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Acknowledgements

We acknowledge the sovereignty of Aboriginal and Torres Strait Islander Peoples as the original custodians of Australia and acknowledge and pay respects to Elders past, present and future.

We acknowledge all those involved in the development of this resource. The revision of this resource involved the commitment and contribution of many people.

Description of the artwork

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

Over the years a lot of research has been undertaken in Aboriginal and Torres Strait Islander communities into aspects of health, wellbeing and experiences. Some research is very helpful and benefits lots of people in areas like health and medicine, education and social science. However, not all research has been of benefit for Aboriginal and Torres Strait Islander Peoples and communities. These problems mean that it is important that research is done in an ethical way.

Ethical conduct of research is about the rights and responsibilities of Aboriginal and Torres Strait Islander Peoples and communities to be involved in all aspects of research undertaken in their communities and organisations. Ethical conduct of research is about making sure the research journey respects the shared values of Aboriginal and Torres Strait Islander Peoples and communities as well as their diversity, priorities, needs and aspirations; and that research is of benefit to Aboriginal and Torres Strait Islander Peoples and communities as well as researchers and other Australians.

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

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About this resource

The information in this resource comes from two key national publications which set out the ground rules for the ethical conduct of research involving people:

• *National Statement on Ethical Conduct in Human Research 2007*
• *Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders* (Public consultation draft, 2017).

The resource aims to support research participants, Aboriginal and Torres Strait Islander Peoples and communities to:

• Make decisions that ensure the research journey respects Aboriginal and Torres Strait Islander Peoples’ and communities’ shared values, diversity, priorities, needs and aspirations.
• Make decisions that ensure the research journey benefits Aboriginal and Torres Strait Islander Peoples and communities as well as researchers and other Australians.
• Recognise and understand their rights and responsibilities in being involved in all aspects of research.
• Better understand the steps involved in making research ethical.

Intended audience

This document is intended primarily for use by research participants and Aboriginal and Torres Strait Islander Peoples and communities, but will also be a useful resource for researchers and for others interested in understanding more about such research.

Research agreements

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

The agreement should be comprehensive to cover all aspects of the research, incorporating ethical standards appropriate when working with Aboriginal and Torres Strait Islander Peoples. A full list of issues to be covered can be found on page 11.
Starting a research journey

There are several ways a research journey can be started.

- **Researcher-driven research** – when researchers select a topic, approach communities and organisations and ask permission to do the research.
- **Government or industry requested research** – research may be carried out in partnership with government departments, mining companies, pharmaceutical companies, universities, research institutes and other private businesses.
- **Community-requested research** – when communities or organisations identify the topic, approach a researcher and ask them to do the research.
- **Community-driven research** – when an organisation or community has identified an important issue and uses its own research team to undertake this research.

Regardless of who comes up with the research idea or who does the research, it is important to think about whether or not the research is right (ethical and appropriate) for Aboriginal and Torres Strait Islander Peoples, communities and organisations. This thinking should happen throughout the research journey and should be informed by:

- recognising the diversity and **values** of Aboriginal and Torres Strait Islander Peoples and communities
- recognising and understanding an individual’s **rights** about actively participating in research through a negotiated research agreement
- recognising the mutual responsibilities of participants and researchers in the conduct of the research.

There are also plenty of questions to ask throughout the research journey to keep research ethical and appropriate. For the purposes of this resource, the research journey is presented as eight steps:

1. Building relationships
2. Developing the research idea
3. Developing the project and seeking agreement
4. Data collection
5. Analysing the data and making sense of the findings
6. Report writing
7. Sharing and translating the results into action
8. Learning from experience.

These steps are summarised in Table 1 (see page 14), which you can use as a way of checking whether the research you or your community is involved in is on track. As shown in Table 1, the two fundamental issues of core values and rights about participation underpin each of the steps. More information about each of the steps, including questions to ask at each step, is provided on pages 17–30.
The six core values

How people see the world is generally informed by their own cultural experiences, values, norms and learning. Values are what people think and believe are important to their way of life. Values also shape how a person acts or behaves.

Aboriginal and Torres Strait Islander Peoples and communities each have their own established and respected values and protocols, and unique ways of expressing their different values. Each community or organisation has the right to express how these core values, and any unique values, will be addressed in research. The following six values are identified as being important to all Aboriginal and Torres Strait Islander Peoples (core values) and should be reflected throughout the research journey:

![Figure 1 – the six core values](image)

Each of these core values is briefly described below. If you’d like to read more about them, see Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders.

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2 Adapted from Keeping Research on Track: A guide for Aboriginal and Torres Strait Islander peoples about health research ethics 2005
Spirit and integrity
This is the most important value that joins all Aboriginal and Torres Strait Islander Peoples’ values together. The first part, spirit, is about the ongoing connection and continuity between Aboriginal and Torres Strait Islander Peoples’ past, current and future generations. The second part, integrity, is about the respectful and honourable behaviours that hold Aboriginal and Torres Strait Islander values and cultures together.

Cultural continuity
Research can harm Aboriginal and Torres Strait Islander Peoples’ and communities’ knowledge, cultures, languages and identity. This value is about research being done in a way that protects the rights of Aboriginal and Torres Strait Islander Peoples to uphold, enjoy and protect their knowledge, cultures, languages and identity, in terms of individuals and as communities.

Equity
Aboriginal and Torres Strait Islander Peoples and communities have experienced many inequities due to being discriminated against and marginalised. Aboriginal and Torres Strait Islander Peoples recognise the equal value of all individuals. One of the ways that this is shown is in commitment to fairness and justice. Equity affirms and recognises Aboriginal and Torres Strait Islander Peoples’ right to be different.

Reciprocity
Aboriginal and Torres Strait Islander Peoples’ way of shared responsibility and obligation is based on our diverse kinship networks. This keeps our ways of living and family relationships strong. These responsibilities also extend to caring for country and all within it and involve sharing benefits from the air, land and sea, redistribution of resources, and sharing food and housing.

Respect
Respect for each other’s dignity and individual ways of living is the basis of how Aboriginal and Torres Strait Islander Peoples live. Within Aboriginal and Torres Strait Islander Peoples’ cultures, respect strengthens dignity and dignity strengthens respect. A respectful relationship encourages trust and co-operation. Strong culture is built on respect and trust, and a strong culture encourages dignity and recognition, and provides a caring and sharing environment. Issues like free, prior and informed consent and negotiating an agreed outcome through a formal research agreement are important.

Responsibility
All Aboriginal and Torres Strait Islander communities recognise the same most important (core) responsibilities. These responsibilities involve caring for country and all within it, kinship bonds, caring for others, and the maintenance of cultural and spiritual awareness. The main responsibility is to do no harm to any person or any place. Sometimes these responsibilities may be shared so that others may also be held accountable.
Rights about participating in research
Participants have a right, and indeed, a responsibility, to be involved in all aspects of research undertaken in their communities and organisations. A participant’s rights should be reflected throughout the research journey (see pages 17–30) and Table 1 (see page 14) shows the concept of the rights about participation underlying each step of this journey.

The right to self-determination
In 2007, after more than 20 years of negotiations at the United Nations (UN) level, Indigenous peoples globally welcomed the adoption of the UN Declaration on the Rights of Indigenous Peoples, which Australia endorsed in 2009. Australia’s Aboriginal and Torres Strait Islander Peoples have advocated for the Articles in the Declaration to be recognised in policies and programs to address human rights and cultural recognition. The right to self-determination means that Aboriginal and Torres Strait Islander Peoples have the freedom to live well and to live according to their values and beliefs. There are four ways in which Aboriginal and Torres Strait Islander Peoples exercise self-determination:

1. Having a choice in determining their development paths and how their lives are governed.
2. Participating in decisions that affect their lives.
3. Having control over their lives and future including economic, social and cultural development.
4. Having the means by which every person might achieve their full potential.

The right to say yes
A community, organisation or person has the right to say yes and be involved in research. Agreeing to participate in research means free, prior and informed consent is sought and given:

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

---DRAFT--

The right to say no up front
There may be occasions where researchers approach communities or organisations with research proposals whose questions and/or outcomes do not address community priorities or the project is not conducted at a suitable time for the community. In such a case the community has the right to say no.

The right for Aboriginal and Torres Strait Islander ways of doing things to be respected
Respect for Aboriginal and Torres Strait Islander ways of doing things can be monitored by setting up a local steering committee or advisory group to arrange frequent feedback between the research team and community members. Elders play an important role in the community and are often represented on these committees and groups.

The right to have input into the research agenda
There are several ways that Aboriginal and Torres Strait Islander Peoples and communities can shape research to ensure that it focusses on their prioritised needs:

- go along with research agendas such as NHMRC’s Road Map II
- establish their own research agenda
- work in partnership with researchers to make sure the research has positive outcomes and meets Aboriginal and Torres Strait Islander Peoples’ and communities’ needs and expectations
- identify what research is of low priority.

The right to commission research that meets priority needs
Aboriginal and Torres Strait Islander Peoples and communities can also commission research that is wanted and needed. This can be done by approaching local Aboriginal and Torres Strait Islander community controlled health services or other community-based organisations; Aboriginal and Torres Strait Islander units in local universities or local research organisations; and Aboriginal and Torres Strait Islander sections in local, state and federal governments. It is important to note that not all Aboriginal and Torres Strait Islander community controlled health services or other community-based organisations have the time or resources to provide assistance, but they might be able to provide further contacts.

The right to negotiate a different focus for the research
Researchers may approach Aboriginal and Torres Strait Islander communities and organisations to be involved in research projects. Communities and organisations have the right to negotiate the focus of the proposed research by asking the following questions:

- Does the proposed research address community priorities and needs?
- Does the proposed research comply with the community’s cultural ways?

The right to request more time to talk about the research proposal
Participants and communities have the right to request more time to talk about the research. Requesting more time to talk about the research proposal sometimes results in researchers going elsewhere to do the research. However, researchers should consult and engage with communities and individuals early in the process to allow plenty of time to work through the proposal and any issues that people have. Participants or communities might also wish to explore the research topic with other researchers when ready to do so.

The right to expect respect for culture, values and beliefs
Making sure that the research processes, timelines and expected outcomes are appropriate to the shared culture and values of Aboriginal and Torres Strait Islander Peoples and communities is important.
conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders (Public consultation draft, 2017) supports the expectation that Aboriginal and Torres Strait Islander Peoples and communities should have their culture and values respected. It recognises Aboriginal and Torres Strait Islander Peoples’ connection to their past; the strength drawn from the body of knowledge, values and wisdom that is their heritage; and also from the lived experiences of colonisation.

The right to seek advice and support to negotiate a formal research agreement

Research does require resources such as people, time and money to be available. For example, interpreters might be required during the negotiations or staff may be required to help research assistants. Aboriginal and Torres Strait Islander Peoples and communities have the right to seek advice and ask for assistance to negotiate agreements. Aboriginal and Torres Strait Islander Peoples and communities also have the right to expect negotiation of a new agreement if anything substantial changes in the project. There are a range of organisations that may be able to assist in the negotiation process. A formal research agreement should cover:

- intellectual property rights
- copyright arrangements
- timing of research
- free, prior and informed consent which also includes recordings of photographs, audio and video
- withdrawal from the research project
- benefits
- publication
- translating research findings or outcomes
- data use, access and storage
- use of photographs, audio and video
- use of community or organisational facilities
- community priorities related to timing
- conflict resolution processes
- monitoring of progress milestones
- process and a contact if counselling is required because of a traumatic experience in the project
- an appropriate Human Research Ethics Committee (HREC) contact
- any other matters the communities or organisations feel are important.

The right to check on the researcher’s track record

When communities or organisations employ researchers to work with them as part of the recruitment process, it is good practice to check on the researcher’s track record of working with Aboriginal and Torres Strait Islander Peoples. This will help participants and communities ensure that the research team has the required knowledge and experience to work in partnership in a way that acknowledges the community’s culture and values.

Communities have the right to request a list of all researchers with their qualifications to ensure that there are the appropriate skills engaged in the research.

The right to suspend or withdraw from a research project

Aboriginal and Torres Strait Islander Peoples and communities have the right to suspend or withdraw their participation from a research project if there is a breach of the formal research agreement or of the way communities and/or organisations would like things done. The Human Research Ethics Committee (HREC)
that approved the research project may be able to help if this happens (see page 16 for more about ethics
approvals and HRECs).

If trust is broken, participants and communities have the right to:
- ask the HREC contact person for help
- contact the institution where the HREC is from
- contact the ombudsman in the relevant state or territory
- contact the Human Rights and Equal Opportunity Commission.

The rights to assert ownership of intellectual property and shared copyright
Aboriginal and Torres Strait Islanders Peoples have the right to assert ownership of the intellectual property
related to the information that is provided to the research project (e.g. data obtained from records).
Copyright issues are also linked with rights to intellectual property, and additional sets of rights attach to this
concept. The terms ‘intellectual property’, ‘copyright’ and ‘ownership’ are defined in the glossary.

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

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

- **Principle 3: The rights of Indigenous peoples to their intangible heritage must be recognised.**
  Research projects should be conducted in accordance with the principle of Indigenous peoples’
  rights to maintain, control, protect and develop their intangible heritage, including their cultural
  heritage, traditional knowledge, traditional cultural expressions and intellectual property.

- **Principle 4: Rights in the traditional knowledge and traditional cultural expressions of Indigenous
  peoples must be respected, protected and maintained.**
  Indigenous traditional knowledge and traditional cultural expressions are part of the heritage
  that exists in the cultural practices, resources and knowledge systems of Indigenous peoples,
  and that are passed on by them in expressing their cultural identity.

To respect, protect and maintain these rights, researchers must have a good understanding of the
nature of Indigenous traditional knowledge systems, traditional cultural expressions and intellectual
property.5

This means anything that is written, spoken or created by Aboriginal and Torres Strait Islander Peoples,
whether it is a story, a painting, a sculpture, an object, a dance, a song, or music (cultural practices), and any
knowledge of their land, culture or kinship that is used to express their cultural identity, is considered to be
the intellectual property of the contributor and should be respected as such (that is, contributors should
maintain their intellectual property). It is acknowledged that Aboriginal and Torres Strait Islander Peoples’

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5 Australian Institute of Aboriginal and Torres Strait Islander Studies (2012) *Guidelines for Ethical Research in Australian
intellectual property continues to expand via inclusion of contemporary creative and original works that have originated from Aboriginal and Torres Strait Islander cultural heritage.

Additional information about intellectual property management and copyright, as these relate to Aboriginal and Torres Strait Islander Peoples, can be found in the Australia Council for the Arts document *Protocols for producing Indigenous Australian writing*, including a checklist of things to consider. Some other resources about intellectual property and copyright are provided in the ‘Further resources’ section on page 31.

**The eight steps of the research journey**

Research is a process that aims to find something out, or make decisions about what is the best product or approach to a problem or situation. Research may be conducted at a local, regional or national level. Research may also involve collaboration internationally with other Indigenous populations of colonised countries. The research journey involves people with the appropriate skills working with Aboriginal and Torres Strait Islander Peoples and communities to look for answers to a specific issue, question or circumstance, or to find ways to solve a problem.

This section walks through eight steps of the research journey, which are also summarised in Table 1 (see page 14). Each step starts with a brief introduction followed by a list of questions to help keep research on track, ethical and appropriate. The eight steps are:

1. Building relationships
2. Developing the research idea
3. Developing the project and seeking agreement
4. Data collection
5. Analysing the data and making sense of the findings
6. Report writing
7. Sharing and translating the results into action
8. Learning from experience.

Not every research project will have all of the steps, and the steps may not always happen in the same order. Sometimes a step may be skipped. Other times participants and communities may need to take a step back, and ask the questions again so that trust can be maintained and there is confidence that the research process is on the right track. You’ll see that sometimes we suggest similar questions are asked for more than one step. This is because some questions are important to continue asking during different stages of the research.

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### Table 1: Keeping the research on the right track – a checklist of the eight steps research process

<table>
<thead>
<tr>
<th>#</th>
<th>Steps</th>
<th>Researcher’s tasks</th>
<th>Community/organisational involvement</th>
</tr>
</thead>
</table>
| 1 | Building relationships            | • Contact and meet the appropriate representatives from Aboriginal or Torres Strait organisations or communities.  
                                  | • Meet key local key people.  
                                  | • Find out about local protocols.  
                                  | • Contact and visit local Aboriginal or Torres Strait organisations.  
                                                                                       | • Prepare a list of the community’s and organisation’s codes of behaviour (protocols and values) for the researchers.  
                                                                                       | • Prepare a list of priority issues.  
                                                                                       | • Choose a mentor to work alongside the researchers.  
                                                                                       | • Community and organisational feedback into the appropriateness of research.  
                                                                                       | • Select the HREC contact person (see page 16).                                           |
| 2 | Developing the research idea      | • Explaining the big research picture.  
                                  | • Explaining the research process, roles and responsibilities.  
                                                                                       | • Negotiation and decision-making.  
                                                                                       | • Work with communities to fill out ethics approval forms to go to HREC (see page 16).  
                                                                                       | • Feedback into appropriateness of research agenda and methodology.  
                                                                                       | • Assess risks and benefits of proposed research.                                         |
| 3 | Developing the project and seeking agreement | • Finalise the research proposal and agreement.  
                                                                                       | • Sign research agreement when everybody is happy.  
                                                                                       | • Develop a research project plan.  
                                                                                       | • Jointly develop the ethics application for approval.  
                                                                                       | • Do not start the project without ethics approval.                                      |
                                                                                       | • Make sure there is a clear explanation of the research agreement which all community members can understand.  
                                                                                       | • Request different approaches if required.  
                                                                                       | • Jointly develop the ethics application for approval.  
                                                                                       | • Provide a letter of community and organisation support.  
                                                                                       | • Ensure the research project plan is workable.                                           |
| 4 | Data collection                   | • Training Aboriginal and Torres Strait Islander Peoples in data collection if relevant.  
                                                                                       | • Working ethically with participants to collect data.                                      | • Research participants sign individual consent forms.  
                                                                                       | • Community and organisational participation.  
                                                                                       | • Regular meetings with researchers to discuss and review progress.                      |
| 5 | Analysing the data and making sense of the findings | • Look at the information that has been collected to see what it means.  
• Prepare the findings in a clear statement that everybody can understand.  
• Hold community meetings and get feedback on the analysis. | • Attend community meetings to make sure that there is understanding about the meanings gained from the data.  
• Talk about whether the findings are important to communities and organisations.  
• Make sure any meanings that are important to communities are included in the findings. |
|---|---|---|
| 6 | Report writing | • Maintain constant relationships with communities and organisations when writing all reports.  
• Gain feedback from participating organisations and communities regarding appropriateness and accuracy of reports.  
• Acknowledge all local co-authors.  
• Meet funding body’s needs for report writing. | • Get communities and organisations involved in the preparation and presentation of report information.  
• Check that the communities and organisations are properly acknowledged in reports.  
• Check that there is agreement about the information in the reports.  
• Ask for a plain English community report. |
| 7 | Sharing and translating the results into action | • Present findings to organisations and community.  
• Publish and broadcast the findings.  
• Initiate research translation strategy. | • Make sure that the research findings are presented to the communities and organisations first, before being broadcast outside.  
• Develop strategies for local translation of research findings as appropriate. |
| 8 | Learning from experience | • Reflect on the process and the effectiveness of the role and performance of the researchers.  
• Help the communities and organisations to work out the effectiveness of their involvement at each stage of the research process. | • Evaluate if this research has been good for the community.  
• Identify the good and not so good outcomes.  
• Is there anything that could be changed next time? |
Ethics applications to Human Research Ethics Committees (HRECs)

Human Research Ethics Committees (HRECs) are responsible for the ethical review of research and they determine whether research proposals are ethically acceptable. Research proposals need to respect basic human rights and shared values, have high quality and appropriate research methods, and provide evidence that they include skilled and experienced people and available resources to undertake the research. HRECs also check that research proposals are in accordance with relevant laws, regulations, codes, standards and guidelines. This means that you can check with an HREC if you have any concerns about the research. However if an HREC’s assessment believes that a methodology or approach needs to be amended to better comply with ethical standards then the HREC will provide advice on suggested changes. HRECs review applications, receive progress reports and can consider any concerns regarding the ongoing research process for those projects that it has approved. An important part of any research agreement is to identify an HREC contact person. Establishing a relationship with this contact person can help community and organisational representatives feel confident about raising any concerns they may have about the way the research is progressing. See below for more information about HREC membership.

What people make up an HREC?

The complexity of human involvement in research means that the resolution of complex and often competing considerations can be challenging. The composition of HRECs is intended to reflect this complexity. The minimum membership of an HREC includes:

• a chairperson
• at least two ‘non-research’ people (one male and one female)
• at least one person with knowledge of, and current experience in, the professional care, counselling or treatment of people (e.g. a nurse or allied health professional)
• at least one person who performs a pastoral care role in a community (e.g. an Aboriginal elder, a minister of religion)
• at least one lawyer
• at least two people with current research experience that is relevant to research proposals to be considered at the meetings they attend.

This membership should have equal numbers of males and females; and at least one third of the members should be from outside the institution for which the HREC is reviewing research. The institution should ensure that the HREC has access to the expertise necessary to enable it to address the ethical issues arising from the categories of research it is likely to consider. This may necessitate going outside the HREC membership.

HRECs are generally located within universities, research organisations, hospitals and government departments. Some HRECs specialise in reviewing ethics proposals for research involving Aboriginal and Torres Strait Islander Peoples and have predominantly Aboriginal and Torres Strait Islander members. These HRECs are often referred to as Aboriginal Human Research Ethics Committees (AHRECs). Other HRECs may also have special expertise in reviewing ethics proposals for research involving Aboriginal and Torres Strait Islander Peoples and communities or have sub-committees for that purpose. Communities can request that a particular HREC should be involved in the research approval process.

The National Statement on Ethical Conduct in Human Research 2007 (the National Statement) is a guideline that sets out values and principles that apply to all human research to promote ethically good human research. To do this, it requires that participants be given the respect and protection that is due to them; and fostering research that benefits the community. The National Statement is used by researchers conducting research with people, and HRECs use it review research proposals. People involved in research might find it useful too.
1. Building relationships
The first step in any research journey is about building relationships. This refers to the researchers and Aboriginal and Torres Strait Islander Peoples and communities getting to know one another. As well as being the first step, it is important to maintain relationships throughout the whole research journey. In talking with one another and talking about how strong working relationships can happen with researchers, it is important to talk about Aboriginal and Torres Strait Islander Peoples’ core values and ways of doing things (protocols – see below). During this stage Aboriginal and Torres Strait Islander Peoples and communities also need to think about whether or not the research team has the knowledge, skills and experience to do this research.

Protocols
Protocols are a written list of guidelines developed by communities and/or organisations to set out how they expect outside stakeholders to engage with them. Protocols may refer to customary as well as national or international laws, which then make up a certain set of standards for the organisation or community. Providing a set of protocols to outside stakeholders helps them to better understand the organisation’s or community’s views, cultural values and beliefs, and ways of doing business.7

Researcher knowledge, skills and experience
Not all researchers have experience of working with Aboriginal and Torres Strait Islander Peoples or experience in research involving Aboriginal and Torres Strait Islander Peoples and communities. If participants or communities are looking for a researcher to undertake a project, or have been approached by a researcher to be involved in a project, the participants and community need to determine if the researcher has the appropriate experience and potential for trust with the community.

There are three things to check about the researcher:
- their knowledge, skills and capabilities, including cultural competence
- their resources and budgets
- their experience working with Aboriginal and Torres Strait Islander Peoples and communities.

There are several ways to see if a researcher or researchers meet the above criteria:
- Yarn with your mob – use community networks to see if the researcher has previously worked with Aboriginal and Torres Strait Islander Peoples and communities and whether this experience worked well or not so well.
- Ask the researcher – talk directly to the researcher about other projects they have done with Aboriginal and Torres Strait Islander Peoples and communities. Consider whether the researcher has enough resources and support to do the research in a way that meets your needs and expectations.
- Referees or a CV – ask the researcher to provide referees (contacts) for past projects. Get a copy of the researcher’s academic qualifications and history of their previous research and work experience. Check with any organisations that are listed as referees or in a CV to verify past projects and discuss the conduct of the research and any concerns you may have.
- Publications – check whether the books, journal articles and experience of the researcher are relevant to the proposed research topic.

7 Adapted from the United Nations Environmental Programme http://staging.unep.org/communityprotocols/index.asp.
• Use the internet – use the internet selectively to discover more information about the researcher and the proposed research.

Working with researchers with limited or no experience

Working with researchers who have no or little experience in working with Aboriginal and Torres Strait Islander Peoples and communities can be good as it is an opportunity for two-way sharing of knowledge, skills and values.

However, it is important that a researcher with little or no experience of working with Aboriginal and Torres Strait Islander Peoples and communities is able to show:

• a commitment to relationships with key individuals or organisations within the community
• an understanding of Aboriginal and Torres Strait Islander Peoples’ shared cultural values, and, specifically, how the host communities/organisations express these values in relation to research
• a focus on how the research will benefit Aboriginal and Torres Strait Islander Peoples and communities
• the intention, where possible and appropriate, to employ local researchers and community members in the research process
• a willingness to build lasting relationships by listening to and learning from Aboriginal and Torres Strait Islander Peoples
• an understanding that mentoring ‘both ways’ will be undertaken, that is a willingness for the researcher to learn from the community while contributing their knowledge and experience back to the community
• an understanding, including through mentoring, of the potential and actual difficulties that Aboriginal and Torres Strait Islander Peoples face when being involved in research.

A good way to help researchers with little or no experience is to work together with a mentor. The mentor may be a local Aboriginal or Torres Strait Islander researcher who works between the community and the outside researcher at all stages of the research. Partnerships between researchers, mentors and the community benefit everyone in several ways:

• the researchers develop knowledge and an understanding of working with Aboriginal and Torres Strait Islander Peoples and communities
• the mentor assesses their cultural competency and guides them throughout the project
• the mentor strengthens capacity and develops research skills
• the community is assured that the researchers are being guided to conduct the research in a manner that respects the community’s values and rights.

Questions to ask the research team

Here are some questions to ask the research team. Use the six core values, participant rights and your own set of criteria to decide if the answers to the questions will keep research on track, ethical and appropriate:

• Who are the research team (including students)? Which organisations are they from? What knowledge, skills and experience do they have to do research with Aboriginal and Torres Strait Islander Peoples and communities?
• Why were we approached?
• What other communities or organisations were invited to be involved in the research? What were their concerns?
• Are the researchers aware of current issues in our communities?
• Does the proposed research allow time and resources for the research team to get to know Aboriginal and Torres Strait Islander Peoples before they start collecting data?
• Does the research team have the appropriate skills involved in the research (e.g. medical, social or counselling expertise)?
• How can members of our communities or organisations be involved in the research?
• Will Aboriginal and Torres Strait Islander Peoples get formal and/or informal qualifications as a result of being part of the research team? If so, how?
• Which HREC has reviewed the project, was it approved and who is the HREC contact person? (See page 16 for more about HRECs.)

Questions for the Aboriginal and Torres Strait Islander participants and communities
Here are some questions to ask yourselves. Use the six core values, participant rights and your own set of criteria to decide if the answers to the questions will keep research on track, ethical and appropriate:
• Are the researchers respecting our values and ways of doing things (protocols)?
• If the research involves both Aboriginal and Torres Strait Islander Peoples is there consultation with representatives from both groups.
• Have we explained our community’s or organisation’s standards of behaviour (protocols and processes) to the researchers?
• Have we made it clear to the researchers that we can and will suspend or even stop (terminate) the research project if it is not meeting our ethical and cultural standards?
• Have we chosen a mentor to guide and work alongside the researchers?
• Have we made sure that the researchers have allocated resources to fund the work of our mentor?
• Have the researchers given our communities or organisations enough time to be involved in ways that are acceptable to our peoples? If not, are we still willing to be involved?
• Have the researchers allowed for flexibility in the timing of the research project so that if there are other priorities such as ‘sorry business’ that they respect our community’s rights and need to stop for however long it is necessary?
• Are we ready to enter into this relationship?
• Should we:
  - Go ahead with the proposed research?
  - Go ahead with the research but with changes to the processes, outcomes or even how the research question is framed?
  - Not go ahead with the research?
2. Developing the research idea

Developing the research idea involves exploring and planning all aspects of the research. This stage is where Aboriginal and Torres Strait Islander Peoples and communities may think broadly about what they want, what the researchers want, how the research might benefit the community or organisation, and what risks there might be. This is the time to explore all the possibilities to make sure that Aboriginal and Torres Strait Islander Peoples and researchers understand each other and get the most out of the research. It is a time to share in shaping the research to meet the needs of Aboriginal and Torres Strait Islander Peoples. Things to think about and discuss with researchers include:

- the focus of the research
- management of the project, including if this might be done via steering or advisory committees
- levels of participation
- skills development for Aboriginal and Torres Strait Islander Peoples
- outcomes or other benefits for the community from the project
- plans to translate findings to improve policy, practice, and/or service delivery.

There are many different ways of doing research. Some of the ways different types of research are classified are described on page 22.

Questions to ask the research team

Here are some questions to ask the research team. Use the six core values, participant rights and your own set of criteria to decide if the answers to the questions will keep research on track, ethical and appropriate:

- What is the aim of the research?
- What will the research be about?
- What are the researchers getting out of this research?
- What are the social, cultural, physical and economic (if any) benefits for:
  - individuals (financial, social, health)
  - organisations (human, financial, resources)
  - communities (cultural continuity, reputation)?
- What are the expected costs to individuals, organisations and communities (including inconvenience)?
- What are the potential risks in participating in the research?
- How will our confidentiality and privacy be protected?
- How will the research build capacity and capability?
- How will the researchers address trauma or difficulties that anyone might experience as a result of participating in this research? How will the researchers deal with this?
- Is there a risk management strategy?
- Does the research team have the appropriately qualified researchers working on this project?

Questions for the Aboriginal and Torres Strait Islander participants and communities

Here are some questions to ask yourselves. Use the six core values, participant rights and your own set of criteria to decide if the answers to the questions will keep research on track, ethical and appropriate:

- Is the research right for us?
- Do we all understand what this research will be about?
- Is this research a priority for our communities and organisations?
• Does this research meet our priorities and goals?
• What are we getting out of the research?
• What community or organisational and individual consent processes are required? Are these appropriate?
• Can our communities and organisations afford these costs? If not, what can we do?
What are the common types of research?

Research can be classified in many different ways, including on the basis of the methodology (ways of conducting research) of the research, the knowledge it creates, the user group and the research problem it investigates. Below are some definitions of research:

- **Basic research** is done to improve or add to knowledge and can be applied to human, animal and plant populations and objects or subjects. It is referred to as basic, pure, and/or fundamental research. The main aim is to expand our knowledge.

- **Applied research** is designed to solve practical problems of the modern world, rather than to gain knowledge for knowledge’s sake. The goal of applied research is to improve the human condition. It focusses on analysis and solving social and real life problems.

- **Descriptive research** is used to describe certain things about a population or a fact, experience or trend (something perceived or experienced) being studied. It does not answer questions about how/when/why the certain things about a population occurred. It attempts to determine, describe, or identify ‘what’ is. It is generally divided into three types:
  - **Observation**: concentrates on observing the subject in both natural and laboratory methods to draw the conclusions on the research.
  - **Case study**: the case study method looks at or studies in depth a situation in real life and usually involves a report about a person, group, or situation that has been studied over time.
  - **Survey**: Use of a survey involves collecting information about people or communities in an organised way. This may include using questionnaires or interviews to ask people about issues that are important to their wellbeing.

- **Analytical research** concentrates on the process of the final result rather than giving importance to the result. Analytical research attempts to establish the reasons behind/for a relationship/association or how it came to be and usually concerns itself with investigating what is the cause and what effect it has on the relationship.

- **Quantitative (numbers)**
  Quantitative research usually involves collecting information and turning it into numerical (numbers) form so that statistical calculations can be made and conclusions drawn. It involves counting and measuring (e.g. the number of cigarettes smoked each day or weight and blood pressure readings).

- **Qualitative (stories)**
  Qualitative research is a broad methodological (way of conducting research) approach that covers many research methods. Qualitative methods examine why decision-making is carried out and how it is performed, not just what, where, when, or who. Qualitative research is collecting, analysing and interpreting (understanding meaning) data by observing what people do and say. Qualitative research refers to the meanings, definitions, characteristics, symbols, images, and description of things. It uses different methods of collecting information, such as individual, in-depth interviews and focus (small) groups. Qualitative research often presents thematic (common themes from the information gathered) analysis or non-quantitative (no numbers) types of investigation.

- **Evaluation and quality assurance activities**
  Evaluation is a process used to decide the worth or value of an intervention, program or methodological (ways of conducting research) approach. It is sometimes considered research in its own right. See *Ethical Considerations in Quality Assurance and Evaluation Activities 2014* (NHMRC).
3. Developing the project and seeking agreement

In this step, the research idea is turned into a research project. Developing the research project should involve:

- a research agreement that is developed with your community and/or organisation and is based on free, prior and informed consent
- jointly developed ethics application
- provision of letters of support from appropriate community and/or organisational structures
- a plan that describes how the project will be looked after (project management).

Research agreement

A research agreement should be developed based on the principle of free, prior and informed consent. The agreement should clearly explain the project including roles and responsibilities so that everybody understands what the proposed research is all about and what it will look like. The agreement may be developed jointly with the researcher or by the researcher. There is an extensive list of requirements for a negotiated formal agreement on page 11 earlier in this document. The Guidelines for Ethical Research in Australian Indigenous Studies 2012 (GERAIS) from the Australian Institute of Aboriginal and Torres Strait Islander Studies also provide advice about the sort of things that should be in research agreements (see page 13 of the GERAIS).

The agreement should also be used to help manage the research project. Any changes to the project should be discussed and reflected in the agreement. This may involve amending the agreement or developing a new agreement. If this is the case, the amendments must be sent to the HREC for additional approval.

Letter of support

Once everyone understands the research question, agrees with the details of how the research will be done, and has read and is happy with the ‘ethics application form’, then it is time to provide a letter of community or organisation support. This letter will go with the researcher’s application to the HREC. The letter should provide information to the HREC so that the committee can see that your organisation/community thinks that the research is a priority area and that the researchers have appropriately consulted with and worked with the your organisation/community in the development of the research proposal and ethics application.

A letter of community or organisation support for the project should not be provided if people are not happy with every detail of the research project. It may be beneficial to wait until the necessary changes have been made and agreed to by all parties.

Looking after the project

It is good practice to provide regular updates and information to participants and the community and to organise meetings to discuss progress, concerns and issues. Communication between researchers and communities and organisations should continue through all stages of the research journey. There are several ways for your community and/or organisation to monitor the project:

- a local steering committee
- a community reference group
- a cultural mentor who keeps everything on track
- research assistants who train with and work alongside the researchers.
Questions to ask the research team

Here are some questions to ask the research team. Use the six core values, participant rights and your own set of criteria to decide if the answers to the questions will keep research on track, ethical and appropriate:

- Is there a clear description (plain or local language) of the research project?
- When will the research start? Is this negotiable?
- Who is funding the research and what will the funding cover (e.g. human resources, equipment, office space)?
- Will there be any opportunity for employing and training Aboriginal and Torres Strait Islander individuals?
- What will the communities or organisations be expected to pay for?
- What is expected ‘in-kind’ (use of our community’s time or organisation’s time, resources, equipment etc.)?
- Is there a risk management strategy to deal with counselling for trauma or difficulties that the participant may experience as part of the research?
- Who will be on the steering or advisory committee?
- Who is looking after the project? What are their contact details?
- Is the project on track in terms of time frames, budget and milestones?
- Does the project plan include regular feedback meetings to allow regular discussions between researchers, participants, organisations and other community members?
- What opportunities are there for checks and balances? For example, will the researchers be reporting to and liaising with our community or organisation at each step in the research journey?
- Are there agreed arrangements for suspending or stopping the research?
- How is the data (research information) to be stored?
- Is the data being linked to any other data?
- How may the data be used in the future? Who may use the data? Who is the contact for this?
- Who owns the data?
- If biological materials (e.g. blood, tissue) are collected as part of the research what happens to these at the end?
- Are photographs or videos going to be taken and why?
- What are the outcomes to date?
- How will the findings and outcomes from the project be translated into policy, practice, and/or service delivery?
- What stage is the HREC approval up to? Has the research proposal been submitted to an HREC and received approval?
- Has the name of an HREC contact person been included in the research agreement?
- How will the results of the research be published?

Questions for the Aboriginal and Torres Strait Islander participants and communities

Here are some questions to ask yourselves. Use the six core values, participant rights and your own set of criteria to decide if the answers to the questions will keep research on track, ethical and appropriate:

- Does the proposal to the HREC address relevant Aboriginal and Torres Strait Islander values?
- Do we understand what is meant by ‘free, prior and informed consent’?
- Have the researchers given us information and consent forms that we can easily understand?
• Do we need an interpreter?
• Have we explained the details of the proposed research?
• Does everyone still understand what this research is about and where it is going?
• Are the methods for research culturally and personally appropriate?
• Who will be on the steering or advisory committee (if there is a committee)?
• Have we received a copy and read the project plan?
• Are we happy that everything important is in an agreement that we are happy to sign?
• Are we happy to provide a letter of support for the research?
• Are there any difficulties so far?
• Are enough people involved?
• Do we need to make any changes to the research agreement between the researchers and our communities or organisations?
• Are the protocols or processes of our community or organisation being observed?
• Can our community or organisations use the data?
• Does the proposal clearly state community benefit?
• What situations or outcomes would trigger the need for renegotiation between our community or organisation and the researchers?
4. Data collection

Data collection is when information is being collected during the research. Data may take many forms such as stories, pictures, or statistics that describe how many people are affected. Information (data) may be collected from many places including health records, people, statistical collections and other sources. Data collection may also include blood or body tissue samples. The management of the data collection process includes:

- getting informed consent from each individual to participate in the research
- allowing authorised access to information
- making sure that participants know how the research data will be used as a result of the research (reports, publications, DVD or audio recordings, conferences, etc.)
- making sure that participants know where, how and the period of time that the data will be kept in storage
- having the option to either have the data returned to participants at the end of the storage period or whether to destroy it
- ensuring that all the information collected is kept confidential and, where appropriate, de-identified.

Questions to ask the research team

Here are some questions to ask the research team. Use the six core values, participant rights and your own set of criteria to decide if the answers to the questions will keep research on track, ethical and appropriate:

- How and where is the data being stored?
- How is the data going to be used?
- How will community protocols be applied on who can have access to the data once it is stored? Is the data only being used for this project as agreed?

Questions for the Aboriginal and Torres Strait Islander participants and communities

Here are some questions to ask yourselves. Use the six core values, participant rights and your own set of criteria to decide if the answers to the questions will keep research on track, ethical and appropriate:

- Do participants feel that they are able to give their informed consent (for photograph use, specimen use, testing with children, etc.)?
- Do participants understand what data are being collected and how all the information will be kept safe?
- Do participants understand how their data will be used and what will happen to it at the end of the research?
- What do participants ‘know’ about how the researchers have handled data in other research projects?
- Have we completed protocols on who can access the data once it is stored?
5. Analysing the data and making sense of the findings

This step involves the research team looking at the information that has been collected to see what it shows and what it means. The researchers and your community and/or organisation need to talk about what the information that has been collected means for each of you. It is important to understand the results of the research and to talk about what this means for your community or organisation.

Questions to ask the research team

Here are some questions to ask the research team. Use the six core values, participant rights and your own set of criteria to decide if the answers to the questions will keep research on track, ethical and appropriate:

- What are the steps involved in analysing the data (and future re-analysis)?
- How will the research team explain or present the findings to the community?
- What is the role of our community and/or organisation in the analysis and interpretation of the data?
- What happens if participants disagree with the research team’s interpretation?

Questions for the Aboriginal and Torres Strait Islander participants and communities

Here are some questions to ask yourselves. Use the six core values, participant rights and your own set of criteria to decide if the answers to the questions will keep research on track, ethical and appropriate:

- Do participants understand and agree with what the researchers present as the findings?
- How do we want the findings presented back to the community?
- Are the findings important to communities and organisations?
6. Report writing

Once the data is analysed the next step involves putting the information (findings) together to tell the story. This includes explaining what has been learned in the study, discussions about the findings and making recommendations. It is important for your community or organisation to have input at this stage to make sure that the information is presented in ways that are culturally appropriate. It is also important that the report acknowledges community contribution, authorship, intellectual property and shared copyright, as stated in the research agreement.

Questions to ask the research team

Here are some questions to ask the research team. Use the six core values, participant rights and your own set of criteria to decide if the answers to the questions will keep research on track, ethical and appropriate:

- What types of materials will be produced from the project findings: reports, publications, conference papers, presentations, CD, DVD or community report?
- Will written materials be in plain language, local language or both?
- Will the researcher(s) be happy to agree that the Aboriginal and Torres Strait Islander participants will maintain ownership of our intellectual property rights over the information provided by us in this research?
- Will Aboriginal and Torres Strait Islander participants and our community receive a copy of the final production of the research?
- Who is/are the author or co-authors?
- Will the researcher(s) be happy to share copyright with the co-authors from the community?
- How will our communities and organisation be recognised or acknowledged? (This should not be in conflict with individual and community concerns about being identified.)
- What will happen if we (Aboriginal and Torres Strait Islander participants and/or our communities or organisations) are unhappy with any of the reports or with the way the reports have been written up?
- Does the funding body have any specific report writing requirements?

Questions for the Aboriginal and Torres Strait Islander participants and communities

Here are some questions to ask yourselves. Use the six core values, participant rights and your own set of criteria to decide if the answers to the questions will keep research on track, ethical and appropriate:

- Do we understand what maintaining ownership of our intellectual property means?
- If an individual has co-authorship of the final product, do we want to have shared copyright and to understand what that means?
- How will Aboriginal and Torres Strait Islander participants and our communities be involved to comment on the design, structure and drafts of the reports?
- Have we (Aboriginal and Torres Strait Islander participants and communities) given consent to the use of photographs and video recordings?
7. Sharing and translating the results into action

The findings from research projects may be used in different ways (e.g. to improve health, education and quality of life; or to develop or review policies and practices which impact on Aboriginal and Torres Strait Islander Peoples). To ensure the research project contributes to outcomes for Aboriginal and Torres Strait Islander Peoples and communities, it is important that the sharing of results reaches the right people and that they understand what it means.

Sharing the results with other communities, organisations, policymakers and funding bodies may be done in many ways: through community meetings, stakeholder meetings, conference presentations, radio interviews, newspaper articles and publications in journals.

Translating results is about shaping the results into key messages and actions that can be used by government, non-government bodies, policymakers, service providers, organisations, communities and consumers to promote positive change and outcomes.\(^8\)

Questions to ask the research team

Here are some questions to ask the research team. Use the six core values, participant rights and your own set of criteria to decide if the answers to the questions will keep research on track, ethical and appropriate:

- Does the funding body have any special requirements related to releasing the reports?
- Does the research budget cover the costs of printing reports and media broadcasts?
- Does the project have a plan about knowledge translation?
- Will the researchers follow up important findings from the research to get good outcomes for our communities, such as better services?

Questions for the Aboriginal and Torres Strait Islander participants and communities

Here are some questions to ask yourselves. Use the six core values, participant rights and your own set of criteria to decide if the answers to the questions will keep research on track, ethical and appropriate:

- Will there be a media launch?
- Who will be the media contacts?
- Who will be involved in translating important findings into practice (refer to the plan about knowledge translation)?
- Will the researchers assist the organisation/community in translation at the local level if appropriate?

8. Learning from experience
The research journey should be evaluated to see whether:
- the project approach and methods were appropriate to answer the research question, issue or circumstance (evaluation)
- the analysis was conducted properly
- the interpretations and conclusions were valid
- the process and outcomes benefited the participants.

Reflecting on the research journey from a community or organisational perspective helps to identify what activities could be improved for any upcoming or future research projects. It might also identify other important research questions.

Questions to ask the research team and for Aboriginal and Torres Strait Islander participants and communities
- What was good about this journey?
- What was not so good about this journey?
- What have we learned?
- Would we do it again?
- What can we do better next time?
- Where to next?
- Do we need to consider developing or reviewing our own research agenda and protocols?
Further resources

Research ethics guidelines and information

*Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders* (Public consultation draft, 2017)
National Health and Medical Research Council

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

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

*EthicsHub*
The Lowitja Institute

**Human Research Ethics Committees (HRECs)**

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

**Intellectual property**

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

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

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

*Intellectual Property Management*
National Health and Medical Research Council

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

**Terri Janke and Company – Lawyers and Consultants**


**Other information**

*Indigenous Health*
National Health and Medical Research Council
Glossary of terms

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

**Beneficence:** the ethical principle of doing good.\(^9\)

**Community:** is recognised as a complex notion incorporating cultural groups, geographic groups or communities of interest. It may include a group or organisation and is a term used to describe a shared view amongst Aboriginal and Torres Strait Islander Peoples of groups based on culture, language, geography or common interests.

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

**Confidentiality:** The obligation of people not to use private information – whether private because of its content or the context of its communication – for any purpose other than that for which it was given to them.\(^10\)

**Copyright:** Ownership of anything you have created. The legal right granted to an author, composer, playwright, publisher, or distributor to exclusive publication, production, sale, or distribution of a literary, musical, dramatic or artistic work which lasts for 70 years in Australia.

**Community controlled:** A process which allows the local Aboriginal community to be involved in its affairs in accordance with whatever protocols or procedures are determined by the Community.\(^11\)

**Consent:** free, prior and informed consent.

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

**Health:** ‘Aboriginal health’ means not just the physical wellbeing of an individual but refers to the social, emotional and cultural wellbeing of the whole community in which each individual is able to achieve their full potential as a human being, thereby bringing about the total wellbeing of their community. It is a whole-of-life view and includes the cyclical concept of life-death-life.\(^12\)

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\(^12\) National Aboriginal Health Strategy Working Party (1989) *National Aboriginal Health Strategy*
**Human rights:** are rights inherent to all human beings, whatever our nationality, place of residence, sex, national or ethnic origin, colour, religion, language, or any other status. We are all equally entitled to our human rights without discrimination. These rights are all interrelated, interdependent and indivisible.

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

**Indigenous knowledge:** Indigenous peoples have developed a close and unique connection with the country and environments in which they live. They have established distinct systems of knowledge, innovation and practices relating to the uses and management of biological diversity on country and environments. Much of this knowledge forms an important contribution to research and development, particularly in areas such as pharmaceuticals, and agriculture and cosmetic products. In the context of these uses, Indigenous peoples claim that their rights as traditional holders and custodians of this knowledge are not adequately recognised or protected. They demand not only recognition and protection of their traditional knowledge, but also to have a fair and equitable share of any benefits derived from the uses of this traditional knowledge.

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

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

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

**Intellectual property:** generally means original creative works in literary, artistic, industrial and scientific fields that can be protected either by copyright or trademarks. It also means in this context the principle of Aboriginal and Torres Strait Islander Peoples’ rights to the protection and maintenance of Aboriginal and Torres Strait Islander tangible heritage. Intellectual property also exists over the stories told about heritage and cultures. Also see Ownership.

**Justice:** Fairness or protection of rights and punishment of wrongs. In research it is taking into account the scope, and objectives of the proposed research; the selection, exclusion and inclusion of categories of research participants is fair, and is accurately described in the results of the research; the process of recruiting participants is fair; there is no unfair burden of participation in research on particular groups; there is fair distribution of the benefits of participation in research; there is no exploitation of participants in the conduct of research; and there is fair access to the benefits of research.\(^{13}\)


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

Knowledge translation: can be defined as a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically sound application of knowledge to improve health, provide more effective health services and products and strengthen the health care system.\textsuperscript{14} It also applies to other relevant fields such as housing, personal safety and wellbeing, and education.

Mentor: A community or organisation member who helps to make sure that the researchers stay on the right path, and that the project remains within cultural bounds and is safe for everyone involved.

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

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

Ownership: The law governs rights of ownership and possession in tangible (i.e. material objects), non-tangible (such as intellectual property rights, copyright and so forth) and whether such rights may be held. Common examples of tangible goods, include ownership of ‘real’ property such as land and houses, and of ‘personal’ goods such as cars. Under common law it is recognised that there may be several rights to one place, such as over mineral rights to land owned by an individual. The Mabo case (\textit{Mabo versus Queensland} No.2) found that the native title of Aboriginal and Torres Strait Islander Peoples, their rights and interests in land and waters survived the establishment of Crown sovereignty in 1788.\textsuperscript{15}

Privacy: A domain within which individuals and groups are entitled to be free from the scrutiny of others.\textsuperscript{16}

Traditional knowledge: A cumulative body of knowledge, know-how, practices and representations maintained and developed by peoples with extended histories of interaction with the natural environment. These sophisticated sets of understandings, interpretations and meanings are part and parcel of a cultural complex that encompasses language, naming and classification systems, resource use practices, ritual, spirituality and worldview.\textsuperscript{17}

Wellbeing: For Aboriginal and/or Torres Strait Islander Peoples, wellbeing also incorporates health and broader issues of social justice, equity and rights. The significance of culture to wellbeing, and therefore good health, is also demonstrated by using traditional knowledge and the practices of traditional healers, which are adapted by many people for complementary use with western science in an integrated health care system.\textsuperscript{18}

\textsuperscript{14} Adapted from Government of Canada, Canadian Institutes of Health Research, Knowledge Translation, ‘About Knowledge Translation – CIHR’, www.cihr-irsc.gc.ca
\textsuperscript{16} NHMRC, ARC & UA (2007) \textit{National Statement on Ethical Conduct in Human Research 2007}, p.89
\textsuperscript{17} The International Council for Science (2002) \textit{Science and Traditional Knowledge: Report from the ICSU Study Group on Science and Traditional Knowledge}
\textsuperscript{18} Australian Government (2013) \textit{National Aboriginal and Torres Strait Islander Health Plan 2013–2023}, p.9