciprocity recognises all partners’ contributions, and ensures the benefits from research outcomes are equitable and of value for Aboriginal and Torres Strait Islander Peoples and communities.

Reciprocity is reflected through:

- Equitable and respectful engagement with and inclusion of Aboriginal and Torres Strait Islander Peoples, their values and cultures in the proposed research. This includes discussing reciprocal arrangements during the project development phase to ensure they are built into the overall project through agreements with organisations or individuals.
- Ensuring Aboriginal and Torres Strait Islander Peoples and communities have the right to define benefits according to their own values and priorities, and may place greater or lesser value on the various returns than do researchers and others. Benefit in this context describes the establishment or enhancement of capacities, opportunities or outcomes that advance the interests of Aboriginal and Torres Strait Islander Peoples and communities.
- Understanding benefits for Aboriginal and Torres Strait Islander Peoples and communities may:
  - take more than one form (e.g. better services, training, funding, sharing of knowledge and so on)
  - not be immediate (e.g. an intervention may lead to a new service once the project is completed)
  - be of benefit to other people such as those who participated in the project or all Aboriginal and Torres Strait Islander Peoples and communities, or to the wider community as well.
- Respectful discussion to determine where the research process and intended outcomes may not benefit the community.
- Ensuring equitable distribution of benefit by recognising that benefits for researchers are likely to flow on for a long time after the project is completed by way of recognition, reputation and employment.

Demonstrating reciprocity

Research involving Aboriginal and Torres Strait Islander Peoples and communities should:

- Contribute to the wellbeing of Aboriginal and Torres Strait Islander Peoples and communities.
- Identify potential unintended consequences or impact of the research and/or research process and strategies to address these where possible.
- Include what relevant community, regional, jurisdictional and/or international priorities it will address and how it will address existing or emerging needs articulated by Aboriginal and Torres Strait Islander Peoples and communities.
- Express the potential benefits and implications of the project in terms of the values of Aboriginal and Torres Strait Islander Peoples and communities.
- Consider how the values and aspirations of participating Aboriginal and Torres Strait Islander Peoples and communities may have implications for the proposed research project and develop strategies to address these implications.
- Provide evidence of a capacity-building or capacity-strengthening development plan that describes how Aboriginal and Torres Strait Islander Peoples will directly (e.g. training, development and infrastructure) and indirectly (e.g. broader social, economic or political strategies at local, jurisdictional, national or international level) benefit from the project.
Links to National Statement requirements:
1.1d Research that has merit is designed to ensure that respect for the participants is not compromised by the aims of the research, by the way it is carried out, or by the results.

1.10 Respect for human beings is a recognition of their intrinsic value. In human research, this recognition includes abiding by the values of research merit and integrity, justice and beneficence. Respect also requires having due regard for the welfare, beliefs, perceptions, customs and cultural heritage, both individual and collective, of those involved in research.

2.1.2 Risks to research participants are ethically acceptable only if they are justified by the potential benefits of the research.
Respect
Respect is expressed as having regard for the welfare, rights, beliefs, perceptions, customs and cultural heritage (both individual and collective) of persons involved in research. Within Aboriginal and Torres Strait Islander cultures respect is reinforced through, and in turn strengthens, dignity. A respectful relationship induces trust and co-operation.

Respect is reflected through:
- Acknowledging and supporting the rights of people to hold and express different values, norms and aspirations.
- Self-awareness of one’s own beliefs, attitudes and behaviours that may ignore differences between people. This may result in incapacity to understand how research and ideas might be viewed by Aboriginal and Torres Strait Islander communities and contribute to further lack of recognition of cultural difference and diversity.
- Recognising and supporting the individual and collective contribution, interests and aspirations of Aboriginal and Torres Strait Islander Peoples and communities, researchers and other partners in the research process.
- Ensuring trust, openness and engagement of participating communities and individuals is as important as the scientific rigour of the investigation.
- Awareness and understanding that research has consequences for all those involved in the process. These consequences might be intended or unintended, short-term or long-term, positive or negative. Consideration of such consequences should be anticipated at the developmental stage of the research and taken into account throughout all stages of the research process.
- Mutual intent and agreement at the outset of any research project that describes when and how the research will be done, and who will engage in the research process. This agreement must be respected throughout the research process. In this way the values of all parties can be equally respected.

Demonstrating respect
Research involving Aboriginal and Torres Strait Islander Peoples and communities should:
- Show how the project will approach and respond to the diversity of Aboriginal and Torres Strait Islander Peoples and communities, including the way decisions are made.
- Describe how the involvement of Aboriginal and Torres Strait Islander Peoples and communities has been negotiated in the development of an agreement and will continue to be negotiated throughout the research project. When dealing with communities and in seeking HREC approval, where possible researchers should engage with Aboriginal and Torres Strait Islander communities and institutional structures (see page 3 for a definition of HREC).
- Recognise and acknowledge the individual and collective contribution of Aboriginal and Torres Strait Islander Peoples.
- Include activities to promote awareness of cultural difference and diversity.
- Include risk management strategies to prevent, identify and address any harm associated with ignoring cultural difference and diversity.
- Demonstrate free, prior and informed consent for the research and all related activities such as the engagement and consultation process, research agreements, intellectual property agreements, capacity development plans, knowledge translation plans and other relevant strategies. This also relates to the values of equity and reciprocity.
- Provide information on how changes or cancellations to the project will be communicated, negotiated and endorsed by all stakeholders, including HRECs.
1.10 Respect for human beings is a recognition of their intrinsic value. In human research, this recognition includes abiding by the values of research merit and integrity, justice and beneficence. Respect also requires having due regard for the welfare, beliefs, perceptions, customs and cultural heritage, both individual and collective, of those involved in research.

1.11 Researchers and their institutions should respect the privacy, confidentiality and cultural sensitivities of the participants and, where relevant, of their communities. Any specific agreements made with the participants or the community should be fulfilled.

CHAPTER 2.2: GENERAL REQUIREMENTS FOR CONSENT

2.2.1 The guiding principle for researchers is that a person’s decision to participate in research is to be voluntary, and based on sufficient information and adequate understanding of both the proposed research and the implications of participation in it. For qualifications of this principle, see Chapter 2.3: Qualifying or waiving conditions for consent.

2.2.2 Participation that is voluntary and based on sufficient information requires an adequate understanding of the purpose, methods, demands, risks and potential benefits of the research.

2.2.5 Consent may be expressed orally, in writing or by some other means (for example, return of a survey, or conduct implying consent), depending on:
   a) the nature, complexity and level of risk of the research; and
   b) the participant’s personal and cultural circumstances.

2.2.9 No person should be subject to coercion or pressure in deciding whether to participate. Even where there is no overt coercion or pressure, consent might reflect deference to the researcher’s perceived position of power, or to someone else’s wishes. Here as always, a person should be included as a participant only if his or her consent is voluntary.

2.2.13 Within some communities, decisions about participation in research may involve not only individuals but also properly interested parties such as formally constituted bodies, institutions, families or community elders. Researchers need to engage with all properly interested parties in planning the research.

2.2.19 People who elect not to participate in a research project need not give any reason for their decision. Researchers should do what they can to see that people who decline to participate will suffer no disadvantage as a result of their decision.

2.2.20 Participants are entitled to withdraw from the research at any stage. Before consenting to involvement in the research, participants should be informed about any consequences of such withdrawal.
Responsibility
Central to Aboriginal and Torres Strait Islander societies and cultures is the recognition of core responsibilities. These responsibilities include caring for country, kinship bonds, caring for others and the maintenance of harmony and balance within and between the physical and spiritual realms. A key responsibility within this framework is to do no harm, including avoiding having an adverse impact on others’ abilities to comply with their responsibilities. As well, one person’s responsibilities are often not mutually exclusive and relate to the accountability of others (and may be shared with others so that they will also be held accountable).

Responsibility is reflected through:
- Inflicting no harm. There is a clear responsibility for researchers to do no harm to Aboriginal and Torres Strait Islander individuals or communities and or to those things that they value.
- Establishing processes to ensure researchers’ accountability to individuals, families and communities, particularly in relation to the cultural and social dimensions of Aboriginal and Torres Strait Islander life. When engaging Aboriginal and Torres Strait Islanders Peoples and communities in the research enterprise, researchers carry responsibilities in addition to the science of their inquiry. The nexus between their research and community life brings responsibilities for which they or those members of the community with whom they work may be held accountable. Ethical research occurs when harmony between the sets of responsibilities is established, participants are protected, trust is maintained and mutual accountability is clear.

Demonstrating responsibility
Research involving Aboriginal and Torres Strait Islander Peoples and communities should:
- Include risk management strategies to prevent and eliminate threats to the ability of Aboriginal and Torres Strait Islander Peoples and communities to enjoy their cultural distinctiveness. This includes evidence of endorsed agreements that cover intellectual and cultural property, including use of photographs and video recordings of participants, artefacts and significant sites; the management of data, publication arrangements and capacity development plans.
- Give Aboriginal and Torres Strait Islander contributors the opportunity to share in any intellectual property rights over information provided by them for the research project: it is the researcher’s responsibility to negotiate with any institution (for example, a university) that has contractually transferred their intellectual property rights.
- Where there is co-authorship, demonstrate co-ownership by sharing copyright with the co-author and agree in writing on the sharing of intellectual property rights, moral rights and copyright between the researcher and individual contributors, and a community representative organisation, if applicable.
- Demonstrate how the research proposal addresses agreed arrangements regarding publication of the research results, including clear provisions relating to joint sign-off for publication and the protection of individual and community identity, if appropriate.
- The identity of all participants and community is protected in all research output through applying the privacy preserving protocols whereby names, places and other identifying features (including biological samples) are disguised across a dataset including from interview transcripts, diaries and field notes.
  - Further information about publication protocols is available from the Australia Council for the Arts: Protocols for producing Indigenous Australian writing.
- Demonstrate free, prior and informed consent for the research participants and consider potential implications for partners and family members of research participants.
- Discuss and negotiate how the project, including its plan, purpose, methodology, feedback of results and outcomes will be discussed with Aboriginal and Torres Strait Islander Peoples and communities.
• Engage participants and communities to be involved in monitoring and evaluating ethical research practice to minimise the likelihood of any unintended consequences arising from or occurring after the research project.
• Provide evidence of a knowledge translation strategy at the outset of the research that is developed with and endorsed by Aboriginal and Torres Strait Islander Peoples and communities.
• Implement a plan for how the project, including project researchers, will be monitored and what strategies will be used to demonstrate accountability to individuals, families and communities, particularly in relation to the cultural and social dimensions of Aboriginal and Torres Strait Islander life.

Links to National Statement requirements:
1.1 Research that has merit is:
   a) justifiable by its potential benefit, which may include its contribution to knowledge and understanding, to improved social welfare and individual wellbeing, and to the skill and expertise of researchers. What constitutes potential benefit and whether it justifies research may sometimes require consultation with the relevant communities;
   b) designed or developed using methods appropriate for achieving the aims of the proposal;
   c) based on a thorough study of the current literature, as well as previous studies. This does not exclude the possibility of novel research for which there is little or no literature available, or research requiring a quick response to an unforeseen situation;
   d) designed to ensure that respect for the participants is not compromised by the aims of the research, by the way it is carried out, or by the results;
   e) conducted or supervised by persons or teams with experience, qualifications and competence that are appropriate for the research; and
   f) conducted using facilities and resources appropriate for the research.

1.3 Research that is conducted with integrity is carried out by researchers with a commitment to:
   a) searching for knowledge and understanding;
   b) following recognised principles of research conduct;
   c) conducting research honestly; and
   d) disseminating and communicating results, whether favourable or unfavourable, in ways that permit scrutiny and contribute to public knowledge and understanding.

1.5 Research outcomes should be made accessible to research participants in a way that is timely and clear.

1.6 The likely benefit of the research must justify any risks of harm or discomfort to participants. The likely benefit may be to the participants, to the wider community, or to both.

1.11 Researchers and their institutions should respect the privacy, confidentiality and cultural sensitivities of the participants and, where relevant, of their communities. Any specific agreements made with the participants or the community should be fulfilled.
APPENDIX 1: Expert working committee

In January 2015, NHMRC established the Indigenous Research Ethics Guidelines (IREG) Review Working Committee to undertake the review of Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Research 2003 and Keeping Research on Track: A guide for Aboriginal and Torres Strait Islander peoples about health research ethics 2005, in light of the findings of an evaluation of these two guidelines conducted in 2013 and recommendations regarding the revision of these guidelines. The IREG Review Working Committee used the evaluation report and literature review as a basis for developing this revised guideline and its companion publication, Keeping research on track II. The committee provides advice to the Australian Health Ethics Committee (AHEC), which has overseen the review. The membership of the IREG Review Working Committee is provided below.

IREG Review Working Committee membership

<table>
<thead>
<tr>
<th>Member</th>
<th>Membership expertise</th>
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</thead>
<tbody>
<tr>
<td>Ms Chrissy Grant (Chair)</td>
<td>Institution-based nominee from a Human Research Ethics Committee with expertise in Aboriginal and Torres Strait Islander research.</td>
</tr>
<tr>
<td>Professor Samar Aoun</td>
<td>Member of National Statement Review Working Group; member of Australian Health Ethics Committee 2012–15.</td>
</tr>
<tr>
<td>Professor Yvonne Cadet-James</td>
<td>Researcher with expertise in Aboriginal and Torres Strait Islander research.</td>
</tr>
<tr>
<td>Professor Tom Calma AO</td>
<td>Researcher with expertise in Aboriginal and Torres Strait Islander research.</td>
</tr>
<tr>
<td>A/Professor Terry Dunbar</td>
<td>Researcher with expertise in Aboriginal and Torres Strait Islander research.</td>
</tr>
<tr>
<td>Ms Summer May Finlay</td>
<td>Expertise in Aboriginal and Torres Strait Islander health policy and research.</td>
</tr>
<tr>
<td>A/Professor Jane Freemantle</td>
<td>Researcher with expertise in Aboriginal and Torres Strait Islander research.</td>
</tr>
<tr>
<td>A/Professor Daniel McAullay</td>
<td>Member of Australian Health Ethics Committee 2015–18.</td>
</tr>
<tr>
<td>Mr Romlie Mokak</td>
<td>Expertise in health policy.</td>
</tr>
<tr>
<td>Dr Sanchia Shibasaki</td>
<td>Torres Strait Islander researcher with expertise in health research.</td>
</tr>
</tbody>
</table>

Previous working committee members

<table>
<thead>
<tr>
<th>Member</th>
<th>Membership expertise</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mr Mick Gooda (Chair)</td>
<td>Community leader.</td>
</tr>
<tr>
<td>January 2015 – November 2015</td>
<td></td>
</tr>
<tr>
<td>Professor Lester-Irabinna Rigney</td>
<td>Indigenous education expertise.</td>
</tr>
<tr>
<td>January 2015 – February 2016</td>
<td></td>
</tr>
<tr>
<td>Mr Daniel Kelly</td>
<td>State-based nominee from a Human Research Ethics Committee with expertise in Aboriginal and Torres Strait Islander research.</td>
</tr>
<tr>
<td>January 2015 – March 2016</td>
<td></td>
</tr>
</tbody>
</table>
Further resources

Research ethics guidelines and information

*Keeping research on track II* (Public consultation draft, 2017)
National Health and Medical Research Council

*Evaluation of the National Health and Medical Research Council documents: Values and Ethics: Guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research 2003 and Keeping Research on Track: a guide for Aboriginal and Torres Strait Islander peoples about health research ethics 2005*
National Health and Medical Research Council, the Lowitja Institute and the Australian Institute of Aboriginal and Torres Strait Islander Studies

*National Statement on Ethical Conduct in Human Research 2007*
National Health and Medical Research Council, Australian Research Council & Universities Australia

*Guidelines for Ethical Research in Australian Indigenous Studies 2012*
Australian Institute of Aboriginal and Torres Strait Islander Studies

*EthicsHub*
The Lowitja Institute

**Human Research Ethics Committees (HRECs)**

*Human Research Ethics Committees*
National Health and Medical Research Council

**Intellectual property**

*Protocols for producing Indigenous Australian writing*
Australia Council for the Arts

*Indigenous cultural rights and engagement policy*
National Museum of Australia

*Indigenous cultural and intellectual property rights*
National Copyright Unit on behalf of the Copyright Advisory Groups (Schools and TAFEs)

*Intellectual Property Management*
National Health and Medical Research Council

*KLC Intellectual Property and Traditional Knowledge Policy*
Kimberley Land Council

*Terri Janke and Company – Lawyers and Consultants*

Janke, T (1998) ‘*Our Culture: Our Future: Report on Australian Indigenous Cultural and Intellectual Property Rights*’, Australian Institute of Aboriginal and Torres Strait Islander Studies and the Aboriginal and Torres Strait Islander Commission

**Other information**

*Indigenous Health*
National Health and Medical Research Council

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References

NHMRC (2005) *Keeping Research on Track: A guide for Aboriginal and Torres Strait Islander peoples about health research ethics 2005*, Commonwealth of Australia: Canberra


