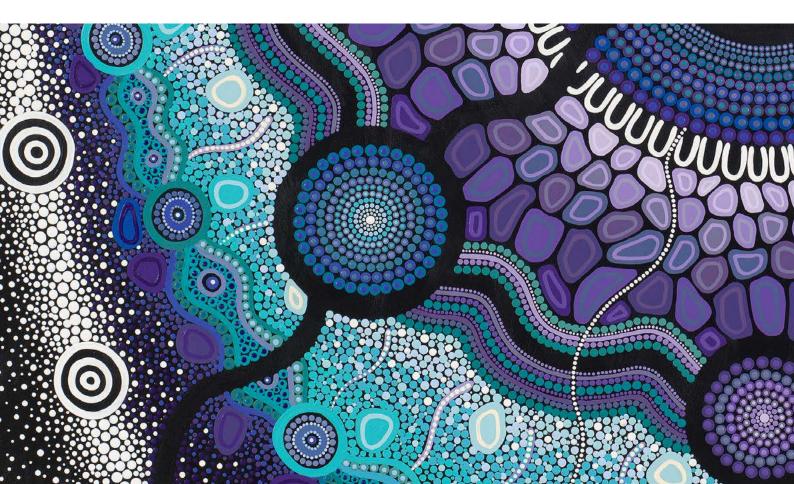




# A Guide to applying The AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research

Warning: Aboriginal and Torres Strait Islander readers should be aware that this document may contain sensitive information, images or names of people who have since passed away.



First published in 2020 by Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS)

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The AIATSIS logo is derived from the Koko Bera-Kungen Shield created by George Wilson, Claude Ponto and John William Malcolm. The logo was first published by the Institute's Council in 1963. Today, AIATSIS continues to work with the families of the creators to develop the story of the shield.

The featured artwork is by Kamilaroi artist Leah Brideson and was commissioned for the AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research. Leah is a descendent of the Kamilaroi people from the Gunnedah region. Leah is a self-taught Aboriginal artist who creates 'Visual Yarns' or stories through her paintings, in which are inspired from her Country, her family history, her culture and the local landscape. Leah also works for the ACT Education Directorate as a Cultural Integrity Coordinator, supporting schools and teachers to embed Aboriginal and Torres Strait Islander cultures in the curriculum whilst using art as a platform to share her culture and educate the wider community. The artwork is now part of the AIATSIS Collection.

#### Title: Warranggal Baynyi ('strong ripple' in Gamilaraay language)

This piece represents a strong ripple of perspectives, relationships and knowledge in Aboriginal and Torres Strait Islander research. Encompassing the central principal of integrity, the open pathways of understanding, respect, relationship building and reciprocity connect the four principles of leadership, self-determination, impact and value and sustainability and accountability (four outer circles). All concepts within this piece are interconnected with the relationship Aboriginal and Torres Strait Islander people have with the land, water and sky and holistically acknowledges our strengths, knowledge, beneficence and cultural integrity.

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# The AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research – why a new Code?

AIATSIS first published ethics guidelines in 1999 and, at the time, they represented a new approach to research ethics that repositioned Indigenous peoples from subjects of research to partners in research. The guidelines were regularly revised to reflect developments in critical areas that had emerged since previous editions. To mark the twentieth anniversary of the AIATSIS guidelines, we have undertaken a comprehensive review to ensure that AIATSIS continues to set the highest standards of ethics and support for human rights in Aboriginal and Torres Strait Islander research. While the principles in the 2012 edition are largely retained, they have been reorganised into a new framework and augmented to reflect emerging standards and developments.<sup>1</sup>

The review was guided and informed by the AIATSIS Research Ethics Committee, the AIATSIS Research Advisory Committee, the AIATSIS Council, roundtables of Pro Vice Chancellors (Indigenous), consultation with key stakeholders, public submissions and expert advice.

<sup>1</sup> For cross-references to the fourteen principles in the previous AIATSIS Guidelines for Ethical Research in Australian Indigenous Studies 2012 (GERAIS), <u>https://aiatsis.gov.au/research/ethical-research/guidelines-ethical-research-australian-indigenous-studies</u>

# How to apply the AIATSIS Ethics principles

This guide provides advice for researchers in applying the principles in the AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research (the AIATSIS Code of Ethics or this Code). It is also useful for ethics review bodies to identify practical ways in which the principles should be evident in project design. The best ethical research practice occurs in the partnership, design and planning stages of a project. However, ethical practice permeates every stage of the research process and should be revisited regularly as research proceeds. In addition, where a researcher or community encounters a project that is already underway, it is important to take stock of the ethical underpinnings of the project and adjust as required. In acknowledging this, this Guide to Applying the AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research provides practical information on how you may apply the principles in four main stages of your research:

- 1. getting started
- 2. implementing your project
- 3. communicating research results
- 4. post-project.

This Guide is designed to encompass a range of different project methodologies:

- quantitative methods (surveys, big data, statistics)
- qualitative methods (ethnographic, case studies, interview based)
- mixed methods (participatory action, focus groups, workshops)
- working with documents (historical, archival, discourse analysis).

The Guide offers a range of best practices and ideas for any person engaging in ethical research. For more detailed information specific to particular types of research, for example large surveys, please refer to the supporting case studies on the <u>AIATSIS Ethics webpage</u>.<sup>2</sup>

We plan to expand our range of resources and tools. If you have suggestions for or contributions to the AIATSIS ethics resources, please contact us at <u>ethics@aiatsis.gov.au</u>

<sup>2</sup> AIATSIS n.d. Ethical Research, <u>https://aiatsis.gov.au/research/ethical-research</u>

#### 1. Getting started

- **1.1 Establishing priorities**
- 1.2 Self-reflection and cultural capability
- 1.3 Understanding Indigenous cultural intellectual property
- 1.4 Indigenous engagement and project governance
- 1.5 Setting up a research partnership and collaboration
- 1.6 Negotiating and reaching agreement
- 1.7 Defining benefits
- 1.8 Managing risk
   1.9 Research agreements
- 1.10 Project design and planning for impact
- 1.11 The ethics process

#### 2. Project implementation

- 2.1 Obtaining informed consent
- 2.2 Gathering the data
- 2.3 Interpreting and analysing the data
- 2.4 Reviewing, revising and finalising

#### 3. Communicating research results

- 3.1 Authorship and attribution
- **3.2 Writing for publication**
- 3.3 Publication

#### 4. Post-project

- 4.1 Indigenous data governance
- 4.2 Storage and archiving
- 4.3 Access and use
- 4.4 Post-project engagement
- 4.5 Monitoring and compliance

Figure1: Research stages

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## 1. Getting started

#### **1.1** Setting priorities for research

Before you conduct any research, you should consider if your proposed research project is addressing a priority that has been determined or agreed upon by Aboriginal and Torres Strait Islander peoples, whether at a national or local level. Aligning your research with these priorities, rather than asking Indigenous communities to contribute to your interests, is a key to the principle of Indigenous-led research.

There are national priority setting exercises such as the <u>Uluru Statement from the Heart</u><sup>3</sup>, or the <u>National</u> <u>Agreement on Closing the Gap</u><sup>4</sup> that includes four priority areas for reform, a series of targets and measures and evidence and data needs, primarily addressed to socio-economic change. National studies such as the AIATSIS Prescribed Bodies Corporate (PBC) Survey<sup>5</sup> contain information on needs and aspirations of Traditional Owner groups, among other sources.

Institutions such as universities may have established consultation or advisory mechanisms to determine Indigenous research strategies that respond to the needs and priorities of their Indigenous stakeholders or local communities.

Locally, it is beneficial to engage with Indigenous organisations to find out about their aspirations and priorities, and some may have existing research needs specifically identified.

#### 1.2 Self-reflection and cultural capability

The capability and competency of the research team is a key consideration in ethical review of research. Researchers or teams undertaking Aboriginal and Torres Strait Islander research must demonstrate that they have experience, knowledge and understanding of the cultural context in which they are working. No research is purely objective and no researcher is without bias. Before undertaking Australian Indigenous research, it is important to reflect on your own worldview and how that might affect the research. For example:

- Are you the right person to be doing the work?
- Are you or your collaborative researchers working with Aboriginal and Torres Strait Islander researchers?
- What cultural or disciplinary strengths or biases do you bring to the research?
- Are you working within your own community? How will this impact your research?
- What is your motivation for doing this research and what will you bring to the research?
- What is the Aboriginal and Torres Strait Islander involvement in the research, for example through governance and/or partnerships?
- How culturally competent is the research team?
- Are you able to accept criticism and adapt your approach in response?
- Have you considered any unconscious bias you may have and your standpoint?

Aboriginal and Torres Strait Islander worldviews and Western worldviews differ on the origins of authority. While authority in Western systems is given through roles and bureaucracy, authority in Aboriginal and Torres Strait Islander communities is based on age, cultural knowledge and relationships. In many Aboriginal

<sup>3</sup> National Constitutional Convention 2017, Uluru Statement from the Heart, https://ulurustatement.org/the-statement

<sup>4</sup> Closing the Gap in Partnership 2020, National Agreement on Closing the Gap, <u>https://www.closingthegap.gov.au/sites/default/</u> <u>files/files/national-agreement-ctg.pdf</u>

<sup>5</sup> Prescribed Bodies Corporate Survey, <u>https://aiatsis.gov.au/prescribed-bodies-corporate-survey-2019</u>

and Torres Strait Islander cultures, Elders — as distinct from others who may hold specific offices or jobs — are the bosses. The process of decolonising research includes recognising and honouring the role and status of Elders in Aboriginal and Torres Strait Islander culture and putting them at the centre of the research process.

Cultural competency means having the awareness, skills and know-how to account for all backgrounds, experiences and knowledge in your interactions with others. Consider whether the cultural competency of your project team might be improved by a course or some further learning. There are a number of cultural competency training courses available that are specifically directed toward Aboriginal and Torres Strait Islander contexts, some of which can be completed online or delivered by the Aboriginal and/or Torres Strait Islander community with whom you will be working. Cultural competency is a life-long journey and you should consider taking part in cultural learning opportunities relevant to your current capabilities and proposed research.

#### 1.3 Understanding Indigenous Cultural and Intellectual Property

Researchers have a responsibility to understand the interaction of knowledge systems and legal systems in research practice. All Aboriginal and Torres Strait Islander research involves the use of Indigenous Cultural and Intellectual Property (ICIP) in one form or another. ICIP refers to all aspects of Indigenous peoples' cultural heritage, including the tangible and intangible.<sup>6</sup>

Cultural heritage includes:

- laws, philosophical traditions and spiritual beliefs
- knowledge and knowledge systems (scientific, agricultural, technical, ecological and ritual knowledge)
- cultural expression (stories, designs and symbols, literature and language)
- performances (ceremonies, dance and song)
- cultural material (including, but not limited, to arts, crafts, ceramics, jewellery, weapons, tools, visual arts, photographs, textiles and contemporary art practices)
- human remains, human tissue, genetic information<sup>7</sup> and material obtained or derived from human tissue (including plasma, proteins, DNA and RNA, for example), or processed forms of material of this kind
- knowledge about genetic resources<sup>8</sup>
- secret and sacred material and information (including sacred and/or historically significant sites and burial grounds)
- the documentation of Indigenous peoples' heritage in all forms of media such as films, photographs, artistic works, books, reports and records taken by others, sound recordings and digital databases
- connections to land, waters, natural resources and ecologies
- cultural places, sites and landscapes.
- 6 Kearney, J and Janke, T 2018, Rights to Culture: Indigenous Cultural and Intellectual Property (ICIP), Copyright and Protocols, Terri Janke and Company, <u>http://www.terrijanke.com.au/single-post/2018/01/29/Rights-to-Culture-Indigenous-Cultural-and-Intellectual-Property-ICIP-Copyright-and-Protocols</u>

<sup>7 &#</sup>x27;Genetic information' refers to all information about a person's health and physical well-being. It can include information about a person's gender, race, height, weight, and other features that are related, in whole or in part, to that person's genetic inheritance. See <u>Australian Law Reform Commission</u>: <u>https://www.alrc.gov.au/publication/essentially-yours-the-protection-of-human-genetic-information-in-australia-alrc-report-96/03-coming-to-terms-with-genetic-information/what-is-genetic-information/</u>

<sup>8 &#</sup>x27;Genetic resources' means genetic material of actual or potential value. 'Genetic material' means any material of plant, animal, microbial or other origin containing functional units of heredity (<u>Convention on Biological Diversity</u>, Article 2, <u>https://www.cbd.int/convention/text/</u>).

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#### 1.3.1 Indigenous Cultural and Intellectual Property Rights

Indigenous Cultural and Intellectual Property Rights refer to the rights of Indigenous peoples to:

- own, control and maintain their ICIP
- ensure that any means of protecting ICIP is based on the principle of self-determination
- be recognised as the primary guardians and interpreters of their cultures
- authorise or refuse the use of ICIP according to their own law
- maintain the secrecy of Indigenous knowledge and other cultural practices
- guard the cultural integrity of their ICIP
- be given full and proper attribution for sharing their cultural heritage
- control the recording of cultural customs, expressions and language that may be intrinsic to cultural identity, knowledge, skill and teaching of culture<sup>9</sup>
- publish their research results.

When undertaking Australian Indigenous research, it is important that you:

- understand the relevant laws and policies for the protection and maintenance of Indigenous intangible heritage, and international standards such as <u>The Protection of Traditional Cultural Expressions/Expressions</u> of Folklore: Revised objectives and principles, and <u>The Protection of Traditional Knowledge</u>: Revised objectives <u>and principles</u>, and the 2003 UNESCO <u>Convention for the Safeguarding of the Intangible Cultural Heritage</u><sup>10</sup>
- be aware of current laws and standards, both internationally and in Australia, that relate to specific areas of research, for example areas of biology, including genomics and ethnobotany
- consider how a proposed use of intangible heritage might affect the future use of that cultural heritage by others who are entitled to inherit it.

When using genetic resources and associated knowledge, it is important that you:

- understand and implement the <u>Convention on Biological Diversity</u> 1992 and the <u>Nagoya Protocol</u> <u>on Access to Genetic Resources and the Fair and Equitable Sharing of Benefits Arising from their</u> <u>Utilization to the Convention on Biological Diversity</u><sup>11</sup>
- refer to the National Health Genomics Policy Framework and Implementation Plan 2018–2021<sup>12</sup>
- enter into access and benefit sharing agreements if collection of genetic resources is sought, even if the uses are non-commercial
- disclose the use of Indigenous genetic resources and/or knowledges associated with genetic resources in research outcomes (e.g. patent applications)
- promote the equal recognition of Indigenous knowledge holders who collaborate with scientists as 'inventors' and promote joint ownership of intellectual property (such as patents and plant breeders' rights) as outcomes, as best practice.

10 https://www.wipo.int/meetings/en/doc\_details.jsp?doc\_id=132330; https://www.wipo.int/meetings/en/doc\_details.jsp?doc\_id=144441; https://ich.unesco.org/en/convention

12 https://www1.health.gov.au/internet/main/publishing.nsf/Content/national-health-genomics-policy-framework-2018-2021

<sup>9</sup> Kearney, J and Janke, T 2018 Rights to Culture: Indigenous Cultural and Intellectual Property (ICIP), Copyright and Protocols, Terri Janke and Company, <u>http://www.terrijanke.com.au/single-post/2018/01/29/Rights-to-Culture-Indigenous-Cultural-and-Intellectual-Property-ICIP-Copyright-and-Protocols</u>

<sup>11</sup> https://www.cbd.int/convention/text/; https://www.cbd.int/abs/text/

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While there are various legislative instruments in place, the AIATSIS Code of Ethics can assist in ensuring best practice is met while addressing the requirements of the legislation, where there is a gap in the legislation in a particular jurisdiction, or with regard to particular types of research.

It is also important to note that ICIP rights are not well reflected in Australian copyright law. While copyright laws cover things in material form, ICIP rights extend to all forms of tangible and intangible heritage and culture. Some of the ways that copyright legislation does not adequately address ICIP rights include:

- Australian copyright law covers ideas in a material form, for example the written form. In contrast, Aboriginal and Torres Strait Islander knowledge and stories derive from an oral culture, meaning they were not written down but were shared in a spoken form.
- The period of copyright in Australian law is the life of the author plus seventy years, whereas Aboriginal and Torres Strait Islander stories have existed for hundreds and thousands of years.
- Copyright law is focused on managing commercial advantage and not the cultural integrity of knowledge and works. For example, it does not protect stories that might, in Indigenous culture and law, be considered sacred and restricted to initiated people or to people of different genders or ages.
- Copyright focuses on individuals' rights rather than communal rights such as those that apply to traditional stories, the rights in which are held jointly and for future generations.<sup>13 14</sup>

For these reasons, ICIP in Australia is primarily regulated though agreements and protocols. As a result, you may need to enter into a legally binding agreement to transfer rights that you may hold or acquire under Australian law as the result of your research to Indigenous partners and collaborators to protect their ICIP.

#### 1.4 Indigenous engagement and project governance

The AIATSIS Code of Ethics complements the <u>Australian Code for Responsible Conduct of Research<sup>15</sup></u> and the <u>National Statement on Ethical Conduct in Human Research<sup>16</sup></u> and has moved from a model of consultation and participation to an engagement model. This is a different standard and may require a rethinking of previous practice. Different types of research require different, or sometimes multiple, forms of engagement with Aboriginal and Torres Strait Islander peoples. It is useful to think about types of engagement on a spectrum that takes into consideration the number of people engaged and the depth of that engagement.

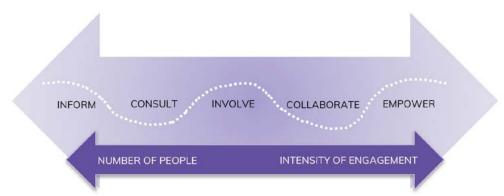


Figure 2: Engagement spectrum adapted from IAP2: International Association for Public Participation. Source: AIATSIS Core Cultural Learning: Aboriginal and Torres Strait Islander Australia (Foundation Course) 2016.

<sup>13</sup> Janke, T 2007, Protocols for producing Australian Indigenous writing, Australia Council for the Arts, Sydney, https://www.australiacouncil.gov.au/workspace/uploads/files/writing-protocols-for-indigeno-5b4bfc67dd037.pdf

<sup>14</sup> Australia Council for the Arts, Protocols for using First Nations Cultural and Intellectual Property in the Arts, Sydney, https://www.australiacouncil.gov.au/workspace/uploads/files/protocols-for-using-first-nati-5f72716d09f01.pdf

<sup>15</sup> https://www.nhmrc.gov.au/sites/default/files/documents/attachments/grant%20documents/The-australian-code-for-theresponsible-conduct-of-research-2018.pdf

<sup>16</sup> https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2007-updated-2018

- **Inform:** provide factual information and data to help people understand a problem or project and to look for opportunities and/or solutions, or to explain outcomes of a project and/or decisions taken, the reasons they were taken, and the intended benefits.
- **Consult:** obtain feedback from communities, hear concerns and aspirations, and gather information to help guide the development of projects, analysis, alternatives and/or decisions.
- **Involve:** provide a two-way exchange of information throughout the process that encourages meaningful discussion and provides an opportunity for people to influence outcomes.
- **Collaborate:** work in partnership with Aboriginal and Torres Strait Islander people to ensure all parties are able to provide input and formulate options and preferred solutions.
- Empower: place decision making in the hands of the research partners, participating group or community.

For some projects, you will be working with a clearly defined community, for example, working within a particular locality or with a First Nation or Traditional Owner group, but for other projects, the 'community' may not be place based — it may be regional, national or online, such as for a national survey. Or it may be determined by another factor, such as age, gender or occupation, for example, conducting research with Aboriginal and Torres Strait Islander mothers working in the Australian Public Service. For research that extends beyond the bounds of a residential community or First Nation community, it will be important for you to recognise the diversity of Indigenous communities, to consult widely and where possible to have Indigenous leadership and/or researchers directly engaged on the project.

For research that involves particular community/ies or organisations, you will need to negotiate a partnership based on strong decision making and governance as the best option (this takes place at the Collaborate and Empower end of the scale). Partnership options may include:

- co-designing the project together, including joint development of aims, outcomes and methods
- negotiating a research agreement together that best meets the needs of the community and the project
- joint project leadership
- employment of staff from the community
- ownership of data consent, re-use and long-term access to data
- joint authorship
- joint project representation and communication, for example, co-presenting at conferences.

For other projects, such as large-scale surveys or policy analysis, Indigenous leadership may be demonstrated through:

- having Indigenous members of the project team as lead investigators or senior staff
- partnering with a national or regional Indigenous organisation or local/regional research-approval committees
- working with an Indigenous project steering committee that has a genuine say in project design and planning and monitoring
- engage with Indigenous scholars and specialists for project advice and review
- project/user testing with an Indigenous reference group.

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If you as a researcher inherit a partially completed project, you should first seek appropriate guidance as to whether or not the project should continue. One consideration will be the extent of participation already negotiated with the Indigenous organisation/community. Some of the ways to ensure meaningful participation by Aboriginal and Torres Strait Islander peoples include to:

- employ Aboriginal and Torres Strait Islander project staff
- form an Aboriginal and Torres Strait Islander committee to provide advice for remaining parts of the project, in particular in analysis and conclusions
- seek involvement from Aboriginal and Torres Strait Islander organisations or corporations that may have a shared interest in the topic.

#### **1.5** Setting up a research partnership and collaboration

For many types of Aboriginal and Torres Strait Islander research, there is benefit in grounding the research in particular local contexts and case studies. A strong research partnership and collaboration negotiated at the beginning of the project will provide you with the foundation for an ethical project that has benefits for all stakeholders.

#### 1.5.1 Initial consultation and relationship building

To ensure that Aboriginal and Torres Strait Islander peoples are full partners in the research and can determine their involvement, it is important to engage with them and their communities prior to formally starting the project. Where possible, work with communities and/or committees to determine the aims, goals and design of the project; the roles and responsibilities of the research team and communities; and where resources and funding might be sourced and how they will be distributed.

When you are undertaking initial consultations:

- identify the organisations or individuals that have cultural authority to represent and make decisions about collective rights and interests and cultural heritage
- identify Indigenous regional, local and community and/or other organisations that have relevant skills, knowledge or interests
- understand the legal framework under which you are working, in terms of local Indigenous, state, national and international laws and policies
- identify the appropriate Aboriginal and Torres Strait Islander communities and individuals to involve in discussing research aims, methods and outcomes
- work with local people to understand and best fit the project with the research needs and priorities of the community
- engage or enlist local researchers or cultural liaison and engagement experts from within the community to better understand the local language(s) (where applicable), decision making and customary laws.

#### 1.5.2 Identifying the right people to work with

When beginning initial discussions with a community, it is important that you identify the right people to speak with to ensure fair representation across the community, where appropriate. Traditional Owners and Elders play an important role in any community and may be a first point of contact. Some steps that may help to identify the right people include:

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- identify any written research protocols or other community protocols that need to be followed (note that many communities may have developed their own protocols for conducting research)
- approach a representative organisation, such as a native title corporation, land council or cooperative
- in some case an Elders Council or law bosses might be the appropriate authority but to access such bodies you may require a community contact
- ask if there are groups or families whose interests are not represented by the organisations you are liaising with and seek advice about how to engage with them
- be respectful of local differences, for example between family groups, or differences in gender or age and how you can be appropriately inclusive, which may involve holding multiple meetings with separate groups
- acknowledge that consultation is an ongoing process and that this is just the beginning it may take time to find the most appropriate people to work with.

#### 1.5.3 Evidence of support

If a community or organisation decides to go ahead with a project, evidence of support will be required for ethics review to demonstrate that the partnership and negotiations have been carried out in good faith.<sup>17</sup> The conventional way of providing such evidence is through letters of support. However, evidence may also be provided in other ways, such as through a partnership agreement or project sponsorship by the community. For example, it may cause offence for a HREC to ask for letters of support for a project that is sponsored or auspiced by the community themselves. Indeed, it may be more appropriate for the community to seek letters of support from their university partners. Therefore, human research ethics committees (HRECs) need to be conscious of how evidence of community support is provided.

A letter of support or other evidence of support should demonstrate the organisation's understanding of their role, obligations and responsibilities of support for and involvement with your research. This is particularly important for projects involving local case studies and qualitative research. If the project does not involve a clear 'community', the evidence of support may instead come from an Indigenous organisation, advisory committee or leadership body with which you are working. In some low-risk, small-scale projects involving research with individuals or families, evidence of support from the individual or family may be sufficient.

#### 1.6 Negotiating and reaching agreement on key issues

A genuine partnership or collaboration spans the entire research process including post-project completion. It is important that, as far as possible, a mutual agreement is reached about all aspects of the research process before your research begins.

This may be an agreement between collaborating institutions and researchers and/or between researchers and participant or partner organisations.

You should always conduct negotiations in good faith, which involves full and frank disclosure of all available information. Negotiations should be entered into with an honest view to reaching an agreement.

When you are undertaking the initial stages of negotiating a partnership agreement:

- identify and observe any written research protocols or other community protocols that need to be followed
- allow appropriate individuals for the area/topic to be identified from within the community
- discuss and respect cultural practices and how they may impact use of research data in the future, for example mourning protocols may restrict use of the names and images of deceased persons

<sup>17</sup> The National Statement, Chapter 4.7.10, p. 79.

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- communicate with relevant individuals and organisations by appropriate means (face-to-face meetings are always desirable), and consider the budgetary and funding implications of such visits for the individuals and organisations
- consult widely enough to ensure that the research project gains the perspectives of the whole community it affects
- provide people with clear information ahead of time before meetings regardless of whether a project has a tight deadline or not providing people enough time with project information to discuss with their own families and networks before having to make a formal decision is an important part of free, prior and informed consent
- give an honest account of the experience and expertise of the research team and identify if and how members of the community may add to the capabilities of the team
- clearly define and explore the purpose and nature of the study; who is carrying it out and funding it; how it will be governed; the objectives of the research and the likely risks, impacts and consequences of the study; the methods that will be used and the types of information that may be collected or produced; and the kinds of research outputs, publication and commercialisation that might be anticipated
- discuss the level of commitment and involvement the partner organisations and the community are willing to offer and the resources needed
- negotiate and agree how the data and any secondary data will be used, whether solely for the research purpose or to be shared or stored for future use by others (note that any secondary use of data requires agreement from the appropriate community governance groups)
- discuss and include a plan for dispute resolution and facilitated conversation and when this would be required to be followed.

These early discussions ensure that when people are deciding to consent to the project they are well informed and have had time to consider whether the project meets the needs of their community. This early process is also beneficial to you as the researcher, because you are less likely to find yourself in the situation of having consent for your project refused after conditional funding has been provided.

Ask the relevant ethics review committee if these initial discussions require early-stage ethics review. (See 1.11.2 Staged ethics review)

<u>Collaborative Research: A guide supporting the Australian Code for the Responsible Conduct of Research<sup>18</sup></u> should also be read and referred to when negotiating and reaching agreement on key issues.

#### **1.7** Defining benefits

The benefits from research should be defined through discussion with Aboriginal and Torres Strait Islander research partners, participants, or project governing bodies. This includes providing all the relevant information to allow partners to weigh potential benefits against possible risks or disadvantages.

When you are negotiating benefits:

- aim to make the benefits to the community, or individual participants, proportionate to the demands of their participation
- ensure that, where the benefits are not general (for example, employment on the project or financial compensation), they are allocated in cooperation with the group

<sup>18</sup> https://www.nhmrc.gov.au/sites/default/files/documents/attachments/Collaborative-Research-Guide-20.pdf

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- be prepared to pay those contributing to the research in recognition of the value of their contributions, particularly where significant time or expertise is given (including the expertise of traditional knowledge holders), beyond normal personal or community commitments
- ensure that payments or financial benefits accruing to the participants are considered by a human research ethics committee.
- consider indirect benefits to Indigenous communities such as support for the archiving of materials relating to intangible cultural heritage, including (but not limited to) field notes and recordings that document language, cultural practices and ethnobotanical knowledge
- ensure that, if such benefits are provided, appropriate measures are in place and access is managed to protect secrecy and/or confidentiality of materials
- do not overstate the benefits of the research to the participants, organisations or communities
- discuss the potential for unexpected outcomes and how they will be addressed and communicated.

#### 1.8 Managing risks

Research can involve risks and these should be clearly articulated and communicated to participants and communities when you are negotiating an agreement. Risk may be to participants, researchers or organisations so, in determining risk, you will need to identify who will be affected and assess the likelihood and extent for each risk. Participants must be made aware of any potential risks and that information must be included in the participant information sheet and consent form.

Perception and experience of risk may be different from an Indigenous perspective so if you are a non-Indigenous researcher you should seek advice in identifying and managing risks.

Areas that may involve risk include, but are not limited to:

- research that involves participants under the age of 18
- confidential information and likelihood of re-identification, particularly with small communities or specific experiences
- research focussed on suicide, mental illness, loss, trauma or grief
- research that may include or reveal illegal or criminal behaviour or activities
- participants who are experiencing or have in the past experienced substance misuse or domestic and family violence
- real or perceived conflicts of interest between and within Indigenous communities, and conflict of interest with the researcher
- research that may involve or reveal culturally restricted information and knowledge
- physical risks to participants or researchers
- harassment or bullying
- burdensome nature and general inconvenience of the research
- reinforcing negative stereotypes or deficit profiling
- legal risks and reporting obligations when issues are identified as part of the research project
- people or groups that may have different consideration or challenges engaging or participating in research, such as people who are incarcerated, people with disabilities, and individuals or communities for whom English is not a first language.

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When you are assessing risk:

- consult with stakeholders and eligible participants
- consult institutional requirements for identifying and managing risk
- determine the risks for both the life of a project and ongoing<sup>19</sup>
- provide an honest assessment of risk
- develop a mitigation strategy for each risk<sup>20</sup>
- determine how risks can be minimised, transferred or shared
- consider barriers to participation in research and how these can be removed, minimised or overcome
- develop a harm protocol to deal with any harm or trauma the project is likely to cause
- obtain additional support and services to enable the harm protocol to be enacted
- develop monitoring processes to ensure that risks are adequately managed.<sup>21</sup>

#### 1.9 Research agreements

Research with Indigenous partner organisations or communities should begin with the negotiation of a research agreement based on free, prior and informed consent, bearing in mind that negotiation will continue throughout the project and that reformulating the research project is always a possibility. A research agreement may range from an informal consent form for small-scale projects to a protocol or a memorandum of understanding, or to a legal contract for some large-scale projects. Note that research agreements may have legal implications.

When you are negotiating research agreements:

- identify who should enter into the agreement, and on whose behalf the agreement is made
- base the agreement on good faith negotiations and free, prior and informed consent
- consider whether independent legal advice is required by either, or both, parties and who will bear the costs of advice received
- determine the information to be included in the agreement, based on initial discussions and negotiations (other details may be better placed in a project proposal).

Agreements you enter into should include the mutual understanding of:

- processes and timing for informing representatives of the community of the progress of the research and reporting any results
- process to extend the agreement, if required
- what happens if a party withdraws, and what should be done with that party's contributions to the research project up to the date of the withdrawal
- how disputes will be handled should they arise, for example through mediation
- how complaints can be made, to whom, and how they will be handled
- the involvement of individuals in the interpretation of the results and the preparation of any publications (see also Part B: 3. Communicating research results)

<sup>19</sup> The National Statement, Chapter 2.1.3(a), p. 14.

<sup>20</sup> The National Statement, Chapter 2.1.3(d), p. 14.

<sup>21</sup> The National Statement, Chapter 5.5.1–5.5.6, p. 96.

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- the identification or otherwise of individuals involved in the research and whether those who take part in the research are to be acknowledged in any publication
- the culturally appropriate way that those who wish to be identified and acknowledged are identified and acknowledged
- how intellectual property rights and moral rights will be shared between the researcher and individual contributors, and community representative organisations (note that it is the researcher's responsibility to negotiate with any institution, such as a university, to which they have contractually transferred their intellectual property rights)
- the ownership of research results, their forms and presentation, including institutional ownership of data, archiving of data, individual rights of researchers and participants, and collective rights of Aboriginal and Torres Strait Islander community groups
- plans for succession and who should speak in the future about how the data or other outcomes of the project might be used
- how costs are to be attributed and how financial or in-kind contributions are to be acknowledged and/ or accounted for
- how Indigenous leadership is being achieved.

Your project may require additional considerations, for example:

- agreement in relation to the rights and responsibilities in ownership of, and access to, recordings of Aboriginal and Torres Strait Islander performances and activities, especially where those recordings are likely to be distributed and shared in ways such as digital and social media
- future community control over access to, and use of, any research results, including print, pictorial, audio, video and digital materials (consider developing a separate data management plan; <u>see 4.1.</u> <u>Indigenous data governance</u>)
- separate access and benefit-sharing agreements if the research includes the collection of genetic resources from Indigenous lands, even if the uses are non-commercial
- separate publishing agreements if the work is to be commercialised.

#### 1.10 Project design and planning for impact

Project planning begins once the right people have been identified and the aims and goals of your research have been established with all project partners. When designing projects be aware of relevant Indigenous methodologies and theoretical frameworks and build those into the project design where appropriate.

When planning your project, consider starting from the point of outcome and benefit, rather than activities and resources. A Publicly Funded Research Agencies' working group tasked with developing a common understanding of approaches, terminology and reporting of research impact has produced a set of principles that give consideration to the societal benefits of research.<sup>22</sup> In short, the principles are premised on how the desired impact and objectives of the research should determine the activities and budget. To do this consider using the planning process shown at Figure 3.

<sup>22</sup> Australian Research Council 2019, Research Impact Principles and Framework, <u>https://www.arc.gov.au/policies-strategies/</u> strategy/research-impact-principles-framework

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#### Impact

Cultural, social, economic, environmental and other benefits to society or populations

#### Inputs

Project income and funding, staff and infrastructure

#### Outcomes

Local outcomes for community and other partners/stakeholders, for example, job creation and policy implementation

#### Activities

Project activities, for example, community engagement, conferences and workshops, research work and training, and methodologies

#### Outputs

Project outputs, for example, publications, collections, patents, online resources and policies

Figure 3: Impact pathway

The <u>Australian Research Council</u> (ARC) defines research impact as the contribution that research makes to the economy, society, environment or culture, beyond the contribution to academic research.<sup>23</sup>

Further information can be found in the <u>ARC Engagement and Impact Assessment 2018–2019</u> national report and the <u>Excellence in Research Australia</u> reports.<sup>24</sup>

You need to plan for and design good impact evaluation at the beginning of your research project and assess it throughout the delivery stages. There should be an agreed methodology to create, collect, analyse and share the data collected as part of impact evaluation. Community decision-making must be at the forefront of evaluations of impact and the design of the research impact focus. There may be an assumption that qualitative methods are more difficult to assess; however, the evaluation design and methods should be carefully considered. Methods chosen should be appropriate to answer the evaluation questions.

Aboriginal and Torres Strait Islander approaches and methodologies are well suited to qualitative evaluation, such as storytelling and yarning circles.

<sup>23</sup> Australian Research Council, 2019.

<sup>24</sup> https://www.arc.gov.au/excellence-research-australia; https://dataportal.arc.gov.au/El/NationalReport/2018/

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#### 1.10.1 Budgets and activity plans

Ensure your activity plans and budgets reflect the ethical engagement you have planned. For example, your budget may need to include appropriate community engagement expenses; sufficient time and funds for multiple visits; paid participation of individuals, organisations and community-based researchers; genuine costing of in-kind contributions of community organisations and partners; involvement of partners in research communication through seminars or conferences; return of materials and research results; and planning for and undertaking evaluation.

#### 1.11 The ethics process

Ethics review is not just a compliance exercise or risk mitigation strategy. Research can have both immediate impacts on communities and individuals involved, and longer-term impacts as part of the evidence base on which critical policy and practice is founded. For these reasons, it is critical that you consider the ethics component of each project. You need to give the ethical review process adequate time and resources that should be built in to your project time frames and budgets.

In addition to the AIATSIS Code of Ethics, you should make yourself familiar with ethical guidelines under Australia's national framework for ethical and responsible conduct of research and be aware of ethical standards and practices in your own field or discipline.<sup>25</sup>

If you are an Aboriginal or Torres Strait Islander researcher or organisation undertaking your own research, the cultural protocols associated with the AIATSIS Code of Ethics may come as second nature and it may seem that external ethics review is unnecessary for these elements. However, ethical review can contribute to how you manage risks to individual participants, legal protection of communal ICIP, sustainable data management and ensuring you are incorporating best practice.

#### 1.11.1 Where do researchers go for ethics review?

Many Australian research institutions such as universities have an institutional ethics committee that is registered as a human research ethics committee (HREC) with the National Health and Medical Research Council. Aboriginal and Torres Strait Islander community-based/controlled organisations may also have an ethics review process, which may not be a formal HREC, but which you should investigate in addition to contacting formal HRECs. These less formal processes could offer you useful advice and input that would assist you with your ethics application.

If you are a researcher who is not affiliated with an Australian organisation that has a HREC, you can refer to the HRECs listed on <u>NHMRC's website</u>.<sup>26</sup>

Organisations that establish HRECs are required to set out and publicise their terms of reference, including their relationship to non-affiliated or independent researchers.<sup>27</sup>

For Aboriginal and Torres Strait Islander research, it is a requirement of the AIATSIS Code of Ethics that you seek review from a HREC that has Aboriginal and Torres Strait Islander membership and experience in reviewing Aboriginal and Torres Strait Islander research.<sup>28</sup> This includes:

- people who have networks with Aboriginal and Torres Strait Islander peoples and/or knowledge of research with Aboriginal and Torres Strait Islander peoples
- people familiar with the culture and practices of Aboriginal and Torres Strait Islander peoples.

<sup>25 &</sup>lt;u>Australian Code for the Responsible Conduct of Research</u> and any other specific guidance for research involving animals and specific areas of biomedical research (e.g. reproductive technology, organ and tissue donation, among others) that have also been published.

<sup>26</sup> NHMRC 2018, List of Human Research Ethics Committees registered with NHMRC, <u>https://www.nhmrc.gov.au/sites/default/files/</u> <u>documents/attachments/registered-hrecs.pdf</u>

<sup>27</sup> The National Statement, subsection 5.1.27(c), p. 86.

<sup>28</sup> The National Statement, section 4.7, pp. 77–79.

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AIATSIS maintains an independent HREC that, for a fee, considers external applications. The committee is a specialist committee in Aboriginal and Torres Strait Islander research and has a majority Indigenous membership. AIATSIS also provides training to other HRECs in the application of this Code. There are also other specialist Indigenous HRECs, such as the Aboriginal Health Research Committees in various States.<sup>29</sup>

#### 1.11.2 Staged ethics review

The types of methods used in a research project will influence the type of ethics process that is applicable and when ethics review is required. Increasingly, co-design methodologies bring ethical considerations forward into the planning and design stages of the project that may require early ethics review, for example in relation to consent and ICIP. A quick way to gauge whether you should get an early-stage ethics review is to ask yourself whether you want to record the conversations regarding project design and collaboration, whether you will want or need to use the information in published form, and/or whether you want to write about the co-design process down the track. If the answer to any of these questions is yes, then you will need an early-stage ethics review.

A human research ethics committee will commonly require you to provide the following information for an early-stage ethics review:

- an outline of any project funding, aims and design so far
- biographies of project staff
- the process for partnership and collaboration
- draft research agreement (to be finally negotiated after ethics approval)
- any project documentation that will be provided to potential partners.

Once the design phase of the research is complete, you can seek ethics review for the next stages of the project.

#### 1.11.3 Ethics application planning

You should work with the ethics committee secretariat to seek advice throughout the development of a proposal. The secretariat will provide support such as key information to assist you, in terms of meeting the committee's expectations and requirements, that could save you considerable time during the ethics assessment process. Note that ethics approval must be received prior to the commencement of the research; HRECs cannot provide retrospective approval.

Ensure the research plan allows enough time for submission and return of questions to the HREC. While the National Statement directs HRECs to avoid duplication in assessment of ethical clearances, you may still be required to seek ethics review from multiple ethics committees across multiple jurisdictions for your research.<sup>30</sup> Be aware of submission dates of the HREC, they are often a couple of weeks in advance of the meeting date.

The AIATSIS ethics <u>website</u> has information on the AIATSIS ethics application process. Note that other HRECs may have different processes.

Key questions for you to consider include:

- Which HREC will you be required to submit to (consider that you may need to apply to multiple committees)?
- What are the costs?
- 29 NHMRC 2018, Ethical Guidelines for Research with Aboriginal and Torres Strait Islander Peoples, <u>https://aiatsis.gov.au/research/ethical-research</u>
- 30 The National Statement, section 5.3, p. 93.

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- Are there any local and/or state legislation or other guidance such as guardianship boards or privacy legislation that need to be considered?
- Are there other researchers who have submitted ethics applications with whom you could speak so that you can learn from their experiences?

Most research institutions and universities will have established procedures, based on the level of risk involved in the project, that outline the level of ethics review required. The National Statement requires that research involving Aboriginal and Torres Strait Islander peoples and their data must undergo HREC review.<sup>31</sup>

#### 1.11.4 Role and purpose of ethics review

A HREC will provide advice and, ultimately, either approve or not of a research proposal based on the ethical aspects. During the ethics review process, a committee will look to increase the quality of the project by minimising the risk of harm and ensuring the research is not an unjustified burden to anyone involved. Research benefits should outweigh any burden.

The core purpose of ethical review in Aboriginal and Torres Strait Islander research is to provide Australian Indigenous communities that are involved in the research with assurance that their rights, culture and heritage are respected, that the aims and methods of the research are clear and have merit, and that they will share in the results of the work. Research practice must actively acknowledge, protect and help to maintain Indigenous knowledge, as well as ensure that Indigenous knowledge is used in a manner accepted and informed by Indigenous owners of that knowledge.

Ethics review ensures that research is designed and carried out in ways that respect and value Aboriginal and Torres Strait Islander peoples. Unethical behaviour and unethical research can not only have a significant impact on those involved in the research but may also extend to others indirectly affected by the project.

### 2. Project implementation

Implementing the research methods and collecting the data begins once your project has been designed, partnerships formed, research agreements negotiated (where relevant) and the ethics application has been approved.

During the implementation stage it is important that you:

- be flexible and remember that unforeseen factors may affect or delay the research
- respect cultural protocols at all times, including kin obligations, mourning practices (sorry business) and ceremonial practices (including men's and women's business)
- continue consultation about matters as they arise and be willing to renegotiate objectives and modify the project
- continue to seek consent and be prepared if consent is withdrawn<sup>32</sup>
- report back to the community as the research is being carried out<sup>33</sup> this may be done in meetings or by using a range of online communication methods
- recognise that Indigenous individuals or communities may have more pressing priorities that may impinge on the research time frames.

<sup>31</sup> The National Statement, subsection 5.1.6(b), p. 84. Note that the National Statement is currently under review (at October 2020).

<sup>32</sup> The National Statement, Chapter 2.2.8, p. 17.

<sup>33</sup> The National Statement, Chapter 4.7.3 (c), p. 78.

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#### 2.1 Obtaining informed consent

The consent form is a record of an agreement and the process of informed consent between you, the researcher, and individual participants on the conditions, rights and obligations of both parties. It ensures that the participants are aware of all the potential risks and benefits of the project.

Consent forms are different from research agreements. Research agreements concern the overall project partnerships and design and involve collective consent to support a project. Informed consent concerns the sharing of stories and data by individuals in the community for the purpose of analysis and study.

Informed consent is a process of communication between a participant and you that results in the participant's authorisation or agreement to participate in the project.<sup>34</sup>

In conjunction with a plain language statement about the research project, which may also be referred to as the participant information sheet, a consent form is required. A consent form will aid in informing the contributors about the research. More importantly, this should provide enough information for participants to determine if they want to give their consent to be involved in the research you plan to conduct, in accordance with the project plan. The consent form and participant information sheet must also include information about how to make inquiries or complaints about the research.

A plain language statement and a record of informed consent are both required for ethical review. Consent is required to be informed and voluntary, and be given before you start the research. The National Statement provides a variety of ways to express consent.<sup>35</sup>

Informed consent does not exist unless all relevant information is provided and in an accessible form, which may require it to be translated into the preferred language of Aboriginal and Torres Strait Islander participants. This could be an Indigenous language or a variety of English.

When you are negotiating individual consent and agreement:

- take time to discuss with participants, and allow enough time for them to consider, all of the information
- use an interpreter where necessary to ensure mutual understanding
- recognise that individuals are free to say no and ensure that they are aware that they can say no<sup>36</sup>
- recognise that individuals can withdraw their consent and ensure they are aware that they can withdraw, the process for doing so, and the implications of their withdrawal (for example, that the project may continue with other participants)<sup>37</sup>
- ensure that the consent process includes both a plain language statement and a consent form signed by the participants, or that oral (verbal) consent is received and recorded<sup>38</sup>
- ensure that both the consent form and the plain language statement are translated into preferred languages, where required, or are presented in visual or other user-friendly formats<sup>39</sup>
- consider using a consent model that requires consent at each stage of the project
- be aware that community consent through a research agreement may be required before individual consent is sought<sup>40</sup>
- ensure that individuals are made aware of any community partnerships and support.

<sup>34</sup> The National Statement, subsection 2.2.4, p. 16.

<sup>35</sup> The National Statement, subsection 2.2.5, p. 16.

<sup>36</sup> The National Statement, subsection 2.2.19, p. 18.

<sup>37</sup> The National Statement, subsection 2.2.20, p. 18.

<sup>38</sup> The National Statement, subsection 2.3.6(d), p. 21.

<sup>39</sup> The National Statement, subsection 5.2.17(b), p. 90.

<sup>40</sup> The National Statement, subsection 2.2.13, p. 18.

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#### 2.2 Gathering the data

A useful resource when considering research data is the <u>Management of Data and Information in</u> <u>Research: A guide supporting the Australian Code for the Responsible Conduct of Research,<sup>41</sup> which</u> defines the responsibilities of institutions and researchers.

Best practice ethical research recognises and respects the principles of Indigenous self-determination, which includes the right of Indigenous peoples to manage the access, collection and use of their information (see 4.1. Indigenous data governance).

When you are gathering data:

- ensure that research agreements include agreement about how data will be gathered
- recognise that Aboriginal and Torres Strait Islander peoples may have English as a second, third or fourth language so, if the research is based on interviews with people who prefer to speak an Indigenous language, engage appropriate interpreters and transcribers
- recognise that the expertise of appropriate interpreters and transcribers will need to be paid for<sup>42</sup>
- ensure that methods are compliant with local laws and customs and are explained clearly to all people involved in a culturally suitable way<sup>43</sup>
- before any data is collected, discuss the possibility that participants may disagree with the research team's interpretation
- follow, and clearly explain at each stage, all consent protocols as outlined in the consent form and research agreements
- follow all intellectual property and copyright legislation and ICIP protocols and ensure they are clearly explained to participants
- consider how culturally restricted material will be identified and managed if collected and recorded in the data, and set up a protocol that is acceptable to Aboriginal and Torres Strait Islander partners and participants. If in doubt, assume that you may come across such material and plan accordingly.

#### 2.3 Interpreting and analysing the data

Always refer to the research agreement and any ICIP protocols when you are interpreting and analysing the data, and consider the role of Aboriginal and Torres Strait Islander peoples during this stage. Where practical, Aboriginal and Torres Strait Islander researchers and peoples may be best placed to lead or guide the interpretation and analyses of the data as part of, or alongside, the project team.<sup>44</sup>

Data interpretation and analysis may also involve secondary data — existing data and data collected for different purposes, such as older historical and ethnographic sources. When you are re-interpreting this data, it is important to collaborate and work together with the people or the descendants of the people who own or are represented in the data. When interpreting national data, such as census data, collaborate with an Indigenous institution, scholars or a working group relevant to the kind of interpretation and analysis that is being undertaken.

<sup>41</sup> https://www.nhmrc.gov.au/sites/default/files/documents/attachments/Management-of-Data-and-Information-in-Research.pdf

<sup>42</sup> The National Statement, subsection 5.2.17(b), p. 90.

<sup>43</sup> The National Statement, subsection 5.2.17(c), p. 90.

<sup>44</sup> The National Statement, subsection 4.7.11, p. 79.

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When you are interpreting and analysing data that concern Aboriginal and Torres Strait Islander peoples' experiences, ensure that:

- the subject matter reflects those perspectives and understandings
- any points of confusion are discussed with the people involved in the data collection
- information with cultural, gender, age or other restrictions has been dealt with according to the research agreement and local Indigenous laws.

See also 4.1. Indigenous data governance.

#### 2.4 Reviewing, revising and finalising

It is good practice to hold meetings with project partners or other project participants to discuss your research results and analysis, recognising that people have the right to disagree with the analysis and provide new or different perspectives.

Within your research agreement, there should be review protocols already negotiated that include:

- revision by Indigenous partners to ensure that the material is interpreted in a culturally appropriate way
- opportunity for people who have been involved in the data collection to review the results or analysis if they choose
- agreement that guidance will be sought from Indigenous partners if the research results are unanticipated or reveal negative outcomes
- mechanisms for reporting back to communities<sup>45</sup>
- advice about public dissemination and discussions with media
- agreement to make results known to appropriate local, state or territory, and national authorities, if requested.

When reporting back to Aboriginal and Torres Strait Islander partners and communities it is important you have established that:

- there is shared understanding and agreement about how the results of research will be shared, including the forms that it will take (such as arts-based, exhibition driven, web-based and/or other creative and/or collaborative community driven outcomes), and how it will be accessed
- outputs or outcomes disseminated to participants are provided in languages that are clear and understandable<sup>46</sup>
- information contained in reports is written in plain language and is relevant, honest and transparent
- other forms of communication are considered in addition to providing a standard report, including face-to-face meetings, semi-structured discussions, presentations, online meeting platforms, and infographic style reports; in some situations reporting via telephone, email and letters may also be acceptable (in preference to no reporting)
- adding strategies for reporting results beyond the publication stage may be appropriate, such as presentations to stakeholders and members, to ensure the community receives these results
- translators and interpreters are engaged during the process, when required.

<sup>45</sup> The National Statement, subsection 4.7.3(d), p. 78.

<sup>46</sup> The National Statement, section 3.1, p. 40.

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## 3. Communicating research results

Communicating the results of research to the public can take many forms. It is important that discussion and agreement about how your research results will be written up, published and disseminated should take place at the beginning of a research project. Forms of publication may include reports or papers in peerreviewed journals; conference presentations, book chapters and books that are made available in print or online; or dissemination via other forms of media such as creative works and performances.

Decisions about the forms of publication, authorship and copyright should form part of your research agreement or consent form and should be formally documented. Note that once you record knowledge and make it into material form it becomes 'property' as defined under Australian law and is protected by Australian copyright legislation. This is why it is imperative that assignment of copyright is carefully considered and formally documented. The <u>Publication and Dissemination of Research: A guide supporting</u> the Australian Code for the Responsible Conduct of Research<sup>47</sup> is a useful resource.

#### 3.1 Authorship and attribution

When you are discussing authorship and attribution there should be agreement about how authorship will be assigned and how contributors will be acknowledged. All contributors and intellectual property rights holders should be consulted.

Authorship is of particular ethical concern given the history of Aboriginal and Torres Strait Islander research, where Indigenous knowledge holders who shared their knowledge were relegated to the role of 'informant'. Researchers should be aware of <u>Authorship: A guide supporting the Australian Code for the Responsible</u> <u>Conduct of Research.</u><sup>48</sup>

When discussing authorship of unpublished material and attribution it is important that you:

- consult with all contributors and IP rights holders about how they wish to be attributed (note that it is unethical to acknowledge or attribute authorship without the express written permission of the author or authoring body)
- agree on the order of authors' names and how they will appear in publications
- ensure that those people who wish to be attributed are, that attribution appears in a prominent place in all publications, and in a culturally appropriate way<sup>49</sup>
- agree on how copyright will be owned or shared where a research project will result in joint authorship of a publication.

#### 3.2 Writing for publication

Works that draw on the knowledge and perspectives of Aboriginal and Torres Strait Islander peoples should reflect those viewpoints. The findings of your research project should be reported to Aboriginal and Torres Strait Islander stakeholders in a way that is accessible to them.

When you are writing for publication:

- consider the specific viewpoints of all research partners and incorporate narratives that reflect those viewpoints
- recognise that the view of one individual or group does not necessarily represent the collective view of all

<sup>47</sup> https://www.nhmrc.gov.au/about-us/publications/australian-code-responsible-conduct-research-2018

<sup>48</sup> https://www.nhmrc.gov.au/about-us/publications/australian-code-responsible-conduct-research-2018

<sup>49</sup> The Australian Code for the Responsible Conduct of Research, R26, p. 4.

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- respect individual's rights to remain anonymous (note that removing or changing someone's personal information name, gender, age, etc. does not mean that they cannot be identified; for example, their prominence in the community and way of speaking may make their comments easily identifiable)
- ensure that the final work to be published is checked and cleared by those who have provided input or have provided knowledge that informs the work, and allow enough time for content to be checked
- if including oral stories or testimonies, retain the original voice of those who have provided them, including their choice of storytelling style and language, which may include their Australian Indigenous language, Creole or a variety of Aboriginal English
- ensure that permission is received to use specific quotes from participants. Consent could be sought in the consent form
- ensure that your work is written in plain English, if it is agreed that it will be written in English (for information about how to write in plain English see <u>Reworking your thesis for book publication</u><sup>50</sup>
- provide copies of all publications arising from your project to partners and collaborators.

#### 3.3 Publication

The NHMRC and ARC support the sharing of outputs from their funded research and have developed open access policies.<sup>51</sup> You are strongly encouraged to share the outputs of your research, which may include publications and data. Once work is published it is in the public domain so it is important to ensure that all stakeholders have a clear understanding of the implications of publication and shared agreement about how the work will be published. You should discuss this and clarify it at the start of the project. The *Publication and Dissemination of Research: A guide supporting the Australian Code for the Responsible Conduct of Research*<sup>52</sup> is a useful document to refer to.

When you are negotiating the publication of research:

- discuss the forms of potential publication, which may include print and ebooks or inclusion on websites where it can be read by anyone
- discuss who will be publishing the work
- discuss the arrangements for republishing the work in another form at a later stage, including who will inherit copyright on the death of current copyright holders
- ensure clearances are in place from the appropriate rights holders to reproduce images and content in published form (note that in addition to seeking clearances from copyright holders, such as the photographers, clearance will also need to be sought from the people who are shown in the image)
- be aware of copyright laws and Indigenous peoples' rights to maintain, control, protect and develop their intangible heritage, including their cultural heritage, traditional knowledge, traditional cultural expressions and intellectual property
- discuss what if any restrictions should be placed on the publication of content in the event of the death of a participant
- discuss any income that may result from the non-commercial publication of the work, for example, <u>Electronic Lending Rights (ELR) and Public Lending Rights (PLR)</u><sup>53</sup> and how that will be shared.

<sup>50</sup> https://aiatsis.gov.au/sites/default/files/2020-09/reworking-your-thesis-book-publication.pdf

<sup>51</sup> NHMRC 2018, Open Access Policy, <u>https://www.nhmrc.gov.au/about-us/resources/open-access-policy</u>; ARC 2017, Open Access Policy, <u>https://www.arc.gov.au/policies-strategies/policy/arc-open-access-policy</u>

<sup>52</sup> https://www.nhmrc.gov.au/about-us/publications/australian-code-responsible-conduct-research-2018#download

<sup>53</sup> https://www.arts.gov.au/funding-and-support/lending-rights

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## 4. Post project

The closure of a project is rarely the end of the matter. There will be ongoing relationships that you formed through effective engagement and, in addition, responsibilities for the use of data and the further development of knowledge arising from your project. Impacts of research can also often only be measured over the long term.

#### 4.1 Indigenous data governance

Indigenous data refers to any information or knowledge (regardless of its format) that is about and may affect Aboriginal and Torres Strait Islander peoples, collectively and individually.

Indigenous data sovereignty refers to Indigenous data that is, or should be, governed and owned by Indigenous peoples from the very creation of that data through its collection, access, analysis, interpretation, management, dissemination, potential future use and storage. The right of Aboriginal and Torres Strait Islander peoples to decide how Indigenous data is used and stored may reflect Indigenous people's priorities, values, cultures, worldviews and diversity, and is central to Indigenous data governance.<sup>54</sup>

When you are establishing data governance arrangements:

- recognise that contributions to research by Aboriginal and Torres Strait Islander peoples should be acknowledged by ensuring ongoing Indigenous governance of the data<sup>55</sup>
- ensure that data reflects Indigenous peoples' diversity, values and priorities
- ensure that, during the early stages of consultation, Indigenous researchers, relevant community members and organisations collaborate and reach agreement on the creation, collection, analysis, interpretation, management, storage, dissemination, re-use, disposal of and access to data and secondary use of data, and formally document what is agreed
- consider developing a separate <u>data management plan</u> that may also assist with managing data postproject; plans should address the allocation of rights and management into the future of raw data and potential secondary use of data as well as outputs
- consider setting up a data governance committee, in addition to the governance framework, which may be necessary or desirable for large-scale or long-term data gathering
- be aware of and adhere to legal requirements on the retention and destruction of data; specific legislation can include <u>Privacy Act 1988</u>, <u>Australian Human Rights Commission Act 1986</u> and <u>Freedom of Information Act 1982</u>.<sup>56</sup>

#### 4.1.1 Data management plans

Your research data management plan should include, as a minimum:

- how and by whom the data will be stored or archived
- who can access the data

<sup>54</sup> Maiam nayri Wingara Indigenous Data Sovereignty Collective and the Australian Indigenous Governance Institute 2018, Indigenous Data Sovereignty Communique, <u>http://www.aigi.com.au/wp-content/uploads/2018/07/Communique-Indigenous-Data-Sovereignty-Summit.pdf</u>

 $<sup>55\;</sup>$  The Australian Code for the Responsible Conduct of Research, R26, p. 4.

<sup>56</sup> Privacy Act https://www.legislation.gov.au/Series/C2004A03712; Human Rights Commission Act https://www.legislation.gov.au/ Series/C2004A03366; Freedom of Information Act https://www.legislation.gov.au/Series/C2004A02562

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- who can use the data and for what purpose
- from whom permission is to be sought to access or use the data and potential secondary use of data in the future an individual, group or organisation
- benefit to Indigenous partners or participants
- practical steps that will be taken to ensure that the data is of a suitable qualitative standard and preservable and manageable in accordance with the views of communities and individuals.

#### 4.1.2 Data access

There is a strong emphasis in the research sector and government for more open data, commonly described by the <u>FAIR principles</u><sup>57</sup>: Findable, Accessible, Interoperable and Reusable. However, this focus on facilitating data sharing does not fully engage with Indigenous peoples' rights and interests and efforts to assert greater control over the application and use of Indigenous data and Indigenous knowledge for collective benefit. To this end, Australian Indigenous researchers and their international colleagues have developed the <u>CARE principles</u> to overlay data access.<sup>58</sup> These are: Collective Benefit, Authority to Control, Responsibility, and Ethics.

- Collective Benefit: Data ecosystems shall be designed and function in ways that enable Indigenous Peoples to derive benefit from the data.
- Authority to Control: Indigenous Peoples' rights and interests in Indigenous data must be recognised and their authority to control such data be empowered. Indigenous data governance enables Indigenous Peoples and governing bodies to determine how Indigenous Peoples, as well as Indigenous lands, territories, resources, knowledges and geographical indicators, are represented and identified within data.
- Responsibility: Those working with Indigenous data have a responsibility to share how those data are used to support Indigenous Peoples' self-determination and collective benefit. Accountability requires meaningful and openly available evidence of these efforts and the benefits accruing to Indigenous Peoples.
- Ethics: Indigenous Peoples' rights and wellbeing should be the primary concern at all stages of the data life cycle and across the data ecosystem.<sup>59</sup>

#### 4.2 Storage and archiving

Establishing how materials will be deposited and the condition under which people can access those materials are important parts of data management and Indigenous governance. To ensure the longevity and appropriate accessibility of the information, it is essential that data is archived and managed well, and is done in accordance with the requirements of Indigenous stakeholders.

When you are storing and archiving data:

- ensure any hard-copy documents are locked in cabinets in a secure space and are disposed of in a secure storage bin at the conclusion of their use
- ensure access to project folders on computer systems is restricted to authorised people only and is password protected

<sup>57</sup> Force11 2016, The Fair Data Principles, https://www.force11.org/group/fairgroup/fairprinciples

<sup>58</sup> GIDA (Global Indigenous Data Alliance) 2018, CARE Principles for Indigenous Data Governance, https://www.gida-global.org/care

<sup>59</sup> CARE Principles, <u>https://static1.squarespace.com/static/5d3799de845604000199cd24/t/5d79c383e904c741c9e9</u> <u>cd86/1568260995760/CARE+Principles+for+Indigenous+Data+Governance\_FINAL\_Sept+06+2019.pdf</u>

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- ensure research products are preserved in an agreed location and format with access and control as negotiated before the project commences, with Indigenous control built-in
- ensure that any individuals and/or organisations that can be consulted in the future about the research products are identified and, with their permission, their contact details stored with the materials
- provide an opportunity for participants to consider depositing the data in the AIATSIS archives or other secure repository, where the participants will be able to determine the access conditions (confidential, publicly available or partially restricted)
- ensure the recognition and protection of Indigenous knowledge continues, in accordance with Indigenous peoples' perspectives, protocols and cultural values
- anticipate that technology will change and consider how that might affect the use and storage of the data in the future
- be aware of appropriate technical standards in relation to the use and storage of data and include metadata protocols that incorporate the perspectives of Aboriginal and Torres Strait Islander peoples in the management of their intellectual property and data.

#### 4.3 Access and use

To ensure ongoing Indigenous governance, it is necessary that you carry out initial and ongoing consultations and formulate agreement about how the data will be accessed, including any restrictions and possible future use of the data.

When you are considering access and use:

- identify who should speak about the potential future use of any data by ensuring that your research
  agreements, participant information sheets and consent forms address any possibility of future access
  and use (note that informed consent may be verbal and would therefore need to be recorded; refer to
  2.1 Obtaining informed consent)
- remember that any new proposed use may also need updated or additional ethics approval and/or reporting to HREC
- de-identify data where required
- be aware of any potential for third-party access to the data and address this in the consent form
- show or distribute restricted material only with express permission from those who provided or are responsible for it
- consider the impact of disclosure of restricted material on the wider cultural source group, and whether wider consultation is required prior to disclosure, particularly, where first disclosures and publications are likely.

#### 4.4 Post-project engagement

Post-project consultation and engagement are important for the ongoing governance of research outputs and outcomes. Maintaining your relationships with research partners and Indigenous stakeholders may also assist with future consultations, which is particularly important for any new proposed use of the research or data. It is essential that your research continues to comply with agreements you make with Indigenous partners and stakeholders regardless of changes in personnel, staff or institutional base.

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Ongoing engagement also provides an opportunity for future research or related actions, including professional and community development. Throughout your career you may continue to use and benefit from knowledge shared by Aboriginal and Torres Strait Islander research partners. Consider acknowledging this contribution by ongoing attribution and acknowledgement and reporting back to communities over time.

#### 4.5 Monitoring and compliance

As a researcher you are accountable to report on research results and ethical aspects of your project to funding bodies, HRECs, partnering organisations and to Aboriginal and Torres Strait Islander people and communities for which the research is being conducted. There are different levels of accountability and you should ensure that there are appropriate, ongoing processes in place for reporting research progress, especially with regard to any actual or potential changes in the ethical conditions or contexts.

You should take appropriate measures in the design, implementation and monitoring of your research project to ensure that, at all stages, it complies with the Code and the principles it contains. You need to be aware of the risks that may result from breaches of the Code (for instance, where compliance with the Code and other guidance are part of a funding contract).

4.5.1 Reporting to funding bodies and partnering organisations

In reporting to your funding bodies and any partnering organisations, you need to be aware that:

- reporting to funding bodies is typically done via a standard report which will then be kept as an official record
- reports to funding bodies and partnering organisations should identify key achievements, delays in the timeline, emerging issues and mitigation strategies and any actual or potential changes in the ethics approval
- cadence of the reporting should be agreed during your project design stage, so consider the utility of reporting weekly, monthly, quarterly, or at the time of completion of project deliverables.

4.5.2 Reporting to Human Research Ethics Committees

When you are reporting to your HRECs be aware that:

- reports should be provided at regular intervals; while this should be at least annually, more frequent reporting may be required<sup>60</sup>
- annual reports are required for the life of the project, to provide updates on progress, maintenance and security of records; compliance with the approved proposal; and compliance with any conditions of approval<sup>61</sup>
- anything that might warrant a review of ethical approval of the project needs to be reported immediately, such as changes to project documents, time frames, locations, data collection tools or the project team.<sup>62</sup>

#### 4.6 Making a complaint

Any failure on your part to comply with this Code may result in complaints raised by research participants, researchers, staff of institutions, students or members of the public. Section 5.6 of The <u>National Statement</u> on <u>Ethical Conduct in Human Research</u><sup>63</sup> outlines provisions for complaints to be made about researchers, or the conduct of research, or about the conduct of a human research ethics committee (HREC) or other ethics review body.

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<sup>60</sup> The National Statement, subsection 5.5.5, p. 96.

<sup>61</sup> The National Statement, subsection 5.5.5, p. 96.

<sup>62</sup> The National Statement, subsection 5.5.6(c), p. 96.

<sup>63</sup> The National Statement, section 5.6.

Complaints may be made if the research:

- does not comply with the principles of this Code
- is being undertaken without formal HREC approval
- does not meet the set conditions made by the approving HREC in the letter of approval or other correspondence
- is conducted in a way that is different to the approved ethics application.

Depending on the nature of the concern, a complaint may be referred elsewhere to a more appropriate body for review.

4.6.1 Making a complaint about researchers or the conduct of research

Complaints regarding allegations of breaches of the AIATSIS Code of Ethics are handled in accordance with the <u>Australian Code for the Responsible Conduct of Research</u>,<sup>64</sup> which describes breaches and research misconduct. The <u>Guide to Managing and Investigating Potential Breaches of the Australian Code</u> <u>for the Responsible Conduct of Research</u><sup>65</sup> outlines, among other areas, specific institutional processes that can be adopted for addressing misconduct.

Breaches include, but are not limited to:66

- not meeting required research standards
- fabrication, falsification or misrepresentation of research data
- plagiarism
- inadequate research data management processes
- lack or failure of adequate supervision of researchers
- failure to acknowledge authorship of others
- inappropriate managements of conflicts of interest
- failure to conduct peer review responsibly.

Other complaints should be managed by institutional policies and processes for dealing with other forms of misconduct such as bullying and harassment.

#### 4.6.2 Making a complaint about a human research ethics committee

Any complaints regarding a human research ethics committee should be made by contacting the research office of the respective institution. This ensures the matter is treated as impartial and handled independently by non-committee members in the first instance.

#### 4.6.3 Process for making a complaint

Processes for making complaints should be made publically available by responsible institutions and clearly outlined in your research project documentation, including on the participant information sheet and consent form. Contact details of the research team, governing body, approving HREC, <u>Office of the</u>

<sup>64</sup> https://www.nhmrc.gov.au/about-us/publications/australian-code-responsible-conduct-research-2018

 $<sup>65 \ \</sup>underline{https://www.nhmrc.gov.au/sites/default/files/documents/attachments/guide-managing-investigating-potential-breaches.pdf$ 

<sup>66</sup> A definition of a breach is given on pp. 4–5, <u>https://www.nhmrc.gov.au/sites/default/files/documents/attachments/guide-</u>

managing-investigating-potential-breaches.pdf

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<u>Australian Information Commissioner</u>,<sup>67</sup> and the <u>Commonwealth Ombudsman's office</u><sup>68</sup> should be listed on the research institution's website and in your relevant research project documentation.

Complainants should provide as much information as possible to ensure the correct project is identified. Complaints should be acknowledged upon their receipt by the responsible institutions. The time taken to investigate and resolve concerns will vary, depending on the nature and complexity of the concern. Anonymous complaints are much harder to investigate and resolve, particularly if more information is required. The complainant should at least consider providing contact details and a preferred contact method in case further clarification is required.

Institutions should ensure that lessons learned from complaints are used to improve future practice.

4.6.4 Concerns about handling or investigation of the complaint by the institution

If you feel your complaint was not treated with due process by the relevant institution, there are further steps you can take. Reviews of institutional processes used to manage and investigate potential breaches of the Australian Code for the Responsible Conduct of Research are undertaken by the <u>Australian</u> <u>Research Integrity Committee</u> (ARIC),<sup>69</sup> which was jointly established by the Australian Research Council (ARC) and the National Health and Medical Research Council (NHMRC). ARIC aims to ensure that, in investigating potential breaches of the Code, institutions observe proper processes. ARIC will not review institutional processes that are still underway unless the application for review alleges institutional delay and/or inaction. ARIC will not enquire into the conduct that is alleged to be a potential breach, only the institutional processes for managing the potential breach.

<sup>67</sup> https://www.oaic.gov.au/privacy/privacy-complaints

<sup>68 &</sup>lt;u>https://www.ombudsman.gov.au/</u>

<sup>69</sup> https://www.nhmrc.gov.au/research-policy/research-integrity/australian-research-integrity-committee-aric

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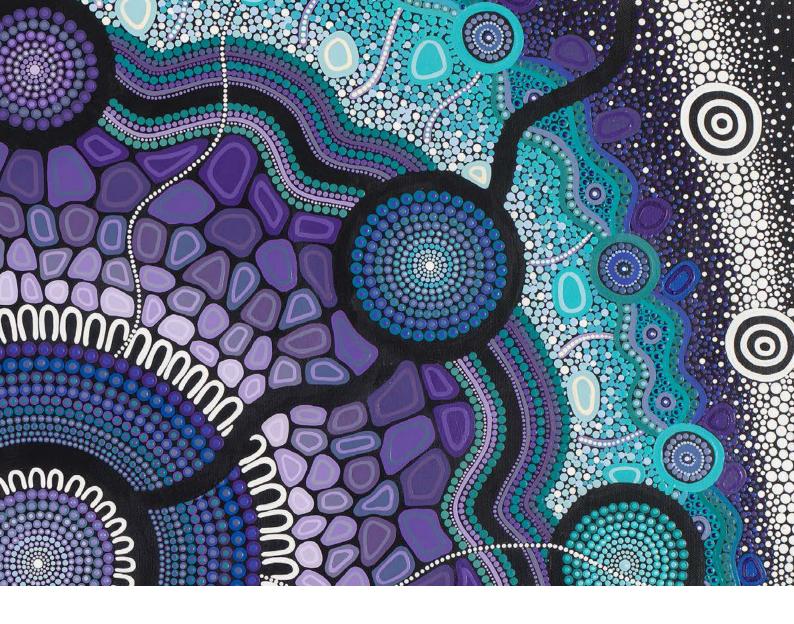
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