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Keeping research on track II

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

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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 respect to Elders past, present and future.

We acknowledge all those involved in the development of *Keeping research on track II 2018*. The revision of this guideline involved the commitment and contribution of many people.

Description of the artwork

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

Introduction

Over the years research has been undertaken into all aspects of Aboriginal and Torres Strait Islander people's lives.[1] While some research has been beneficial in areas such as health, medicine, education and science, not all research has been of benefit.[2] It is therefore important that appropriate processes are in place to ensure that research is considered, meaningful, ethical and beneficial to Aboriginal and Torres Strait Islander people and communities.

There is more information on NHMRC's website about the history of research with Aboriginal and Torres Strait Islander Peoples.

Ethical conduct of research upholds the rights and responsibilities of Aboriginal and Torres Strait Islander people 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. Aboriginal and Torres Strait Islander Peoples and communities each have their own established values and protocols, and their own unique ways of expressing their different values. The term 'Indigenous' is used to describe both Aboriginal and Torres Strait Islander Peoples. There is also difference and diversity within, as well as between, these two groups. In addition, many Aboriginal and Torres Strait Islander people prefer to identify with their language group/s and traditional land/s from where they trace their ancestry.

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

Recognising and respecting diversity throughout the research journey helps to initiate, develop and sustain partnerships and relationships with Aboriginal and Torres Strait Islander Peoples and communities that are based on trust, mutual responsibility and ethics. When conducting research that includes both Aboriginal and Torres Strait Islander Peoples, researchers must consult and work with relevant stakeholders from both groups.

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

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

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

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

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

About this guideline

This guideline 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 people 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.

The information in this guideline comes from two key national publications which set out the requirements for the ethical conduct of research:

- *National Statement on Ethical Conduct in Human Research* (the National Statement)
  The National Statement is the principal guideline setting out the requirements for the ethical design, review and conduct of all human research in Australia. The National Statement is about four main principles: respect; research merit and integrity; justice; and beneficence. The National Statement provides guidance on the ethical considerations that are relevant to the way that research is designed, reviewed and conducted.
- *Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders 2018* (the Guidelines).
  The Guidelines apply to all research with Aboriginal and Torres Strait Islander Peoples and communities. The Guidelines should inform all steps in the research process including conception (the initial idea), design (plan of the research), conduct (ways of doing the research), reporting (what happened), and dissemination of findings (circulation to relevant bodies) regarding research with Aboriginal and Torres Strait Islander Peoples and communities. The Guidelines apply to all researchers, whether they are Aboriginal or Torres Strait Islander people, other Australians or international researchers.

When using this guideline, researchers, participants and communities should think about the values and principles it is based on and how these can best be put into practice in different research projects. The eight steps of the research journey are like this too (see page 17). 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.

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

Intended audience

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

Starting a research journey

There are several ways a research journey can be started. It may be researcher-driven; requested by government, industry or community; or community-driven.

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 people, 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 people 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
- recognising the importance of **research and knowledge being translated** in ways that are meaningful and that will have benefits for Aboriginal and Torres Strait Islander people and communities.

There are also plenty of questions to ask throughout the research journey to keep research ethical and appropriate. For the purposes of this guideline, 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 18), which can be used as a way of checking whether research 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 the core values is provided on pages 7–8 and information on rights about participation is provided on pages 9–16. More information about each of the steps, including questions to ask at each step, is provided on pages 22–38.

Research agreements

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

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

More information about research agreements can be found on page 12.

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:

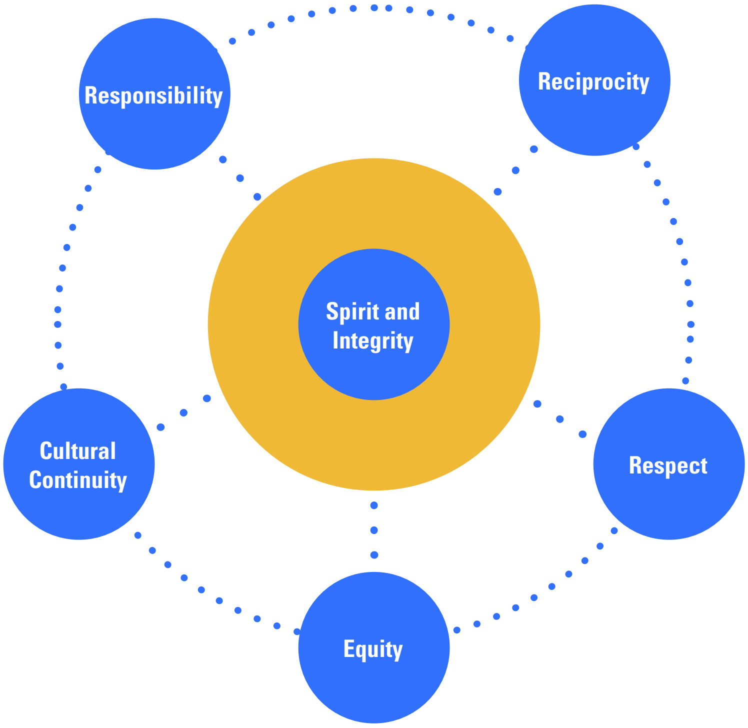

Figure 1 — the six core values[3]

Each of these core values is briefly described below. To find out more about these values, see *Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders 2018*.

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[3] 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 conducted 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 people and communities have experienced inequities as a result of discrimination and marginalisation. 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 diverse kinship networks. This keeps 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. Seeking consent and negotiating an agreed outcome through a formal research agreement are important ways of demonstrating respect.

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 9–16) and Table 1 shows the concept of the rights about participation underlying each step of this journey (see page 18).

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 *UN Declaration on the Rights of Indigenous Peoples* 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.[4] 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 the time required for the consultation and consensus processes.
- **Informed**: implies that information about the project is provided in a clear and understandable way. This includes the nature, size, pace, reversibility and scope of any proposed project or activity; the purpose of the project as well as its duration; locality and areas affected; a preliminary assessment of the likely economic, social, cultural and environmental impact, including potential risks; people likely to be involved in doing the project; and procedures the project may entail. This process should also explain that participants can decline to consent or withdraw consent during the research project. Participants must be kept fully informed if the project or process changes and in situations when early or interim results are identified. Information must be clear 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 the information, then they have not been informed.[5]

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[4] For example, see https://www.humanrights.gov.au/publications/hreoc-social-justice-report-2002-self-determination-freedom-live-well#9.

[5] Adapted from https://www.humanrights.gov.au/publications/2005-international-conference-engaging-communities-free-prior-and-informed-consent.

The National Statement uses slightly different terms to describe these same principles and states that respect for people involves giving due scope to people's capacity to make their own decisions. In research, this normally means that participation is the result of a choice made by participants — commonly known as 'consent'.

The National Statement specifies that consent has the following conditions: consent should be a **voluntary** choice (free), and should be based on **sufficient information** before any activity begins (prior) and **adequate understanding** of the purpose, methods, demands, any risks and potential benefits of the proposed research and the implications of participation in it (informed). Use of the term 'consent' throughout *Keeping research on track II* reflects the application of all three principles as outlined in the National Statement.

Decisions about participation in research may sometimes involve the whole community and not only individuals. Researchers may need to seek community consent as well as individual consent. Research agreements (see page 12) and letters of support (see page 22) can also assist in gaining community consent.

Consent may be expressed orally, in writing or by some other means (e.g. by returning a completed survey, or conduct implying consent such as attending an interview). But this will depend on the nature, complexity and level of risk of the research as well as the participant's personal and cultural circumstances.

See paragraph 2.2.5 of the National Statement.

Talking with participants about the project and seeking their consent should aim for mutual understanding between researchers and participants. This aim means that participants can ask questions and discuss the information and their decision with others if they wish.[6] The type of information that should be given to participants is listed at paragraph 2.2.6 of the National Statement.

Participant information and consent processes should cover all steps in the research process.

For example, if you give consent to have a blood sample taken for research purposes, the researcher must ask you to provide consent for the blood collection procedure AND for what the researchers intend to do with your sample as part of the research (or even after the research has finished). All of this information must be provided to participants before they can give their consent.

The right to say no up front

Individuals, communities and organisations always have the right not to participate in research. This might be for a number of reasons — the research might not address community priorities, or the project might not be conducted at a suitable time for the community, or individuals just may not want to participate. It is important to recognise that, if the research is occurring in or with multiple communities, the right for an individual or community to say no up front does not mean that the research activity can't or won't proceed at all (e.g. it may be possible for it to proceed with other communities).

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[6] National Health and Medical Research Council [NHMRC], Australian Research Council [ARC] & Universities Australia [UA] (2007, updated 2018) *National Statement on Ethical Conduct in Human Research* p.16.

Individuals or communities who decide not to participate in a research project do not have to give any reason for their decision. Researchers should do what they can to see that people who decline to participate will have no disadvantage as a result of their decision.[7] It is important to note that if an individual says no to participating in the research it may still go ahead if the community or organisation decides to participate. The same applies if multiple communities or organisations are asked to be involved in a research project. If one community or organisation decides not to participate, the research may still go ahead with the other communities or organisations.

Also see 'The right to suspend or withdraw from a research project' below.

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, depending on the type of project being undertaken. One way of doing this is by setting up a local steering committee or advisory group to arrange frequent feedback between the research team and community members. Elders and other knowledge holders 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 people 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 3*
- establish their own research agenda, including what is high or low priority
- 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.

The right to commission research that meets priority needs

Aboriginal and Torres Strait Islander people 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 help, but they might be able to provide further contacts.

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[7] NHMRC, ARC & UA (2007, updated 2018) *National Statement on Ethical Conduct in Human Research* p.18.

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 ask for 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. *Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders 2018* supports the expectation that Aboriginal and Torres Strait Islander people 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 written research agreement

It is important for researchers to have a negotiated agreement with Aboriginal and Torres Strait Islander organisations and communities so that each party fully understands what is expected from them and each other. Research does need resources such as people, time and money to be available. For example, interpreters might be needed during the negotiations or staff may be needed to help research assistants. Aboriginal and Torres Strait Islander people and communities have the right to seek advice and ask for help to negotiate agreements. Aboriginal and Torres Strait Islander people 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 help in the negotiation process.

Research agreements should include how researchers, organisations or communities will work together respectfully, define roles and responsibilities throughout the research process, identify conflict resolution and complaint processes, outline communication and dissemination strategies and outline the protection of any intellectual property.

Such agreements will vary in format, formality and complexity, depending on the characteristics of each research project. In some cases (such as research resulting in commercial products), legal documents will likely be required.

There is also information about research agreements in *Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders 2018*.

A research agreement might include (but is not limited to):

- aim of the research
- names of researchers and research institution/s
- funding details
- benefit to the participants and broader Aboriginal and/or Torres Strait Islander population
- commitment of the researchers and the participating organisations and communities
- clarification of roles and responsibilities of researchers and participating organisations and communities
- informed consent process
- data collection, ownership, analysis and storage
- strengthening capacity strategy
- communication and media strategy
- copyright and intellectual property management
- dissemination process, including to communities and key stakeholders
- knowledge translation process
- ceasing the research.

Some organisations have templates for research agreements, consent forms and other research information:

Aboriginal Health and Medical Research Council of New South Wales:
http://www.ahmrc.org.au/ethics.html

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

The right to check on the researcher's track record

When communities or organisations employ researchers to work with them, it is good practice as part of the recruitment process to check on the researcher's track record of working with Aboriginal and Torres Strait Islander people and communities. 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 ask for a list of all researchers with their qualifications to ensure that they have the appropriate skills to be engaged in the research.

The right to suspend or withdraw from a research project

Aboriginal and Torres Strait Islander people and communities have the right to suspend or withdraw their participation from a research project at any stage. This might be if there is a breach of the formal research agreement or of the way communities and/or organisations would like things done, or perhaps they simply do not want to participate any more. Before giving consent to be involved in the research, participants should be informed about any consequences if participants choose to withdraw (e.g. will there still be enough participants for the project to keep going? What will happen to a participant's data that is already in the project if they withdraw part-way through?). The Human Research Ethics Committee (HREC) that approved the research project may be able to help if a project has to be suspended (see page 21 for more about ethics approvals and HRECs).

The right to make a complaint if something goes wrong

Researchers and their institutions should make sure there is a process for receiving, handling and seeking to resolve complaints. There should be contact details or a person to receive these complaints, and these must be easily available to participants.[8]

If something has gone wrong with the research, participants and communities have the right to:

- ask the contact person for help
- contact the institution where the researcher is from
- contact the institution where the HREC is from
- contact the ombudsman in the relevant state or territory
- contact the Australian Human Rights Commission.

The right to assert ownership of cultural and intellectual property and shared copyright

Aboriginal and Torres Strait Islander Peoples have the right to assert and retain ownership of the cultural and intellectual property related to the information that is provided to the research project and control over the use of that data in publications and other copyrighted works. Ownership may take many forms, including as rights recognised under Australian and international intellectual property laws. However, cultural and intellectual property is not limited to only those forms of knowledge.

Even where copyright is transferred to a research team, Aboriginal and Torres Strait Islander communities or contributors may still have protected moral rights. For a detailed definition of copyright terms, see page 41 of the Glossary.

Aboriginal and Torres Strait Islander Peoples have developed a close and unique connection with the country and environments where they live. They have established distinct systems of knowledge, innovation and practices relating to the uses and management of biological diversity on country and environments. This knowledge is part of a wider body of Aboriginal and Torres Strait Islander cultural and intellectual property. A lot of this knowledge forms an important contribution to research and development, particularly in areas such as pharmaceuticals, and agriculture and cosmetic products. In the context of these uses, Aboriginal and Torres Strait Islander Peoples' rights as traditional holders

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[8] NHMRC, ARC & UA (2007, updated 2018) *National Statement on Ethical Conduct in Human Research* p.17.

and custodians of this knowledge have not been adequately recognised or preserved. Given this, Aboriginal and Torres Strait Islander Peoples demand not only recognition and preservation of their traditional knowledge, but also to have a fair and equitable share of any benefits derived from the uses of this traditional knowledge.

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

Likewise, a narrow application of inventorship and 'prior art' in patent law may leave Aboriginal and Torres Strait Islander communities at risk of commercial exploitation or unable to jointly benefit from the commercialisation of their traditional knowledge. Commercialisation means extracting value from intellectual property by marketing a new product, production method or service based at least partly on that intellectual property.[9] Because of these differences, researchers must be sensitive to the limitations of applying standard intellectual property agreements and recognise the differences between intellectual property law and notions of ownership.

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

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.[10]

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[9] IP Australia (2017) *Understand Commercialisation*.

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

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

A number of intellectual property terms are defined in the Glossary on page 41. Some other resources about cultural and intellectual property management and copyright as these relate to Aboriginal and Torres Strait Islander Peoples are provided in the Further resources section on page 39.

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

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 people and communities to look for answers to a specific issue, question or circumstance, or to find ways to solve a problem. Research journeys may look different depending on the type of research that is happening.

This section walks through eight steps of the research journey, which are also summarised in Table 1 (see page 18). Each step starts with a brief introduction followed by a list of questions to help keep research on track, ethical and appropriate. Some questions may not apply to some types of research projects.

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. Sometimes 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. During the whole process, it is important for the researcher, the participants and the community to monitor how things are going and address any issues, and for enough time to be given to each step.

Table 1: Keeping the research on the right track —a summary of the eight steps of the research journey

		#	Steps	Researcher's tasks	Community/organisational involvement
Core values	Rights about participating in research	1	**Building relationships**	• Contact and meet the appropriate representatives from Aboriginal or Torres Strait Islander organisations or communities. • Meet key local people. • Find out about local protocols. • Contact and visit local Aboriginal or Torres Strait Islander organisations. • Select the contact person for information and/or complaints. • Seek information about the community's research priorities and aspirations.	• 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 or knowledge holder to work alongside the researchers. • Seek community and organisational feedback into the appropriateness of the research. • Inform researchers of the community's research priorities and aspirations.
		2	**Developing the research idea**	• Explain the big research picture (the research agenda). • Explain the research process (methodology), roles and responsibilities. • Negotiation and decision-making. • Identify any employment, training and capacity-strengthening opportunities. • Work with communities to fill out ethics approval forms to go to the Human Research Ethics Committee (see page 21). • Work with communities to see how the research can address community research priorities and aspirations.	• Negotiation and decision-making. • Give feedback into appropriateness of the research agenda and methodology. • Ask about employment, training and capacity-strengthening opportunities for Aboriginal and Torres Strait Islander people. • Ask how the community's research priorities and aspirations are addressed in the research. • Assess risks and benefits of the proposed research.
		3	**Developing the project and seeking agreement**	• Finalise the research proposal and agreement, ensuring it addresses all relevant matters (such as intellectual and cultural property and data management). • 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. • Make sure the research agreement addresses all relevant matters, such as intellectual and cultural property and data management. • 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. • If appropriate, organise a community advisory group to assist or guide the research.

		#	Steps	Researcher's tasks	Community/organisational involvement
Core values	Rights about participating in research	4	**Data collection**	• Seek consent from participants, with appropriate reference to detailed information sheet. • Train Aboriginal and Torres Strait Islander people in data collection if appropriate. • Work ethically with participants to collect data. • Comply with relevant privacy legislation.	• Research participants ask any questions relating to the information sheet and research proposal and 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 findings gained from the data. • Talk about whether the findings are important to communities and organisations and if these align with the community's research priorities and aspirations. • Make sure any meanings that are important to communities are included in the findings.
		6	**Report writing**	• Maintain 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 language 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. • If research outcomes result in a partnership, ensure all key stakeholders have input into the development of future strategies or actions.
		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 each stage of the research.	• 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?

Box 1: Human Research Ethics Committees (HRECs)[11]

What is a Human Research Ethics Committee?

Human Research Ethics Committees (HRECs) are responsible for reviewing ethics proposals for research and they determine whether the research is ethically acceptable. Research needs to respect basic human rights and shared values, have high quality and appropriate research methods, and provide evidence that there are skilled and experienced people and available resources to undertake the research. HRECs also check that the research is in accordance with relevant laws, regulations, codes, standards and guidelines.

This means that you can check with the HREC if you have any concerns about the research. If the HREC says that a methodology or approach needs to be amended to comply with ethics standards, then the HREC will provide advice to the researcher on suggested changes. An important part of any research agreement is to identify a contact person for the research project, and they might be from the HREC or the institution where the HREC is from. 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 going.

What people make up an HREC?

Human involvement in research means that resolving 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 that their HREC most often considers.

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 ethics proposals for research. The institution should ensure that the HREC has access to the expertise necessary so it can address the ethical issues arising from the categories of research it is likely to consider. This might mean going outside the HREC membership.

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[11] See NHMRC's website and the *National Statement on Ethical Conduct in Human Research* for more information about HRECs.

Where are HRECs?

HRECs are generally located within universities, research organisations, hospitals and government departments. Some HRECs specialise in reviewing ethics proposals for research with 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 with Aboriginal and Torres Strait Islander Peoples and communities or might have sub-committees for that purpose. Communities can request that a particular AHREC or HREC should be involved in the research approval process.

What rules do HRECs have to follow?

The *National Statement on Ethical Conduct in Human Research* (the National Statement) is an Australian guideline that sets out values and principles that apply to all human research to promote ethically good human research. HRECs use it to review ethics proposals for research. The National Statement requires that participants be given the respect and protection that is due to them, and fosters research that benefits the community. The National Statement is used by researchers to write ethics proposals when they conduct research with people. People participating in research might find it useful too.

HRECs also use *Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders 2018* when they assess ethics proposals. HRECs also use the Australian Institute of Aboriginal and Torres Strait Islander Studies *Guidelines for Ethical Research in Australian Indigenous Studies 2012*.

Important — no part of the research project should start until the HREC has approved the ethics proposal.

1. Building relationships

The first step in any research journey is about building relationships. This means researchers and Aboriginal and Torres Strait Islander people and communities getting to know one another. As well as being the first step, it is important to maintain relationships through 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 people 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.[12] In addition to these and depending on the type of research being undertaken, there might be other protocols that the researchers need to follow or should consult:

- local protocols (e.g. those set out by the Torres Strait Regional Authority)
- other guidelines (e.g. the *Guidelines for Ethical Research in Australian Indigenous Studies 2012* from the Australian Institute of Aboriginal and Torres Strait Islander Studies)
- legislation (e.g. the *Privacy Act 1988*).

Letters of support for research projects

In the field of research, there are requirements for researchers to acquire letters of support for their research projects from community organisations, traditional owner groups and/or community councils.

This will happen when:

- Researchers are engaging or partnering with organisations or communities to develop research proposals and partnerships, and they want to make sure that participating organisations and communities are supportive of the research.
- Researchers are submitting an application to a funding body to fund their research. Funding bodies have certain criteria which researchers have to address to show that the Aboriginal and Torres Strait Islander organisation or community involved feel that the research is needed to improve outcomes, that it is worthwhile and will benefit Aboriginal and Torres Strait Islander people.
- Researchers are submitting an application to the HREC, which is usually attached to the institution where the principal researcher is employed. The role of the HREC is to review applications and to make sure that the participating organisation, group or community supports the research.

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[12] Adapted from the United Nations Environmental Programme https://www.unenvironment.org/resources/report/community-protocols-common-underlying-principles.

When called upon to provide a letter of support, organisations, groups and/or communities have the right to ask researchers to:

- provide a plain language version of the research proposal for their consideration
- meet with representatives from the organisation, group and/or community to present the research proposal
- explain anything that is not clear in the research proposal in relation to the recommended principles and protocols in this guideline.

Researcher knowledge, skills and experience

Not all researchers have experience working with Aboriginal and Torres Strait Islander Peoples or experience in research with Aboriginal and Torres Strait Islander people 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 might also be extra skills the researcher needs if they are working with special groups, such as children. Researchers should be familiar with extra requirements that special groups might need and can check the *National Statement on Ethical Conduct in Human Research* for what they need to consider.

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 people 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 people 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 people and communities. Consider whether the researcher has enough resources and support to do the research in a way that meets the needs and expectations of participants and communities.
- 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.
- Use the internet — use the internet selectively to find out 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 people 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 people 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 or organisations express these values in relation to research
- a focus on how the research will benefit Aboriginal and Torres Strait Islander people 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 people 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 you could ask the research team. The answers to the questions will help you to decide if the research is 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 people and communities?
- Are the researchers aware of the community's research priorities and aspirations?
- 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 people before they start collecting data?
- Does the research team have the right skills involved for 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 people 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 contact person for information or complaints?

Questions for the Aboriginal and Torres Strait Islander participants and communities

Here are some questions you could ask yourselves. The answers to the questions will help you to decide if the research is on track, ethical and appropriate:

- Are the researchers respecting our values and ways of doing things (protocols)?
- If the research includes 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 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, if appropriate, 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 people? 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?
- If our community has research priorities and aspirations, have the researchers addressed our priorities and aspirations?
- Are there any likely benefits (tangible or intangible) that will come back to the community? Have these benefits been agreed on?
- 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 people 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 with a steering or advisory committee
- 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 different types of research are described on page 29.

Questions to ask the research team

Here are some questions you could ask the research team. The answers to the questions will help you to decide if the research is 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 employment and training opportunities for Aboriginal and Torres Strait Islander people?
- What are the social, cultural, physical and economic benefits (if any) 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 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?

- Is there a conflict management strategy, in case there are any disagreements during or after the project?
- Does the research team have the appropriate qualified researchers working on this project?
- Does the funding body have any special requirements during the project or about releasing reports when the project has finished?
- How will cultural and intellectual property be managed throughout and after this project? (See page 14 for more information about intellectual property and copyright).

Questions for the Aboriginal and Torres Strait Islander participants and communities

Here are some questions you could ask yourselves. The answers to the questions will help you to decide if the research is 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?
- Are there any employment, training and capacity-strengthening opportunities for us?
- What individual, community or organisational consent processes are required? Are these appropriate?
- Can our participants, communities and organisations afford any costs? If not, what can we do?
- Have the researchers addressed the management of cultural and intellectual property, so that we can retain ownership of our intellectual property that we will provide for this research? (See page 14 for more information about intellectual property and copyright).

Box 2: What are the common types of research?

There are different types of research, but they all have some things in common. These common things are seven elements that happen in all types of research:

- Developing the research scope, aims, themes, questions and methods
- Recruitment
- Consent
- Collection, use and management of data and information
- Communication of research findings or results to participants
- Dissemination of research outputs and outcomes
- After the project

(see Section 3 of the *National Statement on Ethical Conduct in Human Research*)

These common elements are used in all different types of research. What makes one type of research different from another is the *research methodology*. The methodology is how the research will be conducted and what type of things the researcher is going to find out this way. Some different methodologies and types of research are described below:

- **Observation:** observing the participant in both natural and laboratory settings to draw conclusions on the research.
- **Case study:** looks at a real-life situation in depth and usually involves a report about a person, group, or situation that has been studied over time.
- **Survey:** collecting information about people or communities in an organised way. This may include using questionnaires or interviews or the internet to ask people about issues that are important to their wellbeing.
- **Quantitative (numbers)** usually involves collecting information and turning it into numerical form (numbers) 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)** is collecting, analysing and interpreting information 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 in-depth interviews, focus groups or using the internet.
- **Data linkage** looks at existing data collections and combines or uses them in ways to find new information. Sometimes one place (e.g. a hospital) might already have a set of data that a researcher wants to use. The researcher might be able to link this data to other data in another place (e.g. a health service) to find out new information about this data when it is all put together.

- **Human biospecimens research** is about any biological materials obtained from a person including tissue, blood, urine and sputum. It also includes any derivative of these, such as cell lines. These materials can contain important information that researchers can use, but these materials have to be collected in the proper way before they can be used in research. Researchers also have to be aware of the right ways to retain, store, use and dispose of these materials. See Chapter 3.2 of the National Statement.
- **Genetic or genomic research** is about genes, and it involves generating, gathering, collecting, conveying or using genomic data or information that has hereditary (family) implications. It might also help predict future health for participants as well as their relatives and other family members. Genomic information can be both specific to an individual and specific to relatives of that individual and, in some cases, of significance to human population groups such as Aboriginal and Torres Strait Islander groups that define themselves via their ancestral lineages. See Chapter 3.3 of the National Statement.
- **Longitudinal studies** are long-term studies that run for many years. These studies might use any of the methodologies listed above.
- **Evaluation and quality assurance activities** are processes used to decide the worth or value of an intervention, program or methodology (a way of conducting research). Sometimes this is considered research in its own right. Whether or not it is research, it might still have ethical issues that need consideration by an HREC or another type of review body. See *Ethical Considerations in Quality Assurance and Evaluation Activities 2014*.

The National Statement has more information about these and other different types of research.

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 consent
- a 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 principles of consent (see pages 9–10). 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 by the researcher or jointly by the community and the researcher together. There is a list of items to consider for a negotiated agreement on page 13 earlier in this document. The *Guidelines for Ethical Research in Australian Indigenous Studies 2012* from the Australian Institute of Aboriginal and Torres Strait Islander Studies also provides advice about the sort of things that should be in research agreements.

The research 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 and it changes the conditions in the approved ethics proposal, the amendments must be sent to the HREC for additional approval of any changes to the ethics proposal.

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 or community thinks that the research is a priority area and that the researchers have appropriately consulted with and worked with your organisation or community in the development of the research proposal and ethics proposal.

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 give 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 you could ask the research team. The answers to the questions will help you to decide if the research is 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' (e.g. use of the community's time or organisation's time, resources, equipment)?
- 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, if there is one?
- 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 the 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 this 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 or body tissue samples) 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 happens to these at the end?
- What are the outcomes so far?

- How will the findings and outcomes from the project be translated into policy, practice and/or service delivery?
- What stage is the HREC ethics approval up to? Has the research proposal been submitted to an HREC and received ethics approval?
- Has the name/s of a contact person for information or complaints been included in the research agreement?
- How will the results of the research be published?
- Do the information and consent forms include details about the matters above, so that participants can make an informed decision about participating? Do the written consent forms refer back to the information sheet or provide an opportunity to record participant questions? (See pages 9–10 for more information about consent.)

Questions for the Aboriginal and Torres Strait Islander participants and communities

Here are some questions you could ask yourselves. The answers to the questions will help you to decide if the research is on track, ethical and appropriate:

- Does the ethics proposal to the HREC address relevant Aboriginal and Torres Strait Islander values?
- Do we understand what is meant by consent?
- Have the researchers given us information and consent forms that we can easily understand? Have we or the researchers checked if everyone understands?
- Are all the relevant matters included in the information sheet (e.g. intellectual property, data management, risks and benefits)? Does the consent form make it clear what we are agreeing to?
- Do we need an interpreter?
- Has the research team explained the details of the proposed research?
- Does this research address our community's research priorities and aspirations?
- Does everyone still understand what this research is about and where it is going?
- Are the methods for research culturally appropriate for individuals and groups?
- Who will be on the steering or advisory committee (if there is one)?
- Have we received a copy of the project plan and read it?
- Do we need to make any changes to the research agreement between the researchers and our communities or organisations?
- Are we happy that everything important is in a research 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?
- Are the protocols or processes of our community or organisation being observed?
- Have the researchers obtained the necessary consent or permissions to use data or records from this research (e.g. images, personal quotes, stories) to promote the research?
- Can our community or organisations use the data?
- Does the proposal clearly state the benefits for participants and/or communities?
- What situations or outcomes would trigger the need for re-negotiation 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, records or statistics that describe how many people are affected. Examples of records include published materials, electronic information (emails, websites, CDs, DVDs, videos, films, etc.) and designs. 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. See Element 4 in Chapter 3 of the National Statement for more information about data.

Some data can be sourced from materials in the public domain, including information that is already published or available on the internet. Researchers should consider guidance about the secondary use of data in the National Statement. Researchers should also check with communities to make sure any publically available data about that community that may be used in a new research project is still correct or current.

The management of the data collection process includes:

- getting 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 (e.g. in reports, publications, DVD or audio recordings, conferences, etc.)
- making sure that participants know where, how and for how long 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 (where possible) or have the researchers destroy it
- ensuring that all the information collected is kept confidential and, where appropriate, de-identified.

There is more information about data collection and storage in the *Australian Code for the Responsible Conduct of Research* and researchers should be familiar with this. There are also state, territory and Commonwealth laws about data use, storage, retention or destruction that researchers will need to know about and use in their project (where applicable).

Questions to ask the research team

Here are some questions you could ask the research team. The answers to the questions will help you to decide if the research is 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 you could ask yourselves. The answers to the questions will help you to decide if the research is on track, ethical and appropriate:

- Do participants feel that they are able to give consent (e.g. for photograph use, biological sample use, involvement of children)?
- 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? Will this matter for our project?
- 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 you could ask the research team. The answers to the questions will help you to decide if the research is 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 participants and the community?
- What is the role of participants, our community and/or organisation in the analysis and interpretation of the data?
- Are there any gaps in the data analysis or other areas that should be explored?
- What happens if participants disagree with the research team's interpretation? Is there a way to manage any disagreement?

Questions for the Aboriginal and Torres Strait Islander participants and communities

Here are some questions you could ask yourselves. The answers to the questions will help you to decide if the research is 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 our or other communities and organisations?
- Have the researchers found any gaps in the data analysis or other areas that should be explored? Could these be explored in this research project or another project?

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 you could ask the research team. The answers to the questions will help you to decide if the research is 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 researchers be happy to agree that the Aboriginal and Torres Strait Islander participants will maintain ownership of their intellectual property rights over the information they have provided in this research? Will this be stated in the research outcomes or outputs?
- Will Aboriginal and Torres Strait Islander participants and our community receive a copy of the final production of the research?
- Who is the author? Are there any co-authors?
- Will the researchers be happy to negotiate copyright where appropriate?
- If there are no co-authors from the community, will anyone from the community be acknowledged in the final publication?
- 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 you could ask yourselves. The answers to the questions will help you to decide if the research is on track, ethical and appropriate:

- Do we understand what maintaining ownership of our intellectual property means?
- Do we want to negotiate copyright and do we understand what that means in different types of research projects?
- Do we understand the difference between co-authorship and acknowledgement?
- How will we be involved to comment on the design, structure and drafts of the reports?
- Have we given consent for the use of photographs or video recordings in the reports?

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 or 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 good outcomes for Aboriginal and Torres Strait Islander people 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, media 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.[13] This could mean that partnerships could be formed between these bodies and the community.

Questions to ask the research team

Here are some questions you could ask the research team. The answers to the questions will help you to decide if the research is 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 secure or call for benefits for the community, such as better services or skills development for community members in research methodologies?

Questions for the Aboriginal and Torres Strait Islander participants and communities

Here are some questions you could ask yourselves. The answers to the questions will help you to decide if the research is 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 project's plan about knowledge translation.
- Will the researchers assist the organisation or community in knowledge translation at the local level, if appropriate?
- If a partnership is established as a result of the research findings, how will this be coordinated for key stakeholders?

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[13] Jacobson, N., Butterill, D. & Goering, P. (2003) Development of a Framework for Knowledge Translation: Understanding User Context, *Journal of Health Services Research & Policy,* vol. 8, no. 2, pp.94–99.

8. Learning from experience

The research journey should be evaluated to see whether:

- the project's approach and methods were appropriate to answer the research question, issue or circumstance
- the analysis was conducted properly
- the interpretations and conclusions were valid
- the process and outcomes benefited the participants and/or community.

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 priorities 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 2018
National Health and Medical Research Council
https://www.nhmrc.gov.au/guidelines-publications/ind2

National Statement on Ethical Conduct in Human Research
National Health and Medical Research Council, Australian Research Council & Universities Australia
https://www.nhmrc.gov.au/guidelines-publications/e72

Australian Code for the Responsible Conduct of Research
National Health and Medical Research Council, Australian Research Council & Universities Australia
https://www.nhmrc.gov.au/guidelines-publications/r41

Guidelines for Ethical Research in Australian Indigenous Studies 2012
Australian Institute of Aboriginal and Torres Strait Islander Studies
http://aiatsis.gov.au/research/ethical-research/guidelines-ethical-research-australian-indigenous-studies

EthicsHub
The Lowitja Institute
http://www.lowitja.org.au/ethics

Human Research Ethics Committees (HRECs)

Human Research Ethics Committees
National Health and Medical Research Council
https://www.nhmrc.gov.au/health-ethics/human-research-ethics-committees-hrecs

Intellectual property

Moral Rights
Arts Law Centre of Australia
https://www.artslaw.com.au/info-sheets/info-sheet/moral-rights/

Protocols for producing Indigenous Australian writing
Australia Council for the Arts
http://www.australiacouncil.gov.au/artforms/aboriginal-and-torres-strait-islander-arts/protocols-for-working-with-indigenous-artists/

Factsheet: Access and Benefit-Sharing
Convention on Biological Diversity
https://www.cbd.int/abs/information-kit-en/

Short Guide to Copyright
Department of Communications and the Arts
https://www.communications.gov.au/documents/short-guide-copyright

Types of IP
IP Australia
https://www.ipaustralia.gov.au/understanding-ip/getting-started-with-ip/types-of-ip

Terri Janke and Company – Lawyers and Consultants

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

Janke, T (1998) '*Our Culture: Our Future: Report on Australian Indigenous Cultural and Intellectual Property Rights*', Australian Institute of Aboriginal and Torres Strait Islander Studies and the Aboriginal and Torres Strait Islander Commission (accessed at http://www.austlii.edu.au/au/journals/AILR/1999/51.html#Heading3)

KLC Intellectual Property and Traditional Knowledge Policy
Kimberley Land Council
http://www.klc.org.au/news-media/research-facilitation

Australian Indigenous Cultural and Intellectual Property Protocol
Museum of Applied Arts and Sciences
https://maas.museum/about/governance/policies-and-plans/

Indigenous cultural rights and engagement policy
National Museum of Australia
http://www.nma.gov.au/about_us/ips/policies/indigenous_cultural_rights_and_engagement_policy

Indigenous cultural and intellectual property rights
National Copyright Unit
http://www.smartcopying.edu.au/copyright-guidelines/hot-topics/indigenous-cultural-and-intellectual-property-rights

Intellectual Property Management
National Health and Medical Research Council
https://www.nhmrc.gov.au/grants-funding/policy/intellectual-property-management

Traditional Knowledge
World Intellectual Property Organization
http://www.wipo.int/tk/en/tk/

Research Agreements

Aboriginal Health and Medical Research Council of New South Wales
http://www.ahmrc.org.au/ethics.html

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

Other information

Aboriginal and Torres Strait Islander Health
National Health and Medical Research Council
https://www.nhmrc.gov.au/health-topics/aboriginal-and-torres-strait-islander-health

National Centre for Indigenous Genomics
Australian National University
http://ncig.anu.edu.au/

Glossary of terms

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

Beneficence: The ethical principle of doing good to others.[14]

Commercialisation: Commercialisation means extracting value from intellectual property by marketing a new product, production method or service based at least partly on that intellectual property.[15]

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

Community controlled: A process which allows the local Aboriginal community to be involved in its affairs in accordance with whatever protocols or procedures are determined by the community.[16]

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.[17]

Consent: Seeking consent shows respect for people by giving due scope to people's capacity to make their own decisions. In the research context, this normally requires that participation be the result of a choice made by participants. Consent has the following conditions: consent should be a **voluntary** choice (free), and should be based on **sufficient information** (prior) and **adequate understanding** of the purpose, methods, demands, risks and potential benefits of the proposed research and the implications of participation in it (informed).[18]

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

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

[15] IP Australia (2017) *Understand Commercialisation*.

[16] National Aboriginal Community Controlled Health Organisation, http://www.naccho.org.au/about/aboriginal-health/definitions/.

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

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

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

- right of attribution: this is the right of an author to be identified and named as the author of his/her work
- right against false attribution: this is the right of an author to stop someone else being credited as the author of their work
- right of integrity: this is the right of an author to ensure that his/her work is not subjected to derogatory treatment which is any act in relation to the work that is in any manner harmful to the author's honour or reputation.[19]

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

Health: 'Aboriginal health' means not just the physical wellbeing of an individual but refers to the social, emotional and cultural wellbeing of the whole community in which each individual is able to achieve their full potential as a human being, thereby bringing about the total wellbeing of their community. It is a whole-of-life view and includes the cyclical concept of life-death-life.[20]

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

Indigenous Cultural and Intellectual Property: Refers to all aspects of Indigenous peoples' cultural heritage, including the tangible and intangible. This cultural heritage includes all traditional and cultural knowledge (sciences, plant and animal knowledge, stories, designs and symbols, ritual knowledge, literature and language), cultural objects (including, but not limited to, arts, crafts, ceramics, jewellery, weapons, tools, visual arts, photographs, textiles and contemporary art practices), performances (ceremonies, dance and song), human remains, the secret and sacred (including sites) and documentation of Indigenous heritage.[21]

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

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

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[19] Based in part on: https://www.artslaw.com.au/info-sheets/info-sheet/moral-rights/.

[20] National Aboriginal Health Strategy Working Party (1989) *National Aboriginal Health Strategy*.

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

and legal system. In Australia, the term 'Indigenous' is used to describe both Aboriginal and Torres Strait Islander Peoples. Many Aboriginal and Torres Strait Islander people prefer to identify with their language group/s and traditional land/s from where they trace their ancestry.

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

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

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

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

Justice: Fairness or protection of rights and punishment of wrongs. In research it is taking into account the scope and objectives of the proposed research; the selection, exclusion and inclusion of categories of research participants is fair, and is accurately described in the results of the research; the process of recruiting participants is fair; there is no unfair burden of participation in research on particular groups; there is fair distribution of the benefits of participation in research; there is no exploitation of participants in the conduct of research; and there is fair access to the benefits of research.[22]

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

Knowledge translation: Knowledge translation can be defined as a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically sound application of knowledge to improve health, provide more effective health services and products and strengthen the health care system.[23] It also applies to other relevant fields such as housing, personal safety and wellbeing, and education.

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

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

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

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

[23] Adapted from Government of Canada, Canadian Institutes of Health Research, Knowledge Translation, *'About Knowledge Translation – CIHR'*, www.cihr-irsc.gc.ca.

Privacy: A domain within which individuals and groups are entitled to be free from the scrutiny of others.[24]

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

Traditional knowledge: Traditional knowledge refers to the knowledge, innovations and practices of Indigenous and local communities around the world. Developed from experience gained over the centuries and adapted to the local culture and environment, traditional knowledge is transmitted orally from generation to generation. It tends to be collectively owned and takes the form of stories, songs, folklore, proverbs, cultural values, beliefs, rituals, community laws, local language and agricultural practices, including the development of plant species and animal breeds.[25]

Wellbeing: For Aboriginal and Torres Strait Islander Peoples, wellbeing incorporates health and broader issues of social justice, equity and rights. The significance of culture to wellbeing, and therefore good health, is also demonstrated by using traditional knowledge and the practices of traditional healers, which are adapted by many people for complementary use with Western science in an integrated health care system.[26]

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

[25] https://www.cbd.int/traditional/intro.shtml.

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

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Arts Law Centre of Australia (2016) *Moral Rights*, accessed at https://www.artslaw.com.au/info-sheets/info-sheet/moral-rights/.

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Canadian Institutes of Health Research (2017) *Knowledge translation and commercialisation*, accessed at http://www.cihr-irsc.gc.ca/e/29529.html.

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IP Australia (2017) *Understand commercialisation*, accessed at https://www.ipaustralia.gov.au/understanding-ip/commercialise-your-ip/understand-commercialisation.

Jacobson, N., Butterill, D. & Goering, P. (2003) Development of a Framework for Knowledge Translation: Understanding User Context, *Journal of Health Services Research & Policy,* vol. 8, no. 2, pp.94–99.

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

National Health and Medical Research Council, Australian Research Council and Universities Australia (updated 2018) *National Statement on Ethical Conduct in Human Research 2007*, Commonwealth of Australia: Canberra.

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

United Nations Environmental Programme (no date) *Community protocols for access and benefit sharing*, accessed at https://www.unenvironment.org/resources/report/community-protocols-common-underlying-principles.