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## Contents

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## Key terms

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11.11.11

[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

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## Acknowledgements

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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 

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.

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## Introduction

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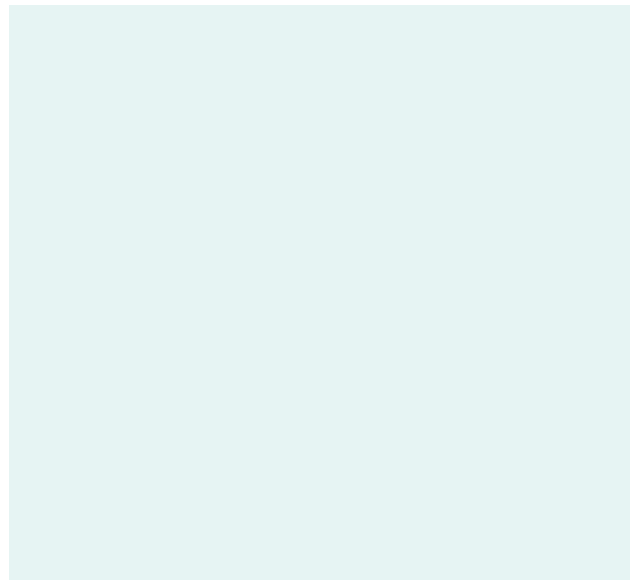
The health, wellbeing and experiences of Aboriginal and Torres Strait Islander Peoples<sup>1</sup> continue to be the focus of much research to promote positive outcomes. Over the years, research has contributed to positive outcomes and benefits in, for example, health, medicine and education, and in 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.<sup>2</sup> 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.



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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'](#), [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

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.

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## Structure of the Guidelines: the six core values

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The six core values (see Figure 1) – spirit and integrity, cultural continuity, equity, reciprocity, respect,



## 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:

- ) searching for knowledge and understanding;
- ) following recognised principles of research conduct;
- ) conducting research honestly; and
- ) 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:

- ) searching for knowledge and understanding;
- ) following recognised principles of research conduct;
- ) conducting research honestly; and
- ) 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.



#### Links to the National Statement:

##### 1.4 In research that is just:

- .) 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.

##### 1. Researchers are responsible for:

- .) designing the research to minimise the risks of harm or discomfort to participants;
- .) clarifying for participants the potential benefits and risks of the research; and
- .) the welfare of the participants in the research context.

##### 1. 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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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.





- Providing information on how changes and/or cancellations to the project will be communicated,

## 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:

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Links to the National Statement:

**1.1** Research that has merit is:

- ) 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;
- ) designed or developed using methods appropriate for achieving the aims of the proposal;
- ) 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;
- ) 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;
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## How to use the Guidelines

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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).<sup>6</sup> 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 [National Health and Medical Research Council \(NHMRC\) Australian Research Council \(ARC\) & Universities Australia \(UA\) Code of Ethics for Human 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.
- [Ethical Conduct in Research with Aboriginal and Torres Strait Islander Peoples and Communities: Guidelines for Researchers and Stakeholders](#) 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.
- [Quality Assurance and Evaluation Guidelines for Research with Aboriginal and Torres Strait Islander Peoples and Communities](#) 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.

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<sup>6</sup> 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 Researchers](#). 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.

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## Related principles

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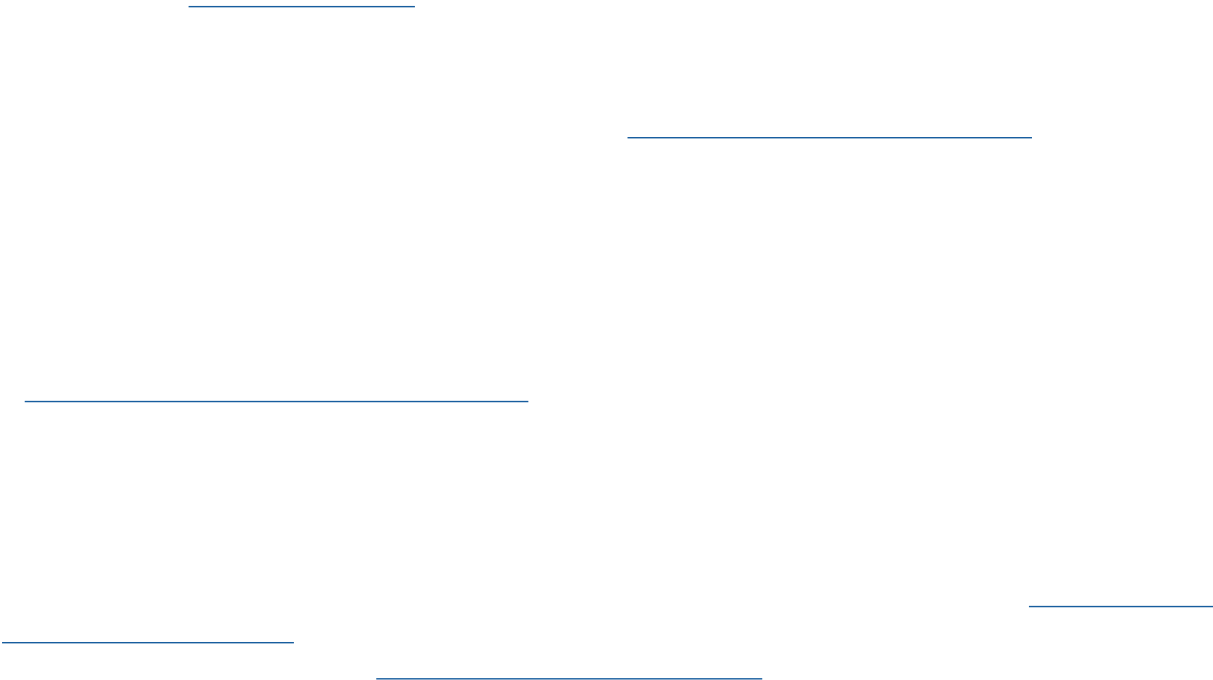
The principles in the Guidelines are consistent with the rights of Aboriginal and Torres Strait Islander Peoples to be involved in all aspects of research undertaken with individuals and within communities and organisations. Some particular principles are detailed below and further information about rights and participating in research are in [\\_\\_\\_\\_\\_](#)

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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



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.

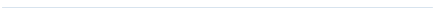
There is also information about research agreements in [\\_\\_\\_\\_\\_](#).

## 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,









## Previous working committee members

Member	Membership expertise
(C 1) 2015 - 2015	C 1, A 1, C 1
2015 - 2016	A 1
D 1 2015 - 2016	E 1, C 1, A 1





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National Copyright Unit

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

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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/>

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

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National Health and Medical Research Council

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

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Australian National University

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

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## Glossary of terms

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**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.<sup>13</sup>

**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.<sup>14</sup>

**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 consultation** 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.<sup>15</sup>

**Community protocols** : 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.<sup>16</sup>

**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 information (prior) and understanding of the purpose, methods, demands, risks and potential benefits of the proposed research and the implications of participation in it (informed).<sup>17</sup>

**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.

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.<sup>18</sup>





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

**Code of conduct:** 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.<sup>24</sup>

**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.<sup>25</sup>

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



