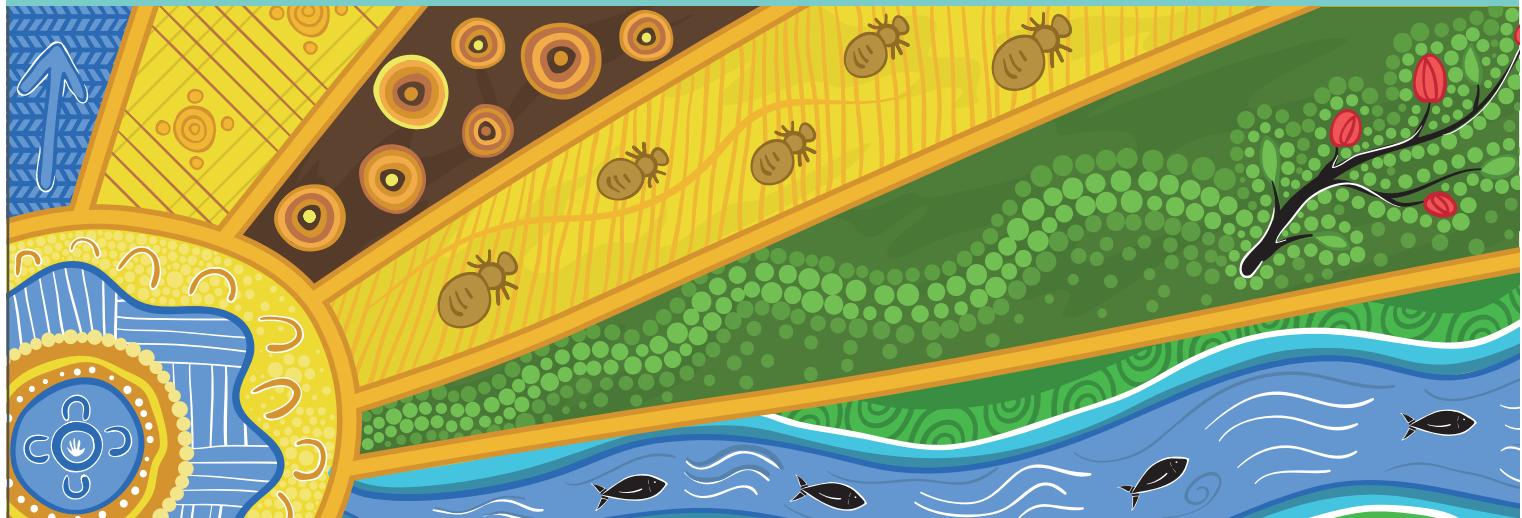




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Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders

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Key terms

AIATSIS**Australian Institute of Aboriginal and Torres Strait Islander Studies:**

a Commonwealth statutory authority with responsibility for providing leadership in Aboriginal and Torres Strait Islander research including ethics and protocols. AIATSIS maintains a national collection of Aboriginal and Torres Strait Islander cultural heritage and uses its role to strengthen and promote knowledge and understanding of Aboriginal and Torres Strait Islander culture and heritage.

AHEC**Australian Health Ethics Committee:** a principal committee of NHMRC.

AHEC is responsible for developing human research guidelines and providing advice on health and research ethics issues.

AHREC**Aboriginal Human Research Ethics Committee:** a Human Research Ethics Committee with predominantly Aboriginal and Torres Strait Islander members that specialises in reviewing research with Aboriginal and Torres Strait Islander Peoples.**ARC****Australian Research Council:** a Commonwealth entity that advises the Australian Government on research matters, administers the National Competitive Grants Program (a significant component of Australia's investment in research and development) and has responsibility for assessing the quality, engagement and impact of research.**Code****Australian Code for the Responsible Conduct of Research:** guides institutions and researchers in responsible research practices. It promotes integrity in research and explains what is expected of researchers by the community.**HREC****Human Research Ethics Committee:** HRECs undertake ethics review of research and determine whether research proposals are ethically acceptable. HRECs are generally located within universities, research organisations, hospitals and government departments.**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.**National Statement****National Statement on Ethical Conduct in Human Research:** the principal guideline setting out the requirements for the ethical design, review and conduct of human research in Australia. It is intended for use by researchers, ethics review bodies such as Human Research Ethics Committees, those involved in research governance and research participants.**UA****Universities Australia:** the peak body representing Australia's 39 comprehensive universities.

Acknowledgements

We acknowledge the sovereignty of Aboriginal and Torres Strait Islander Peoples as the original custodians of Australia and acknowledge and pay respect 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 2018*. 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. The artist, Jordan Lovegrove, is a Ngarrindjeri man and graphic designer.

Introduction

The health, wellbeing and experiences of Aboriginal and Torres Strait Islander Peoples¹ 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.² This absence of benefit can often be understood in the context of ethical considerations related to human research with Aboriginal and Torres Strait Islander people and communities. There is more information on [NHMRC's website](#) about the history of research with Aboriginal and Torres Strait Islander Peoples.

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

- improve the way all researchers work with Aboriginal and Torres Strait Islander people and their communities
- develop and/or strengthen research capabilities of Aboriginal and Torres Strait Islander people and their communities
- enhance the rights of Aboriginal and Torres Strait Islander Peoples as researchers, research partners, collaborators and participants in research.

There are two recognised Indigenous Peoples in Australia: Aboriginal Peoples and Torres Strait Islander Peoples. 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. The term 'Indigenous' is used to describe both Aboriginal and Torres Strait Islander Peoples. There is also difference and diversity within, as well as between, these two groups. In addition, many Aboriginal and Torres Strait Islander people prefer to identify with their language group/s and traditional land/s from where they trace their ancestry.

Diversity in this context can cover a wide range of differences; these can include (but are not limited to) history, knowledge systems, world views, values, beliefs and experiences. This may extend to diversity within communities when more than one nation group resides in the community due to forced removal of people off their lands to other locations as a result of colonisation. Diversity may also include specific family birthright responsibilities and generational differences along with specific religious and spiritual beliefs or socio-economic status.

1 Throughout these Guidelines, the word 'Peoples' is used when specifically referring to Aboriginal and Torres Strait Islander groups, and the word 'people' is used when referring to Aboriginal and Torres Strait Islander individuals. As these are the preferred terms, other terms such as 'First Nations' and 'First Peoples' will not be used in these Guidelines. When quoting from other sources or referencing published works, the original usage in the source is retained.

2 See Bainbridge, R., Tsey, K. and McCalman, J. et al. (2015) ['No one's discussing the elephant in the room: contemplating questions of research impact in Aboriginal and Torres Strait Islander Australian health research'](#), *BMC Public Health*, vol. 15:696–706.

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. When conducting research that includes both Aboriginal and Torres Strait Islander Peoples, researchers must consult and work with relevant stakeholders from both groups.

It is important that research with Aboriginal and Torres Strait Islander people and communities is led by Aboriginal and Torres Strait Islander people and communities. This can mean that the chief researchers and/or members of the research team are Aboriginal or Torres Strait Islander people. It can also mean that research and its priorities are driven and guided by the Aboriginal and Torres Strait Islander communities with whom the research will take place. It is also important to note that most research methodologies and practices have emerged from Western concepts that sometimes do not include other conceptual viewpoints. Aboriginal and Torres Strait Islander-led research can also mean that Aboriginal and Torres Strait Islander standpoints and research methodologies are considered and used in research where appropriate.

In the context of Aboriginal and Torres Strait Islander Peoples, ‘community’ is recognised as a complex notion incorporating cultural groups, geographic groups or groups and organisations sharing common interests. Communities are not always geographically based, and can include non-discrete or disperse groups. ‘Community’ is also a term that can be used to describe a shared view amongst Aboriginal and Torres Strait Islander Peoples.

Sometimes Aboriginal and Torres Strait Islander people are the primary focus of a research project, or sometimes they might be part of a broader group with other Australians also involved in the same project. Sometimes Aboriginal and Torres Strait Islander people might be over-represented in some populations or analysed as a specific group within a larger dataset, even though other Australians are also participating in the same research.

About the Guidelines

In general, ethics guidelines provide a set of principles to ensure research is safe, respectful, responsible, high quality, of benefit to Aboriginal and Torres Strait Islander people and communities and of benefit to research. *Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders 2018* (the Guidelines) defines six core values — spirit and integrity, cultural continuity, equity, reciprocity, respect, and responsibility. Applying these values and other ethical principles will ensure that research conducted with or for Aboriginal and Torres Strait Islander people and communities, or their data or biological samples, is ethically conducted.

The Guidelines are intended for use by researchers and ethics review bodies, such as Human Research Ethics Committees (HRECs). Aboriginal and Torres Strait Islander Peoples, individual research participants, participant groups, the wider community and other stakeholders may also find the Guidelines useful.

Advice about how to use the Guidelines is provided on [page 13](#). This includes information about *Keeping research on track II 2018*, which describes how the values and principles in the Guidelines can be put into practice. Additional principles and concepts relevant to research with Aboriginal and Torres Strait Islander Peoples and communities are set out on [pages 15 to 19](#). Key terms, a glossary and a list of further resources are also provided. More information about the Guidelines is available on [NHMRC's website](#).

Structure of the 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. They ensure all human research undertaken with Aboriginal and Torres Strait Islander people 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. The next section describes the meaning of each value in the context of research. There is some overlap between the values and their descriptions and interpretations. Given the diversity of Aboriginal and Torres Strait Islander people 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.

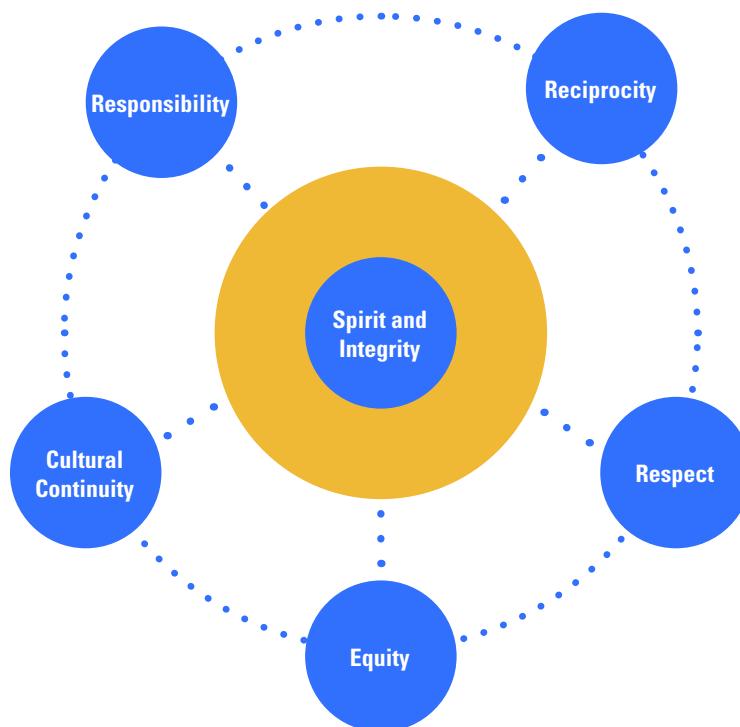


Figure 1 – the six core values³

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 provide examples of how to demonstrate the value, followed by links to relevant sections in the [National Statement on Ethical Conduct in Human Research](#) (the National Statement).

³ 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 the other five values together (see Figure 1). The first part, spirit, is about the ongoing connection and continuity between Aboriginal and Torres Strait Islander Peoples' past, current and future generations. The second part, integrity, is about the respectful and honourable behaviours that hold Aboriginal and Torres Strait Islander values and cultures together.

Spirit and integrity is reflected through:

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

Demonstrating spirit and integrity

Research with Aboriginal and Torres Strait Islander people 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.

Links to the National Statement:

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 preserve 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.
- 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 people 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 respect for the intrinsic values-based expectations and identity of Aboriginal and Torres Strait Islander people and communities.

Demonstrating cultural continuity

Examples of demonstrating cultural continuity in research with Aboriginal and Torres Strait Islander people and communities could include:

- Negotiated participation in cultural events and the sharing of information more broadly (e.g. sacred sites; women's business and men's business).
- Establishing mechanisms that incorporate the balance between collective and individual identity.
- 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.
- Considering the use of Aboriginal and Torres Strait Islander standpoints and methodologies when developing research proposals, where appropriate.

Links to the National Statement:

- 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 that enables Aboriginal and Torres Strait Islander Peoples' culture, history and status to be appreciated and respected.⁴ 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.

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 people and communities to achieve equity in economic, legal, social and health status. In mutually beneficial relationships, the benefits may be tangible or intangible and may take many forms. Some benefits may not relate to the research project in question. The distribution of benefit stands as a fundamental test of equity. The distribution of the benefits of research is also discussed as part of the reciprocity value (see [page 7](#)).

Demonstrating equity

Examples of demonstrating equity in research with Aboriginal and Torres Strait Islander people and communities could include:

- Establishing equitable partnerships between researchers, participants and communities.
- Actively engaging participants and communities in negotiations about the meanings of the research topic and the methods of research.
- Considering (where appropriate) that the first language of the participants be used as part of the communication strategy (e.g. information sheets, consent forms, gathering data, feedback and final reports to participants).
- Ensuring that all legal matters (e.g. intellectual property) are fairly and appropriately addressed in the research agreement or other legal documents (see Cultural and intellectual property on [page 17](#) and Research agreements on [page 16](#)).
- Including participants and communities in all steps of the research process and ensuring that protocols relating to consent have been implemented (see Consent on [page 15](#); see also [Keeping research on track II 2018](#)).

⁴ Distributive fairness and justice is the way that a fair allocation of resources is achieved among diverse members of a community.

Links to the National Statement:

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.

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 people 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 people 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 people and communities may:
 - take more than one form (e.g. better services, training, funding, sharing of knowledge)
 - 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 people 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 acknowledging 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. In mutually beneficial relationships, the benefits may be tangible or intangible and may take many forms. Some benefits may not relate to the research project in question or there may be a lengthy process to realise some benefits. Equitable distribution of benefit is also discussed as part of the Equity value (see [page 6](#)).

Demonstrating reciprocity

Examples of demonstrating reciprocity in research with Aboriginal and Torres Strait Islander people and communities could include:

- Identifying potential unintended consequences or impacts of the research and/or research process and developing strategies to address these where possible.
- Addressing relevant community, regional and/or jurisdictional priorities.
- Addressing existing or emerging needs articulated by Aboriginal and Torres Strait Islander people and communities.
- Establishing the potential benefits and implications of the project in terms of the values and aspirations of Aboriginal and Torres Strait Islander people and communities.
- Providing evidence of a capacity-building or capacity-strengthening development plan that describes how Aboriginal and Torres Strait Islander people and communities will benefit from the project directly (e.g. training, development or infrastructure) and indirectly (e.g. broader social, economic or political strategies at a local or jurisdictional level).

Links to the National Statement:

1.1(d) 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, knowledge, skills, beliefs, perceptions, customs and cultural heritage (both individual and collective) of people involved in research.

Within Aboriginal and Torres Strait Islander cultures, respect is reinforced through, and in turn strengthens, dignity. A respectful relationship promotes 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. A lack of this self-awareness 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 people and communities, researchers and other partners in the research process.
- Ensuring trust, openness and engagement of participating individuals and communities — this is as important as the scientific rigour of the research.
- 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 (see Research agreements on [page 16](#)). This agreement must be respected throughout the research process. In this way, the values of all parties can be equally respected.

Demonstrating respect

Examples of demonstrating respect in research with Aboriginal and Torres Strait Islander people and communities could include:

- Ensuring conditions for consent are satisfied for the research and all related activities (e.g. the engagement and consultation process, research agreements, intellectual property agreements, capacity development plans, knowledge translation plans and other relevant strategies). This means that participant decisions to participate are **voluntary**, the participants are **fully informed**, and that participants **understand** the information. This also relates to the Equity (see [page 6](#)) and Reciprocity (see [page 7](#)) values. See [page 15](#) for more detailed information about consent.
- Outlining how the decision-making process will actively involve Aboriginal and Torres Strait Islander people and communities.
- Negotiating a research agreement with Aboriginal and Torres Strait Islander people and communities that will be continually assessed throughout the research project.
- Engaging with Aboriginal and Torres Strait Islander communities and institutional structures when seeking Human Research Ethics Committee (HREC) approval.⁵

⁵ See [NHMRC's website](#) for more information about HRECs.

- Providing information on how changes and/or cancellations to the project will be communicated, negotiated and endorsed by all stakeholders, including participants, organisations and HRECs (e.g. information sheets, telephone calls, attendance at a community meeting, a board meeting or through a research advisory committee).
- Recognising and acknowledging the individual and collective contribution of Aboriginal and Torres Strait Islander participants and groups (e.g. through acknowledgement in final reports, publications and/or presentations).

Links to the National Statement:

- 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.
- 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:
 - the nature, complexity and level of risk of the research; and
 - 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.

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 the ability of others to comply with their responsibilities. Also, an individual's responsibilities are not limited to them alone and may relate to the accountability of others. Responsibilities may be shared with others so that as a group 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 or to those things that they value. The risk of harm, discomfort or inconvenience to participants and to others must be assessed; and research is ethically acceptable only when its potential benefits justify any risks involved in the research. Information about assessing risk and benefit can be found in [Chapter 2.1 of the National Statement](#).
- 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 Islander people and communities in research, researchers carry responsibilities in addition to the science of their research. The connection between their research and community life brings responsibilities for which the researchers or members of the community may be held accountable. Ethical research occurs when harmony between the sets of responsibilities is established, participants' rights are protected, trust is maintained and mutual accountability is clear. Information about building relationships can be found in [Keeping research on track II 2018](#).

Demonstrating responsibility

Examples of demonstrating responsibility in research with Aboriginal and Torres Strait Islander people and communities could include:

- Negotiating with Aboriginal and Torres Strait Islander people and communities about the project plan, purpose and methodology; feedback of project results and outcomes; and any sharing of intellectual property rights (see [pages 17–18](#) and also [Keeping research on track II 2018](#)).
- Providing all relevant information for the participants prior to seeking consent, so participants and researchers can consider and manage potential implications of research participation for individual participants, communities, and the partners or family members of participants.
- Ensuring the research proposal addresses agreed arrangements about publication of the research results, including clear provisions relating to joint sign-off for publication and ensuring that individuals and/or communities are not identifiable, if appropriate (e.g. through applying privacy-preserving protocols whereby names, places and other identifying features, including biological samples, are removed across datasets such as interview transcripts, diaries or field notes).
- Ensuring that risk management strategies are in place and that these strategies cover all aspects of the research project.
- Engaging participants and communities in monitoring and evaluating ethical research practice to minimise the likelihood of any unintended consequences arising from or occurring after the research project.

Links to the National Statement:

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.

How to use the Guidelines

The Guidelines apply to all research with Aboriginal and Torres Strait Islander people and communities. The Guidelines should inform all steps in the research process including conception (the initial idea), design (planning the research), conduct (ways of doing the research), reporting (what happened), and dissemination of findings (circulation to relevant bodies). The Guidelines apply to all researchers, whether they are Aboriginal or Torres Strait Islander people, other Australians or international researchers.

The application of the Guidelines always requires deliberation on the values and principles and the exercise of judgement, and needs to be considered within the context of different research projects.

The Guidelines should be used in conjunction with the following:

- The [*National Statement on Ethical Conduct in Human Research*](#) (the National Statement) is the principal guideline setting out the requirements for the ethical design, review and conduct of human research in Australia. It is grounded in four main principles: respect; research merit and integrity; justice; and beneficence. This facilitates consideration of the risks and benefits of the research and the level of ethical oversight required. The National Statement aims to be compatible with the interdisciplinary nature of many types and methods of research. The National Statement also has chapters about specific types of research (such as research involving biospecimens, genomics or xenotransplantation).⁶ A research proposal involving Aboriginal and Torres Strait Islander people and communities should meet the requirements of the Guidelines as well as relevant sections of the National Statement.
- The [*Australian Code for Responsible Conduct of Research*](#) (the Code) guides institutions and researchers in responsible research practices. The Code promotes integrity in research and explains what is expected of researchers by the community.
- [*Keeping research on track II 2018*](#) provides advice about how the values and principles in the Guidelines can be put into practice in research projects with Aboriginal and Torres Strait Islander people and communities. It is designed primarily for Aboriginal and Torres Strait Islander people and communities to use when they are considering conducting or being involved with research. It helps people become familiar with the stages in the research journey and make decisions about participating in research. It is also a useful resource for researchers and others interested in research with Aboriginal and Torres Strait Islander people and communities.
- [*Ethical considerations in quality assurance and evaluation activities 2014*](#) is designed to assist organisations in deciding the appropriate level of oversight for quality assurance and evaluation activities. It provides guidance for the consideration of ethical issues and assists in identifying triggers for when quality assurance or evaluations may require ethics review.

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

⁶ National Health and Medical Research Council [NHMRC], Australian Research Council [ARC] & Universities Australia [UA] (2007, updated 2018) [*National Statement on Ethical Conduct in Human Research*](#) (Chapters 3.2, 3.3 and 3.4).

The [Australian Institute of Aboriginal and Torres Strait Islander Studies](#) produces the [*Guidelines for Ethical Research in Australian Indigenous Studies 2012*](#). Researchers may need to use these guidelines as well.

There are various Aboriginal and Torres Strait Islander bodies and organisations that researchers should also engage with, depending on the nature of the research project. These bodies and organisations could be engaged as participants in research, engaged to help researchers recruit suitable participants for research and/or engaged to provide regulatory guidance on the conduct and location of the project.

Related principles

The principles in the Guidelines are consistent with the rights of Aboriginal and Torres Strait Islander Peoples to be involved in all aspects of research undertaken with individuals and within communities and organisations. Some particular principles are detailed below and further information about rights and participating in research are in *Keeping research on track II 2018*. These principles, as well as the six core values, should be reflected in ways appropriate to the context of the research project throughout the eight steps of the research journey. These eight steps are outlined in *Keeping research on track II 2018*.

The 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, the Guidelines affirm the right to self-determination that is contained in Article 1 of the *International Covenant on Civil and Political Rights* and in Article 1 of the *International Covenant on Economic, Social and Cultural Rights*.

Consent

Related to these principles are the rights all people have in terms of **free**, **prior** and **informed** consent in all aspects of the research process. Consent assumes that 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 or community decision-making processes are allowed to operate, and Indigenous peoples' right to choose how they want to live is respected.⁷ 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.
- **Informed:** Implies that information about the project is provided in a clear and understandable way. This includes 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 should also explain that participants can decline to consent or withdraw consent during the research project. 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, 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 the information, then they have not been informed.⁸

⁷ United Nations (2008) *United Nations Declaration on the Rights of Indigenous Peoples*.

⁸ Adapted from 'Free prior and informed consent: Elements of a common understanding', excerpt from the *Report of the International Workshop on Methodologies Regarding Free Prior and Informed Consent E/C.19/2005/3*, Secretariat of the UN Permanent Forum on Indigenous Issues, accessed at <https://www.humanrights.gov.au/publications/2005-international-conference-engaging-communities-free-prior-and-informed-consent>.

The [National Statement](#) uses slightly different terms to describe these same principles and states that respect for people involves giving scope to people's capacity to make their own decisions. In the research context, this normally requires that participation be the result of a choice made by participants. The National Statement specifies that consent has the following conditions: consent should be a **voluntary** choice (free), and should be based on **sufficient information** before any activity begins (prior) and **adequate understanding** of the purpose, methods, demands, risks and potential benefits of the proposed research and the implications of participation in it (informed).⁹ Use of the term 'consent' throughout the Guidelines reflects the application of all three principles as outlined in the [National Statement](#).

Decisions about participation in research may sometimes involve the whole community and not only individuals. Researchers may need to seek community consent as well as individual consent. Research agreements (see below) and letters of support (see [Keeping research on track II 2018](#)) can also assist in gaining community consent.

Consent may be expressed orally, in writing or another way (e.g. by return of a survey, or conduct implying consent such as attending an interview). This will depend on the nature, complexity and level of risk of the research as well as the participant's personal and cultural circumstances.

[See Chapter 2.2 of the National Statement](#).

Communicating information to participants and seeking their consent should not be merely to satisfy a formal requirement. The aim is mutual understanding between researchers and participants. This aim requires an opportunity for participants to ask questions and to discuss the information and their decision with others if they wish.¹⁰ Information that should be provided to participants is listed at [paragraph 2.2.6 of the National Statement](#). Participant information and consent processes should cover all steps in the research process (as outlined in [Keeping research on track II 2018](#)) and any written consent form should refer back to any relevant, detailed information sheet that has been provided to participants.

Research agreements

The purpose of a research agreement is to have a negotiated agreement with Aboriginal and Torres Strait Islander organisations and communities so that each party fully understands what is expected from them and each other. Research agreements are important because they provide protection for organisations and communities involved in the research and for researchers and research institutions. Agreements should be a collaborative process with all parties working together in the development of the agreement. Agreements should include how researchers, organisations and communities will work together respectfully, define roles and responsibilities throughout the research process, identify conflict resolution and complaint processes, outline communication and dissemination strategies, and outline the protection of any intellectual property.

9 NHMRC, ARC & UA (2007, updated 2018) [National Statement on Ethical Conduct in Human Research](#) p.16.

See Chapter 2.2 of the National Statement for further information.

10 NHMRC, ARC & UA (2007, updated 2018) [National Statement on Ethical Conduct in Human Research](#) p.16.

See Chapter 2.2 of the National Statement for further information.

Such agreements will vary in format, formality and complexity, depending on the characteristics of each research project. However, the agreement should be comprehensive and cover all aspects of the research, incorporating ethical principles appropriate when working with Aboriginal and Torres Strait Islander Peoples. In some cases (such as research resulting in commercial products), legal documents will likely be required. When more than one research institution is involved, multi-institutional agreements may be required.

The [*Guidelines for Ethical Research in Australian Indigenous Studies 2012*](#) from the [Australian Institute of Aboriginal and Torres Strait Islander Studies](#) also provides advice about what to include in research agreements.

There is also information about research agreements in [*Keeping research on track II 2018*](#).

Cultural and intellectual property

Aboriginal and Torres Strait Islander Peoples have the right to assert and retain ownership of the cultural and intellectual property related to the information that is provided to a research project and it is important that these rights are respected. Ownership may take many forms, including as rights recognised under Australian and international intellectual property laws. However, cultural and intellectual property is not limited to only those forms of knowledge.

Aboriginal and Torres Strait Islander Peoples have developed a close and unique connection with the country and environments in which they live. They have established distinct systems of knowledge, innovation and practices relating to the uses and management of biological diversity on country and environments. This knowledge forms part of a wider body of Aboriginal and Torres Strait Islander cultural and intellectual property. Much of this knowledge forms an important contribution to research and development, particularly in areas such as pharmaceuticals, and agriculture and cosmetic products. In the context of these uses, Aboriginal and Torres Strait Islander Peoples' rights as traditional holders and custodians of this knowledge have not been adequately recognised or preserved. Given this, Aboriginal and Torres Strait Islander Peoples demand not only recognition and preservation of their traditional knowledge, but also to have a fair and equitable share of any benefits derived from the uses of this traditional knowledge.

Research agreements should cover the management of Aboriginal and Torres Strait Islander cultural and intellectual property rights. It is important to note that Western law may establish different forms of intellectual and cultural property or protect it in different ways to how Aboriginal and Torres Strait Islander Peoples conceive and recognise their cultural and intellectual property. For example, copyright law's conceptions of individual authorship, or the requirement for artistic and literary works to be 'fixed' in a material form, may not guarantee the appropriate recognition or protection of communal or oral forms of knowledge. Copyright law may also not provide sufficient protection for secret or sensitive cultural knowledge and practices from its secondary use by individuals other than the research team.

Likewise, a narrow application of inventorship and ‘prior art’ under patent law may leave Aboriginal and Torres Strait Islander people and communities at risk of commercial exploitation or unable to jointly benefit from the commercialisation of their traditional knowledge.¹¹ Because of these differences, researchers must be sensitive to the limitations of applying standard intellectual property agreements and recognise the differences between intellectual property law and notions of ownership.

Aboriginal and Torres Strait Islander Peoples have the right to discuss co-ownership or to retain ownership of intellectual property. They also have the right to discuss co-authorship and any shared copyright of published and recorded works and performances where this is applicable. This would ensure that Aboriginal and Torres Strait Islander Peoples are able to continue to tell their stories in any form and continue to use the information without complicated circumstances arising.

Aboriginal and Torres Strait Islander cultural and intellectual property has been recognised in the [Australian Institute of Aboriginal and Torres Strait Islander Studies Guidelines for Ethical Research in Australian Indigenous Studies 2012](#) in the form of two principles:

- **Principle 3: The rights of Indigenous peoples to their intangible heritage must be recognised.**

Research projects should be conducted in accordance with the principle of Indigenous peoples’ rights to maintain, control, protect and develop their intangible heritage, including their cultural heritage, traditional knowledge, traditional cultural expressions and intellectual property.

- **Principle 4: Rights in the traditional knowledge and traditional cultural expressions of Indigenous peoples must be respected, protected and maintained.**

Indigenous traditional knowledge and traditional cultural expressions are part of the heritage that exists in the cultural practices, resources and knowledge systems of Indigenous peoples, and that are passed on by them in expressing their cultural identity. To respect, protect and maintain these rights, researchers must have a good understanding of the nature of Indigenous traditional knowledge systems, traditional cultural expressions and intellectual property.¹²

This means anything that is written, spoken or created by Aboriginal and Torres Strait Islander Peoples, whether it is a story, a painting, a sculpture, an object, a dance, a song, or music (cultural practices) and any knowledge of their land, culture or kinship that is used to express their cultural identity, should be considered the cultural and intellectual property of the contributor (and, potentially, their community) and should be respected as such. It is acknowledged that Aboriginal and Torres Strait Islander Peoples’ intellectual property continues to expand via inclusion of contemporary creative and original works that have originated from Aboriginal and Torres Strait Islander cultural heritage.

A number of intellectual property terms are defined in the Glossary on [page 25](#). Some other resources about cultural and intellectual property management and copyright as these relate to Aboriginal and Torres Strait Islander Peoples are provided in the Further resources section on [page 22](#).

This is a complex area, and for detailed information or project-specific guidance, researchers, participants and communities should seek further advice from appropriate professionals in this field.

¹¹ Commercialisation means extracting value from intellectual property by marketing a new product, production method or service based at least partly on that intellectual property (IP Australia, 2017, [Understand Commercialisation](#)).

¹² Australian Institute of Aboriginal and Torres Strait Islander Studies (2012) [Guidelines for Ethical Research in Australian Indigenous Studies 2012](#), pp.5–6

Cultural competency

For research to have merit and integrity, researchers should have appropriate experience, qualifications and competence. Research with Aboriginal and Torres Strait Islander people and communities also requires cultural competence, so researchers can understand and respect cultural differences. Good cultural competence respects cultural differences and is a primary way of demonstrating the core value of respect. This can lead to more effective research that can provide positive results and benefits for Aboriginal and Torres Strait Islander Peoples and communities.

Researchers should receive training or otherwise gain appropriate experience in developing cultural competence prior to undertaking their research with Aboriginal and Torres Strait Islander Peoples and communities. The institutions where researchers are based can play a key role in providing opportunities to develop cultural competence. Use of mentors or other knowledge holders may be an appropriate option, both before research is undertaken and during research projects. Mentors or knowledge holders may be from the institution or from the community with whom research is taking place. There is more information about mentors in [*Keeping research on track II 2018*](#).

Further information

There are many other useful and relevant resources about various aspects of research with Aboriginal and Torres Strait Islander people and communities. Links to other resources are provided in the Further resources section on [page 22](#).

Appendix 1: Expert working committee

The Guidelines and an accompanying companion guide to implementing them ([Keeping research on track II 2018](#)) are revisions of two previous guidelines:

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

In January 2015, NHMRC established the Indigenous Research Ethics Guidelines (IREG) Review Working Committee to undertake the review of Values and Ethics and Keeping Research on Track, 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 a revised guideline and a revised companion guide, [Keeping research on track II 2018](#). These two revised guidelines were released for public consultation from 8 May to 7 July 2017 and 48 submissions were received. Incorporating the feedback received during the public consultation, the IREG Review Working Committee then developed the final revised guidelines. The IREG Review Working Committee provided advice to the [Australian Health Ethics Committee](#) (AHEC), which oversaw the review. These guidelines were recommended for release by AHEC, and then the Council of NHMRC at its meeting on 20–21 March 2018.

The membership of the IREG Review Working Committee is provided below.

IREG Review Working Committee membership

Member	Membership expertise
Ms Chrissy Grant (Chair)	Chair of AIATSIS Research Ethics Committee to June 2014; Ethics Advisor from July 2014 to present.
Professor Samar Aoun	Member of National Statement Review Working Group; member of Australian Health Ethics Committee 2012–15.
Professor Yvonne Cadet-James	Researcher with expertise in Aboriginal and Torres Strait Islander research.
Professor Tom Calma AO	Researcher with expertise in Aboriginal and Torres Strait Islander research.
A/Professor Terry Dunbar	Researcher with expertise in Aboriginal and Torres Strait Islander research.
Ms Summer May Finlay	Expertise in Aboriginal and Torres Strait Islander health policy and research.
A/Professor Jane Freemantle	Researcher with expertise in Aboriginal and Torres Strait Islander research.
A/Professor Daniel McAullay	Member of Australian Health Ethics Committee 2015–18.
Mr Romlie Mokak	Expertise in health policy.
Dr Sanchia Shibasaki	Torres Strait Islander researcher with expertise in health research.

Previous working committee members

Member	Membership expertise
Mr Mick Gooda (Chair) <i>January 2015 – November 2015</i>	Social Justice Commissioner, Australian Human Rights Commission.
Professor Lester-Irlabinna Rigney <i>January 2015 – February 2016</i>	Aboriginal and Torres Strait Islander education expertise.
Mr Daniel Kelly <i>January 2015 – March 2016</i>	State-based nominee from a Human Research Ethics Committee with expertise in Aboriginal and Torres Strait Islander research.

Further resources

Research ethics guidelines and information

[Keeping research on track II 2018](#)

National Health and Medical Research Council

<https://www.nhmrc.gov.au/guidelines-publications/ind3>

[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

<https://www.nhmrc.gov.au/health-ethics/ethical-issues-and-further-resources/ethical-guidelines-research-involving-aboriginal->

[Researching Right Way – Aboriginal and Torres Strait Islander Health Research Ethics: A Domestic and International Review](#)

National Health and Medical Research Council, the Lowitja Institute and the Australian Institute of Aboriginal and Torres Strait Islander Studies

<https://www.nhmrc.gov.au/health-ethics/ethical-issues-and-further-resources/ethical-guidelines-research-involving-aboriginal->

[National Statement on Ethical Conduct in Human Research](#)

National Health and Medical Research Council, Australian Research Council & Universities Australia

<https://www.nhmrc.gov.au/guidelines-publications/e72>

[Australian Code for the Responsible Conduct of Research](#)

National Health and Medical Research Council, Australian Research Council & Universities Australia

<https://www.nhmrc.gov.au/guidelines-publications/r41>

[Guidelines for Ethical Research in Australian Indigenous Studies 2012](#)

Australian Institute of Aboriginal and Torres Strait Islander Studies

<http://aiatsis.gov.au/research/ethical-research/guidelines-ethical-research-australian-indigenous-studies>

[EthicsHub](#)

The Lowitja Institute

<http://www.lowitja.org.au/ethics>

Human Research Ethics Committees (HRECs)

[Human Research Ethics Committees](#)

National Health and Medical Research Council

<https://www.nhmrc.gov.au/health-ethics/human-research-ethics-committees-hrecs>

Intellectual property

Moral Rights

Arts Law Centre of Australia

<https://www.artslaw.com.au/info-sheets/info-sheet/moral-rights/>

Protocols for producing Indigenous Australian writing

Australia Council for the Arts

<http://www.australiacouncil.gov.au/artforms/aboriginal-and-torres-strait-islander-arts/protocols-for-working-with-indigenous-artists/>

Factsheet: Access and Benefit-Sharing

Convention on Biological Diversity

<https://www.cbd.int/abs/information-kit-en/>

Short Guide to Copyright

Department of Communications and the Arts

<https://www.communications.gov.au/documents/short-guide-copyright>

Types of IP

IP Australia

<https://www.ipaustralia.gov.au/understanding-ip/getting-started-with-ip/types-of-ip>

Terri Janke and Company – Lawyers and Consultants

Foster, P. & Janke, T. (2015) 'Keeping cultural knowledge with Indigenous research protocols: a case study on the Kimberley Land Council's Intellectual Property and Traditional Knowledge Policy', *Indigenous Law Bulletin* vol. 8, no.18, pp.17–20 (accessed at <http://www.austlii.edu.au/au/journals/ILB/2015/26.pdf>)

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 (accessed at <http://www.austlii.edu.au/au/journals/AILR/1999/51.html#Heading3>)

KLC Intellectual Property and Traditional Knowledge Policy

Kimberley Land Council

<http://www.klc.org.au/news-media/research-facilitation>

Australian Indigenous Cultural and Intellectual Property Protocol

Museum of Applied Arts and Sciences

<https://maas.museum/about/governance/policies-and-plans/>

Indigenous cultural rights and engagement policy

National Museum of Australia

http://www.nma.gov.au/about_us/ips/policies/indigenous_cultural_rights_and_engagement_policy

Indigenous cultural and intellectual property rights

National Copyright Unit

<http://www.smartcopying.edu.au/copyright-guidelines/hot-topics/indigenous-cultural-and-intellectual-property-rights>

Intellectual Property Management

National Health and Medical Research Council

<https://www.nhmrc.gov.au/grants-funding/policy/intellectual-property-management>

Traditional Knowledge

World Intellectual Property Organization

<http://www.wipo.int/tk/en/tk/>

Research agreements

Aboriginal Health and Medical Research Council of New South Wales

<http://www.ahmrc.org.au/ethics.html>

World Health Organization

http://www.who.int/ethics/indigenous_peoples/en/index10.html

Other information

Aboriginal and Torres Strait Islander Health

National Health and Medical Research Council

<https://www.nhmrc.gov.au/health-topics/aboriginal-and-torres-strait-islander-health>

National Centre for Indigenous Genomics

Australian National University

<http://ncig.anu.edu.au/>

Glossary of terms

Aboriginal and Torres Strait Islander Peoples: In this guideline, this term reflects and respects the cultural diversity of Aboriginal and Torres Strait Islander Peoples and their identities. Aboriginal or Torres Strait Islander Peoples are of Aboriginal or Torres Strait Islander descent and identify as being of Aboriginal and/or Torres Strait Islander origin and are accepted as such by the community with which the person associates.

Beneficence: The ethical principle of doing good to others.¹³

Commercialisation: Commercialisation means extracting value from intellectual property by marketing a new product, production method or service based at least partly on that intellectual property.¹⁴

Community: The term ‘community’ is often used when referring to Aboriginal and Torres Strait Islander Peoples. In this context ‘community’ is recognised as a complex notion incorporating cultural groups, geographic groups or groups sharing common interests. It may include a group or organisation and is also a term used to describe a shared view amongst Aboriginal and Torres Strait Islander Peoples.

Community controlled: A process which allows the local Aboriginal community to be involved in its affairs in accordance with whatever protocols or procedures are determined by the community.¹⁵

Community protocols and standards: Written or implicit cultural and societal ways of doing things (codes) to protect and preserve the wellbeing of the societies (for example, asking permission to enter communities and dressing the right way). Community protocols are rules that the community agrees with on the way they want people to do business with them.

Confidentiality: The obligation of people not to use private information – whether private because of its content or the context of its communication – for any purpose other than that for which it was given to them.¹⁶

Consent: Seeking consent shows respect for people by giving due scope to people’s capacity to make their own decisions. In the research context, this normally requires that participation be the result of a choice made by participants. Consent has the following conditions: consent should be a **voluntary** choice (free), and should be based on **sufficient information** (prior) and **adequate understanding** of the purpose, methods, demands, risks and potential benefits of the proposed research and the implications of participation in it (informed).¹⁷

Copyright: Copyright provides legal protection for people who express ideas and information in certain forms. The most common forms are writing, visual images, music and moving images. Copyright protects literary, dramatic, musical or artistic works, films, sound recording and performances. Copyright vests with the author and, if transferred to another person, the author may retain certain **moral rights**. Moral rights are legal obligations protected under the *Copyright Act 1968* (Cth) to attribute creators and treat their work with respect. Moral rights protect the personal

13 NHMRC, ARC & UA (2007, updated 2018) [National Statement on Ethical Conduct in Human Research](#), p.100.

14 IP Australia (2017) [Understand Commercialisation](#).

15 National Aboriginal Community Controlled Health Organisation, <http://www.naccho.org.au/about/aboriginal-health/definitions/>.

16 NHMRC, ARC & UA (2007, updated 2018) [National Statement on Ethical Conduct in Human Research](#), p.100.

17 NHMRC, ARC & UA (2007, updated 2018) [National Statement on Ethical Conduct in Human Research](#) pp.16–18.

relationship between a creator and their work even if the creator no longer owns the work, or the copyright in the work. There are three types of moral rights:

- right of attribution: this is the right of an author to be identified and named as the author of his/her work
- right against false attribution: this is the right of an author to stop someone else being credited as the author of their work
- right of integrity: this is the right of an author to ensure that his/her work is not subjected to derogatory treatment which is any act in relation to the work that is in any manner harmful to the author's honour or reputation.¹⁸

Country: Aboriginal and Torres Strait Islander Peoples have spiritual, physical and cultural connections to their land. Aboriginal lore and spirituality are intertwined with the land, the people and creation and this forms their cultural identity and sovereignty. Country takes in everything within the landscape – landforms, waters, air, trees, rocks, plants, animals, foods, medicines, minerals, stories and special places. Community connections include cultural practices, knowledge, songs, stories and art, as well as all people: past, present and future.

Health: 'Aboriginal health' means not just the physical wellbeing of an individual but refers to the social, emotional and cultural wellbeing of the whole community in which each individual is able to achieve their full potential as a human being, thereby bringing about the total wellbeing of their community. It is a whole-of-life view and includes the cyclical concept of life-death-life.¹⁹

Human rights: Human rights are rights inherent to all human beings, irrespective of nationality, place of residence, sex, national or ethnic origin, colour, religion, language, or any other status. All people are equally entitled to their human rights without discrimination. These rights are all interrelated, interdependent and indivisible.

Indigenous Cultural and Intellectual Property: Refers to all aspects of Indigenous peoples' cultural heritage, including the tangible and intangible. This cultural heritage includes all traditional and cultural knowledge (sciences, plant and animal knowledge, stories, designs and symbols, ritual knowledge, literature and language), cultural objects (including, but not limited to, arts, crafts, ceramics, jewellery, weapons, tools, visual arts, photographs, textiles and contemporary art practices), performances (ceremonies, dance and song), human remains, the secret and sacred (including sites) and documentation of Indigenous heritage.²⁰

Indigenous knowledge: Indigenous peoples have developed a close and unique connection with the country and environments in which they live. They have established distinct systems of knowledge, innovation and practices relating to the uses and management of biological diversity on country and environments. Much of this knowledge forms an important contribution to research and development, particularly in areas such as pharmaceuticals, and agriculture and cosmetic products.

Indigenous people(s): There is no universally accepted definition for Indigenous peoples. Indigenous communities, peoples and nations are those who have a historical continuity with pre-invasion and pre-colonial societies that developed on their territories. They consider themselves distinct from other sectors of the societies now prevailing on those territories, or parts of them. They form at present non-dominant sectors of society and are determined to preserve, develop and transmit to future generations their ancestral territories, and their ethnic identity, as the basis of their continued existence as peoples, in accordance with their own cultural patterns, social institutions and legal system. In Australia, the term 'Indigenous' is used to describe both Aboriginal and Torres

18 Based in part on: <https://www.artslaw.com.au/info-sheets/info-sheet/moral-rights/>

19 National Aboriginal Health Strategy Working Party (1989) *National Aboriginal Health Strategy*.

20 Museum of Applied Arts and Sciences (2016) *Australian Indigenous Cultural and Intellectual Property Protocol*.

Strait Islander Peoples. Many Aboriginal and Torres Strait Islander people prefer to identify with their language group/s and traditional land/s from where they trace their ancestry.

Indigenous person: One who belongs to Indigenous populations through self-identification as Indigenous and is recognised and accepted by these populations as one of their members.

In-kind: In-kind support is a way of providing support without money (e.g. time, buildings, machines, transport, reference group, mentoring, etc.) to a research project.

Integrity: Integrity generally means doing the right thing in a reliable way. Research integrity is carried out by researchers with a commitment to searching for knowledge and understanding; following recognised principles of research conduct; honesty; and disseminating and communicating results in ways that permit scrutiny and contribute to public knowledge and understanding.

Intellectual property: Intellectual property (IP) refers to creations of the mind, such as inventions; literary and artistic works; designs; and symbols, names and images used in commerce. Common forms of IP recognised under Australian law include copyright, patents, trademarks, designs, trade secrets and geographical indications (e.g. only sparkling wine produced in the Champagne region of France can be called ‘Champagne’). Most IP rights are created by a law of Parliament, e.g. the *Copyright Act 1968* (Cth), *Patents Act 1990* (Cth) and *Designs Act 2003* (Cth).

Justice: Fairness or protection of rights and punishment of wrongs. In research it is 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; the process of recruiting participants is fair; there is no unfair burden of participation in research on particular groups; there is fair distribution of the benefits of participation in research; there is no exploitation of participants in the conduct of research; and there is fair access to the benefits of research.²¹

Knowledge systems: Knowledge systems can include traditional knowledge and new or emerging knowledge. Knowledge systems can also be considered as intellectual property (see **Intellectual property**).

Knowledge translation: Knowledge translation can be defined as a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically sound application of knowledge to improve health, provide more effective health services and products and strengthen the health care system.²² It also applies to other relevant fields such as housing, personal safety and wellbeing, and education.

Mentor: A community or organisation member who helps to make sure that the researchers stay on the right path, and that the project remains within cultural bounds and is safe for everyone involved. Mentors may also be from institutions and mentors may also be referred to as ‘knowledge holders’.

Mob: Regularly used to mean a cohesive group of people, as in my people, my extended family or language group.

Ownership: Ownership is a complex matter and should not be confused with intellectual property or confined to a legally recognised right to possession and exclusive use of land or a thing. Ownership of Indigenous cultural and intellectual property may be shared or communal and may arise through traditional use or occupation. It may extend to the tangible or intangible (for example ‘heritage’).

²¹ NHMRC, ARC & UA (2007, updated 2018) *National Statement on Ethical Conduct in Human Research*, p.10.

²² Adapted from Government of Canada, Canadian Institutes of Health Research, Knowledge Translation, ‘About Knowledge Translation – CIHR’, www.cihr-irsc.gc.ca.

Privacy: A domain within which individuals and groups are entitled to be free from the scrutiny of others.²³

Protocols: A written list of guidelines developed by organisations or communities to set out how they expect outside stakeholders to engage with them.

Traditional knowledge: Traditional knowledge refers to the knowledge, innovations and practices of Indigenous and local communities around the world. Developed from experience gained over the centuries and adapted to the local culture and environment, traditional knowledge is transmitted orally from generation to generation. It tends to be collectively owned and takes the form of stories, songs, folklore, proverbs, cultural values, beliefs, rituals, community laws, local language and agricultural practices, including the development of plant species and animal breeds.²⁴

Wellbeing: For Aboriginal and Torres Strait Islander Peoples, wellbeing incorporates health and broader issues of social justice, equity and rights. The significance of culture to wellbeing, and therefore good health, is also demonstrated by using traditional knowledge and the practices of traditional healers, which are adapted by many people for complementary use with Western science in an integrated health care system.²⁵

23 NHMRC, ARC & UA (2007, updated 2018) [*National Statement on Ethical Conduct in Human Research*](#), p.102.

24 <https://www.cbd.int/traditional/intro.shtml>.

25 Australian Government (2013) *National Aboriginal and Torres Strait Islander Health Plan 2013–2023*, p.9.

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