Griffith University Research Ethics Manual

Research with Australian Indigenous Peoples

V3.9 October 2020

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1.0 Introduction

This Booklet is intended to provide a brief introduction to the issues associated with research involving the participation of Aboriginal and Torres Strait Islander peoples, or research involving issues of significance to Aboriginal and Torres Strait Islander peoples. The Booklet also provides a basis for seeking further information and guidance.

Research involving the participation of Aboriginal and Torres Strait Islander peoples, or research involving issues of significance to Aboriginal and Torres Strait Islander peoples, can often raise significant ethical issues. Aboriginal and Torres Strait Islander people perceive they have been an "over-researched population". Therefore, community ties, building trustworthy relationships and appropriate engagement are extremely important to Aboriginal and Torres Strait Islander people. Events that have impacted upon other Aboriginal and Torres Strait Islander people in the past can have very real relevance to current events and indeed the future. As a consequence, the past behaviour of researchers in their dealings with Aboriginal and Torres Strait Islander peoples, has the potential to create a context of mistrust for current researchers.

It should also be noted that "cultural blindness" can lead to researchers to make significant and serious errors with a potential to impact negatively on participants, further diminishing the view that Aboriginal and Torres Strait Islander people have towards the conduct of research, and ultimately compromise the value of the research itself. This is a situation to be avoided.

Cultural blindness is a failure to recognise one or more of the following:

• the historical experience of Aboriginal and Torres Strait Islander people in research, and the present significance of the shared cultural memory;

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- the distinctiveness, richness and vibrancy of Aboriginal and Torres Strait Islander culture;
- the desire of Aboriginal and Torres Strait Islander people to preserve the integrity of their culture and traditions;
- the important relations for Aboriginal and Torres Strait Islander people between individuals, family, people and the land;
- the historical prejudice and discrimination inflicted upon Aboriginal and Torres Strait Islander people; and
- the potential for research to act positively or negatively on the above;
- to recognise the differences between Aboriginal and Torres Strait Islander peoples especially in language and cultural beliefs.

Griffith University is committed to assisting researchers with the design and conduct of research to the highest possible standards. Consequently, it is never appropriate to exclude Aboriginal and Torres Strait Islander people from a potential participant pool unless there are sound research or ethical reasons (see Commentary Inset 1).

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Commentary Inset 1 – Valid reasons for the exclusion of Aboriginal and Torres Strait Islander people

In accordance with the core ethical principle of **justice** (see Section 1 of the National Statement) and "taking into account the scope and objectives of the proposed research" a potential participant should not be screened/excluded from a project because they are Aboriginal or Torres Strait Islander. It should be noted that NS1.4 also discusses that the recruitment of participants of a project must be fair and there must be a fair opportunity for individuals to enjoy the benefits of participation.

In some circumstances Aboriginal and Torres Strait Islander people will not be present in a potential participant pool because of the framing of the inclusionary criteria (e.g. some diseases are either very rare or not present in Aboriginal and Torres Strait Islander people). In practice this means that while there will not be an exclusionary criteria, they will simply not be present in the potential participant pool.

There can however be situations where such an exclusionary criteria would be valid.

EXAMPLE: The literature may have already identified that Aboriginal and Torres Strait Islander people have a different experience/have different needs/require a more tailored approach. As a consequence a researcher might validly decide to screen a potential participant pool to exclude what might be a confounding variable for the results of the work.

As per NS1.4(a) any such exclusion must be disclosed when the results of a project are reported. There must also be a discussion of why the exclusion was considered appropriate and any impact that this exclusion has upon the transferability of the results (e.g. under the heading of limitations).

In light of the provisions of <u>NS1.4</u>, unless the kind of circumstances discussed above are present, potential participants should not be screened to exclude Aboriginal and Torres Strait Islander people.

It is acknowledged that additional design, conduct and reporting requirements do apply to research involving Aboriginal or Torres Strait Islander people, but their exclusion may silence an important voice, undermine the practical use of the results of a project, and deny them access to potentially valuable benefits.

It is hoped that this booklet will assist researchers and show that a positive engagement with Aboriginal and Torres Strait Islander people can greatly enhance the value and quality of a project.

02.0 National guidance material

The Ethical conduct in research with Aboriginal and Torres Strait Peoples and communities: guidelines for researchers and stakeholders (2018) (Ethical conduct guidelines) document is an extremely useful Australian reference point. The presented principles, the issues and questions for reflection, and the proposed approaches, are likely to be appropriate for all areas of human research.

The principles discussed in these guidelines are:

Spirit and integrity p.4

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- Cultural continuity p.4
- Equity p.6
- Reciprocity p.7
- Respect p.9
- Responsibility p.11

The Australian national reference point for human research ethics is the National Statement on Ethical Conduct in Human Research (2007 updated 2018) (National Statement). Chapter 4.7 of the National Statement discusses research with Aboriginal and Torres Strait Islander Peoples. The chapter discusses the range of issues that must be considered during the design and conduct of Aboriginal of Torres Strait Islander people research.

Ethics reviewers should refer to both the Ethical conduct guidelines and chapter 4.7 of the National Statement during the review of Australian Indigenous research. Chapter 4.7 directs that all research involving Aboriginal and Torres Strait Island Peoples and issues must be reviewed by a HREC. This is the case even when the research is otherwise low risk, or where the research is to be conducted by an Australian Indigenous researcher or is highly respectful of culture and protocols.

Griffith University also uses the <u>Code of Ethics for Aboriginal and Torres Strait Islander</u> <u>Research</u> to inform the ethical design and conduct of Indigenous research, as well as its research ethics review.

Also see the Guide to Applying the AIATSIS Code of Ethics.

Please note after a 12 month implementation period, the Code of Ethics will supersede and replace the *Guidelines for Ethical Research in Australian Indigenous Studies* (GERAIS).

See <u>Booklet 1 of the Griffith University-REM</u> for more about the principles of ethical conduct for human research, <u>Booklet 2</u> for more about research ethics review at Griffith University and <u>Booklet 9</u> for more about risks.

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3.0 Why do special arrangements exist?

It is useful reflecting on why Griffith University has particular arrangements for Aboriginal and Torres Strait Islanders.

In the years since the <u>referendum in 1967</u> there has been a movement towards genuine reconciliation between Aboriginal and Torres Strait Islanders and non-Indigenous Australians. Central to these efforts is mutual respect, healing and unity. As was noted in <u>1.0 of this Booklet</u>, historically, research that involved Aboriginal and Torres Strait Islanders has not been seen by communities as being necessarily beneficial. Some reasons include:

- little or no say in the research from its inception to its conclusion;
- the design of the project has given limited attention to the principles of respect, reciprocity and responsibility;
- researchers have not conducted themselves with integrity;
- the outcomes of research have not been reported back to the Aboriginal and Torres Strait Islander community and did not benefit participants; and
- the intellectual and cultural knowledge of Aboriginal and Torres Strait Islander peoples is not acknowledged or remunerated.

Therefore, the NHMRC and the Australian Institute of Aboriginal and Torres Strait Islander Studies issued guidelines to inform the design, review, conduct and reporting of Aboriginal and Torres Strait Islander research. Consequently, Griffith University has produced this booklet to guide ethical and respectful research in this area.

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4.0 When should this book be consulted?

This manual should be consulted at inception of your research idea and throughout the research project. Indeed, many researchers can mistakenly conclude that their research does not involve Aboriginal and Torres Strait Islander people or issues because the researcher is not purposively recruiting Aboriginal or Torres Strait Islander people. This is not in fact the only reason why these guidelines should be used.

In addition to the purposive recruitment of Aboriginal or Torres Strait Islander people these guidelines should be used if any of the following circumstances apply:

- 1. Participants will be asked to indicate if they are an Aboriginal or Torres Strait Islander person and/or their Indigeneity is a variable of interest in the data collected;
- 2. The sampling criteria geographic (e.g. location and whether the individual lives with a particular medical condition) means that significant proportion of potential participants will be Aboriginal or Torres Strait Islander people (see Commentary Inset <u>2</u>);
- 3. The research will involve matters, issues, topics, phenomena or problems that are of special interest or significance to

Commentary Inset 2 – Sampling criteria where there will be a significant recruitment of Aboriginal and Torres Strait Islander people

In some cases, a researcher might not initially conceive of a project as being work with Aboriginal and Torres Strait Islander people, but in practice the sampling criteria mean that there may in fact be a significant number of potential participants who are Aboriginal or Torres Strait Islander people.

EXAMPLE: A project will be conducted in the far north of Queensland and will recruit persons who have a diabetes related eye condition/vision impairment. Even if such a project is not described as Aboriginal and Torres Strait Islander research, the geographic location and the inclusionary criteria (an eye complaint related to diabetes) means that the project should be considered Indigenous research.

The potentially subjective assessment to make is at what point is the recruitment of Aboriginal and Torres Strait Islander people, as a subset of the total participant pool, significant. This cannot/shouldn't be expressed in purely numerical or percentage terms.

- 1. Is the recruitment of Aboriginal or Torres Strait Islanders purposive, rather than coincidental. If the recruitment is purposive the project should be considered Indigenous research.
- 2. Is the Indigeneity of participants a variable of interest for the analysis of the data and potentially for the reporting of results? If so the project should be considered Indigenous research.
- 3. Is the topic under investigation or the area of research of established interest for Aboriginal and Torres Strait Islander people (see Commentary Inset 3)? If so the project should be considered Indigenous research

Aboriginal or Torres Strait Islander people (see Commentary Inset 3); or

4. Involvement of Aboriginal and Torres Strait Islander people may expose them to risks associated with the project that may be of more significance to them than to non-Aboriginal participants..

All these situations describe Aboriginal and Torres Strait Islander research. Consequently, human research across a broad range of disciplines, traditions methods and questions, may have to be classified as Aboriginal and Torres Strait Islander research.

The question of whether a project is Indigenous research should be considered very early in its design so that the issues discussed in this booklet can be considered and addressed. Researchers should also then build in sufficient time into th5e project time line to consider and address the ethical and practical issues identified in the research.

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5.0 Ethical principles for Aboriginal and Torres Strait

Islander Research

The National Statement on Ethical Conduct in Human Research (2007 updated 2018) sets out the principles of ethical conduct in human research. These are discussed in Booklet 1 of this Manual.

However, in addition to the principles outlined by the National Statement, the Ethical conduct in research with Aboriginal and Torres Strait Peoples and communities: guidelines for researchers and stakeholders (Ethical conduct guidelines) and Guidelines for Ethical Research in Australian Indigenous Studies (GERAIS) (currently under review) also outline a number of key values and ethical principles for research with Australian Indigenous people and communities. This is a reflection of the historical experience of Aboriginal and Torres Strait Islanders in terms of research. special considerations that can apply, the status of this group as an "over researched population", and the potential for research in this area to perpetrate social inequalities and prejudices.

A proposed project that is considered to be an activity within the scope of the matters covered by this Booklet (see.4.0) would be assessed against these principles.

Commentary Inset 3 – Issues of special significance to Aboriginal and Torres Strait Islander people

In the case of projects where the sampling criteria does not warrant the project being considered research with Aboriginal and Torres Strait Islander people (see Commentary Inset.2) a project may still be considered Indigenous research if it involves issues of special interest or significance to Aboriginal and Torres Strait Islander people.

It may be possible for non-Indigenous issues to identify whether an issue if of special significance based upon reporting in the academic or popular press reporting.

Some example issues are outlined below. In the event a non-Indigenous researcher is unsure whether an issue of special significance to Aboriginal and Torres Strait Islander people they should seek the advice of the <u>Indigenous Research Unit</u> (see 5.2).

Some example issues of established special significant to Aboriginal and Torres Strait Islander people include (but are not limited to):

- 1. Matters relating to the history of reconciliation in Australia, current reconciliation activities in Australia and the future of reconciliation in Australia.
- 2. The history of Aboriginal and Torres Strait Islander people, including individual figures of historical interest/note.
- 3. Public sector programs (including university and other educational bodies) with, for or about Aboriginal and Torres Strait Islander people (e.g. health programs specifically focussed upon Aboriginal and Torres Strait Islander people).
- 4. Historical practices with regards to adoption in Australia (e.g. because of the possibly that it raises matters relating to the Stolen Generation).
- 5. Work relating to deaths in custody.
- 6. Work relating to secret men's or women's business.

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5.1 Ethical conduct guidelines

5.1.1 SPIRIT AND INTEGRITY

The principle of spirit and integrity is discussed in detail on page 4 of the <u>Ethical conduct guidelines</u>. In summary, this principle is the central core value that binds all the other five 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.

An application for ethics clearance can demonstrate that the design, and intended conduct, of a proposed protocol addresses the principle of spirit and integrity by addressing the issues identified in sections 5.1 of this Booklet.

5.1.2 CULTURAL CONTINUITY

The principle of cultural continuity is discussed in detail on pages 4-5 of the Ethical conduct guidelines.

In summary, cultural continuity contributes to a sense of strong, shared and enduring individual and collective identities; includes maintaining the bonds and relationships between people and between people and their environment and also includes responsibilities in respect of spiritual domains.

An application for ethics clearance can demonstrate that the design, and intended conduct, of a proposed project addresses the principle of cultural continuity by:

- Negotiated participation in cultural events and the sharing of information more broadly (e.g. sacred sites; women's business and men's business).
- Establishing mechanisms that incorporate the balance between collective and individual identity.
- Establishing a community advisory group and respecting the community's decisions regarding the way the research is to be conducted from project conception to conclusion.
- Considering the use of Aboriginal and Torres Strait Islander standpoints and methodologies when developing research proposals, where appropriate.

5.1.3 EQUITY

The principle of equity is discussed in detail on pages 6-7 of the <u>Ethical conduct guidelines</u>. In summary this principle is reflected by a commitment to showing fairness and justice that enables Aboriginal and Torres Strait Islander Peoples' culture, history and status to be appreciated and respected.

An application for ethics clearance can demonstrate that the design and intended conduct of a proposed project addresses the principle of equity by:

- Establishing equitable partnerships between researchers, participants and communities.
- Actively engaging participants and communities in negotiations about the meanings of the research topic and the methods of research.
- Considering (where appropriate) that the first language of the participants be used as part of the communication strategy (e.g. information sheets, consent forms, gathering data, feedback and final reports to participants).
- Ensuring that all legal matters (e.g. intellectual property) are fairly and appropriately addressed in the research agreement or other legal documents).
- Including participants and communities in all steps of the research process and ensuring that protocols relating to consent have been implemented.

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5.1.4 RECIPROCITY

The principle of reciprocity is discussed in detail on pages 7-8 of the <u>Ethical conduct guidelines</u>. In summary this principle iis having regard for the welfare, rights, knowledge, skills, beliefs, perceptions, customs and cultural heritage (both individual and collective) of people involved in research. Within Aboriginal and Torres Strait Islander cultures, respect is reinforced through, and in turn strengthens, dignity. A respectful relationship promotes trust and co-operation.

An application for ethics clearance can demonstrate that the design and intended conduct of a proposed project addresses the principle of reciprocity by:

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

5.1.5 RESPECT

The principle of respect is discussed in detail on pages 9-10 of the <u>Ethical conduct guidelines</u>. In summary this principle is expressed as having regard for the welfare, rights, knowledge, skills, beliefs, perceptions, customs and cultural heritage (both individual and collective) of people involved in research. Within Aboriginal and Torres Strait Islander cultures, respect is reinforced through, and in turn strengthens, dignity. A respectful relationship promotes trust and co-operation.

An application for ethics clearance can demonstrate that the design and intended conduct of a proposed project addresses the principle of respect by:

- Ensuring conditions for consent are satisfied for the research and all related activities (e.g. the engagement and consultation process, research agreements, intellectual property agreements, capacity development plans, knowledge translation plans and other relevant strategies). This means that participant decisions to participate are **voluntary**, the participants are **fully informed**, and that participants **understand** the information. This also relates to the Equity and Reciprocity values.
- Outlining how the decision-making process will actively involve Aboriginal and Torres Strait Islander people and communities.
- Negotiating a research agreement with Aboriginal and Torres Strait Islander people and communities that will be continually assessed throughout the research project.
- Engaging with Aboriginal and Torres Strait Islander communities and institutional structures when seeking Human Research Ethics Committee (HREC) approval.
- Providing information on how changes and/or cancellations to the project will be communicated, negotiated and endorsed by all stakeholders, including participants, organisations and HRECs (e.g. information sheets, telephone calls, attendance at a community meeting, a board meeting or through a research advisory committee).
- Recognising and acknowledging the individual and collective contribution of Aboriginal and Torres Strait Islander participants and groups (e.g. through acknowledgement in final reports, publications and/or presentations).

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5.1.6 RESPONSIBILITY

The principle of responsibility is discussed in detail on pages 11-12 of the Ethical conduct guidelines. In summary, recognition of core responsibilities is central to Aboriginal and Torres Strait Islander societies and cultures, including caring for country, kinship bonds, caring for others and the maintenance of harmony and balance within and between the physical and spiritual realms. A key responsibility within this framework is to do no harm, including avoiding having an adverse impact on the ability of others to comply with their responsibilities. Also, an individual's responsibilities are not limited to them alone and may relate to the accountability of others. Responsibilities may be shared with others so that as a group they will also be held accountable.

An application for ethics clearance can demonstrate that the design and intended conduct of a proposed project addresses the principle of responsibility by:

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

5.1.7 RELATED PRINCIPLES

On pages 15 – 19 of the Ethical conduct guidelines, the following related principles are briefly described:

- Consent
- Research agreements
- Cultural and intellectual property.
- Cultural competency

5.2 Code of Ethics for Aboriginal and Torres Strait Islander Research

This code applies to <u>all research with Aboriginal and Torres Strait Islander people</u>, <u>communities and issues</u>. Its standards and provisions are in addition to the National Statement (2007 updated 2018) and the guidance material issued by the NHMRC.

Page 7 of the Code of Ethics articulates ethical considerations for even apparently low risk research and states that review by an "ethics review committee with experience in Aboriginal and Torres Strait Islander research can be of significant benefit". So even is the National Statement (2007 updated 2018) is amended to allow review outside of a HREC, the Code of Ethics suggests review by a HREC would still be good practice.

The AIATSIS research ethics framework described by the Code of Ethics is structured around four principles:

- 1. Indigenous self-determination
- 2. Indigenous leadership
- 3. Impact and value
- 4. Sustainability and accountability.

The core of these principles is the ethical value of integrity and acting in the right spirit, as outlined below in the ethical foundations. Each principle requires a thoughtful consideration of the responsibilities that are elaborated under the following headings:

- recognition and respect
- engagement and collaboration
- informed consent
- cultural capability and learning
- Indigenous led research
- Indigenous perspectives and participation
- · Indigenous knowledge and data
- · benefit and reciprocity
- impact and risk
- Indigenous land and waters
- ongoing Indigenous governance
- reporting and compliance.

The Code of Ethics provides guidance with regard to each of these principles. To be considered ethically justifiable, a project must address each principle.

In accordance with this guidance, projects through their earliest conception, design, and conduct should have Indigenous leadership and guidance.

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6. Sources of advice

Once a researcher has determined whether these guidelines apply to their research (see 4.0 of this Booklet) there are a number of sources of advice and information to assist with the ethical design and conduct of the research. These sources should be appropriately consulted prior to seeking Griffith University for the project.

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6.1 National guidelines

The <u>Ethical conduct guidelines</u> document is an extremely useful reference point, which should be consulted in conjunction with <u>Chapter 4.7 of the National Statement</u>. Another useful reference is <u>Guidelines for Ethical Research in Australian Indigenous Studies</u> (GERAIS) issued by the Australian Institute of Aboriginal and Torres Strait Islander Studies (2013). Even though it was principally written for Indigenous communities and groups, <u>Keeping Research on Track II</u> is a further useful resource for researchers.

The above material should be consulted prior to any institutional or community sources of advice being sought.

6.2 Institutional advice

After having consulted the national guidelines (see 5.1) researchers are encouraged to contact Griffith University's Indigenous Research Unit to discuss their research. The IRU may be able to provide advice or guidance to the researchers, as well as suggest community contact to consult. Researchers may also find it invaluable to attend an IRU workshop and/or seminar prior to undertaking a project in an Aboriginal and/or Torres Strait Islander community, as issues such as ethics and community consultation and engagement are covered at these sessions and may assist researchers in their initial project designs. During the ethical review process an applicant should outline how they have consulted the IRU.

6.3 School advice

Nearly every school and research centre within the University has appointed a member of academic staff to serve as a Research Ethics Advisor (REA) for the area. A REA may be an invaluable source of advice and suggestions for a researcher planning or conducting Aboriginal and Torres Strait Islander research. Visit https://www.griffith.edu.au/ data/assets/pdf_file/O024/177180/Human-Research-Ethics-Contacts-HREC-and-REAs_2019_12_11_pdf for a list of current advisors and their contact details.

6.4 Community advice

An extremely important source of advice to a researcher planning or conducting Aboriginal and Torres Strait Islander research are contacts within the community where the research is based. Indeed, genuine community consultation is a key element of the <u>Ethical conduct guidelines</u>. Almost without exception, a proposed project will need to outline how genuine consultation and engagement will be undertaken during every phase of the project – from early inception to final publication.

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7.0 What does good research mean to Aboriginal and Torres Strait Islander people?

Griffith University considers that answers to this question include that researchers are authentic and genuine in their intentions and hold the integrity of their research in high regard and that Aboriginal and Torres Strait Islander people set their own research priorities or assist in leading setting research priorities.

Aboriginal and Torres Strait Islander people consider building a trustworthy relationship and meaningful engagement essential and that research isn't being undertaken for the sake of research. There needs to be

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a better balance between researcher-driven research and community-driven research as the latter is becoming a core component to research review panels and assessments.

Aboriginal and Torres Strait Islander people want research:

- that benefits;
- is applied where possible;
- does no harm;
- is collaborative; and
- · builds capacity.

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8.0 Community ownership

Different from the potentially limited idea of community approval for a project, ownership captures matters such as:

- 1) Has the framing of a research question been driven by the community;
- 2) Has the community had input into the design of the research;
- 3) During conduct of the research, will feedback and ideas of the community be used to identify challenges and to refine the work;
- 4) Will there be an opportunity for capacity building and/or recognition of advisers, champions or assistants from the community;
- 5) Will there be a flow of benefits to the community or at least a return of results to the community;
- 6) Will the wider reporting of results of the work be respectful to the community?

Unlike an approval by an Elder or community committee, ensuring community sense of engagement and ownership will require careful discussion and time. These considerations are explored in <u>Keeping</u> Research on Track II.

8.1 Is such an approach always required?

The kind of approach described above is not mandatory for all research projects but it is highly recommended for the following reasons:

- 1. This is a sound and positive approach with regards to the principles discussed in <u>6.0</u> of this booklet;
- 2. Following such an approach may increase the chances of a community, group and individuals participating in the project; and
- 3. Such an approach may improve the value/quality of the outputs of a project.

It should be noted that when a research team uses this kind of approach it is more likely the communities, groups and individuals will have a positive experience, increasing the chances they will regard research with less distrust. When applying to Griffith University for a project, researchers should indicate the degree to which the kind of approach discussed at 8.0 will be utilised. If it will not be used the reasons for this should be explained.

8.2 What if there is no single community per se?

In some cases, there will not be a readily definable community to consult with (because the potential participants come from many communities). Examples of this situation include (but are not limited to):

- 1. A public sector agency that employs Aboriginal or Torres Strait Islander people from many communities across Queensland;
- 2. A custodial corrections facility that may have inmates from many different communities; and
- 3. A major hospital with specialisation in the treatment of a chronic medical condition may have patients from many different communities.

The challenge in such situations is that very different cultural protocols, traditions and beliefs may be present in the potential participant population. In such situations research respecting one set of traditions, protocols or beliefs may be very disrespectful to other members of the potential participant population. At best this may impact negatively upon the number of participants in the project, at worst it may alienate some individuals, cause distress or discord, or undermine the efficacy of the project.

Despite the above, it may be possible to identify the relevant community for most potential participants. In which case the researchers should take care to ensure the design and conduct of the work is respectful of all the various relevant communities.

Even if a single community cannot be identified, the researchers should take appropriate steps to ensure that the design and conduct of the research is appropriate and respectful of cultural traditions and protocols. The project must still adhere to the principles discussed at <u>6.0 of this Booklet</u>.

Many of the kinds of institutions described above may have an Indigenous Liaison Officer who may be able to advise and assist with regards to respectful approaches to such matters. The application for Griffith University must discuss the situation with regards to the matters discussed in this section.

8.3 Before or after Griffith University?

A reasonable question for researchers in this area, and indeed for ethics reviewers, is when should the kind of engagement (as discussed above at 8.0) with the relevant community occur. On one hand the design of a project should be informed by the consultation with the community, on the other there may be important ethical considerations that need to be addressed before recruitment, consent and data collection occurs. Even though this may appear to place researchers in a situation of competing demands, in fact it is possible to address both of these imperatives – see below.

Early in the design of a project the research team should consult with the relevant communities in the kind of ways discussed at 8.0. This will help ensure that the value to the communities is maximised, the design is appropriate and respectful, and the communities are interested in being involved in the project. The formal recruitment and consent of individuals should not be conducted prior to ethics clearance and no data for analysis can be collected prior to the clearance. When submitting the project for Griffith University it should be explained what discussion with the communities has already occurred, how this has informed the design of the project, and an assurance provided that recruitment, consent and data collection have not commenced.

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9.0 Community benefits

For some researchers one of the most challenging implications of the principles articulated by the Ethical conduct guidelines (see 6.0 of this Booklet) will be the requirement that research

not only benefit Aboriginal and Torres Strait Islander people and communities, but also that people should be consulted on whether that benefit is considered worthy.

In practice, this means the design and conduct of such a project will need to be based upon a clear insight into the experience and aspirations of Aboriginal and Torres Strait Islander Peoples, involve meaningful dialogue, and a real sharing of the results of the research. This commitment must be demonstrated in the application for ethics clearance. <u>See Booklet 9 of this Manual</u> for more about benefits in human research.

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10.0 Authorship and acknowledgements

Depending upon the direct experience and insights of the research team, the design and conduct of research with Aboriginal and Torres Strait Islander peoples or issues will require the input of advisers or key informants. The cultural, methodological and practical

knowledge shared may have a major impact upon the research project and outputs of the work.

Where cultural knowledge and intellectual property is part of the research, this contribution must be acknowledged. The contributions of Aboriginal and Torres Strait Islander researchers, whether part of the research team or as research participants, must also be acknowledged. This will involve methodological issues, participant recruitment, analysis and interpretation, community protocols and dissemination strategies.

Authorship must be negotiated at the beginning for Aboriginal and Torres Strait Islander team members and where possible, community members, that acknowledges concepts as significant contributions.

In accordance with the above, when considering an output from such a research project researchers must invite advisers/key informants to collaborate in the preparation of the output as a co-author. Advisers /key informants must be acknowledged for the contribution they made to the project. To do less is potentially a breach of the Griffith University Framework.

Commentary Inset 4 – Post project community reactions and impacts upon advisors, research assistants and facilitators

As noted at 12.0 some projects will involve advisors, facilitators and/or research assistants from the community. Researchers must bear in mind that long after he/she has left the community that person may continue to live with the consequences of the research – especially if there has been some form of problem with the project.

In practice this means whenever a local advisor/facilitator/research assistant is involved in the conduct of a project the researchers should have a plan for the end of the project to transparently end the role of the local partner/support person. The approach to these matters should be discussed in the application for Griffith University and might usefully be included in the discussions with the community (see 8.0) and when recruiting the local partner/support person.

If it begins to become evident that the community is in some way unhappy with the project, the researcher(s) should discuss this with the partner/support person and consider how best to mitigate any negative consequences for them. The Office for Research (see contacts) must be promptly notified of the situation and what is being done to minimise the impact on the partner/support person.

If a project ceases early (e.g. because the researchers have collected sufficient data), the researchers and advisors/assistants/facilitator should discuss the early cessation with the community and contact the Office for Research to discuss.

The University's approach to authorship can be found in the <u>Griffith University Framework for the Responsible Conduct of Research</u>, with practical guidance found in <u>RIRS 4</u>.

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11.0 Management of data and materials

The Griffith University Framework for the Responsible Conduct of Research articulates the University's approach to management of research data and materials. Practical guidance on the responsible management of data and materials can be found in RIRS 05. Guidance on privacy as an ethical and regulatory concern can be found in Booklet 23 of the Griffith University-REM.

For research with Aboriginal and Torres Strait Islander people there are additional considerations to be taken into account (e.g. relating to audio visual materials and to human tissues). See 14.0 of this Booklet for more information. It is important that the researchers have a clear understanding of the relevant requirements and protocols of the Peoples with whom they will be working.

The planned management of data and materials should be discussed with the participating communities (see 8.0 of this Booklet) and in the consent for the project (see Booklet 22 of the Griffith University-REM for more about consent).

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12.0 Key Considerations: Research advisers, community researchers, and research assistants

Research teams should engage and/or employ research advisers and community research assistants to ensure they are informed about local and cultural requirements and protocols, to assist with recruitment and/or to assist with data collection (such as conducting interviews).

This approach can be very effective in regard

to the outcomes of a project, but can raise some ethical considerations that need to be understood and addressed. Ideally, research advisors and community research assistants will come from the communities involved in the study or project.

The considerations include:

Commentary Inset 5 – Records about agreements reached with regarding the publication/reporting/sharing of recordings

Audio-visual recordings, (including still images, videos and audio recordings) can be a rich source of data, enhance the quality/impact/value of research outputs, but these also raise important ethical considerations that must be carefully addressed.

When designing a research project involving Aboriginal or Torres Strait Islander Peoples and issues, researchers must have an ethically justifiable plan with regard to the matters discussed at 14.0.0f.this Booklet.

These matters relate to intellectual property, cultural heritage and cultural protocols.

Preferably individual agreements will be reached with regard to each individual sample/work/media. This should discuss how the items will be used, where the item will be published/reported, who will have access to it, and (if relevant) how the artist/creator will be acknowledged. This agreement must also discuss whether permission/agreement can later be withdrawn* how this can be done, and whether in addition to the artist/creator their next of kin can withdraw consent.

* In some cases there may be practical limitations to the degree to which an agreement can be withdrawn. For example: Agreement might be reached to include in a book a photograph of a carving. If agreement was later withdrawn the image must not be used in any reprints, but it is not practicable to delete the image from existing prints of the book.

A record of the agreement must be made e.g. by signing a consent form, in an email or letter or as an audio recording. Where this not possible or appropriate researchers are encouraged to make a detailed file note about the agreement, including the date, time and location, as well as why it was not possible/appropriate to record the agreement in one of the ways discussed above.

The language and format of agreements must be appropriate for lay people and be respectful. Legalistic terminology should be avoided.

Reaching such agreements are not only respectful and ethical, they are likely to foster a more positive and trusting climate with the communities.

Refer to Booklet 22 of this Manual for more about informed consent and Booklet 36 for more about audio-visual recordings in human research.

- i) the appropriate acknowledgement of the significance of their contribution to the research (see 10.0 of this Booklet);
- ii) pressure on individuals to participate (e.g. because the community research assistant is a respected member of the community);
- iii) whether their involvement might give them access to information that will be perceived as breaching confidentiality for some participants;
- iv) potential risks to the research advisers and community research assistants (e.g. cultural expectations); and
- v) how the research advisers and community research assistants might be considered by others (e.g. other community members) see 13.0).

Such matters should be: identified and discussed with the community (see 8.0); considered and addressed during the design of a project; identified and discussed in the application for Griffith University of the project; revisited during the conduct of the project; and continue to be considered during the analysis, reporting and beyond.

Commentary Inset 6 – Use of existing artistic works

The Indigenous cultural protocols issued by the Australian Council for the Arts have been produced to guide the respectful and appropriate engagement of Aboriginal and Torres Strait Islander artists (for example performance of music and dance at a research conference).

The protocols should be used as the standard for researchers accessing and using existing artistic material (such as paintings photographs, stories, recorded music)

It is the responsibility of Griffith University researchers (staff and students) to ensure the protocols are adhered to when engaging Aboriginal and Torres Strait Islander artists and before utilising artistic works in a research project (e.g. analysing a work or including it in a research output).

<u>See Commentary Inset 4</u> for further discussion about some example post project issues that might impact upon research advisers and community research assistants.

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13.0 Genetic Research and retention of human tissues

If a project will involve the extraction of human tissue/cadaveric tissue from Aboriginal or Torres Strait Islander Peoples the researchers should carefully consider the cultural beliefs, traditions and protocols collection and storage of biological samples.

Depending upon the Peoples involved such issues can be highly sensitive and have been mismanaged in the past. If a research project relates to such issues and if the researchers do not already have knowledge of the relevant cultural protocols they <u>must</u> seek advice.

In addition to the typical consent requirements for the extraction of tissues/use of cadaveric tissues, there should be specific discussion of: what kind of future uses are anticipated; for how long it is likely the tissues will be stored and available for reuse; how participants can express their wishes with regards to storage and reuse; and how the participants can later withdraw this consent (so the tissues are destroyed) or how their next of kin can withdraw their consent (e.g. on the event of their death).

See `Further Reading' for more about genetic research with Aboriginal and Torres Strait Islander people.

For more on these matters refer to:

- i) <u>Booklet 32 of the Griffith University-REM</u> for more on the research use of extracted tissues/cadaveric tissues;
- ii) Booklet 42 of the Griffith University-REM for more on retesting; and

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iii) Booklet 22 of the Griffith University-REM for more on consent.

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14.0 Retention of audio-visual recordings and photography

If a project with Aboriginal or Torres Strait Islander people involves the taking of images or creation of audiovisual recordings, the researchers must carefully consider the intellectual property and cultural heritage rights that apply to such work – especially if the material will be shared or published. These rights must be understood and respected ahead of achieving the objectives of the research.

During the planning of a project where images/audio-visual recordings are to be generated researchers must:

- i) Seek advice (see 5.0) and incorporate into the design and conduct of the research, as well as in the reporting of results;
- ii) Discuss ownership, use and storage audio visual material with the communities (see 8.0);
- iii) Discuss and establish the conditions of the production of recordings and use and how these will be reported/published/shared;
- iv) The consent process must seek specific consent for audio visual material including future use;
- v) Maintain records about (iii), including the instructions about individual samples, and have a mechanism (where practical see Commentary Inset 5) for the withdrawal of consent by the individual or their next of kin; and

Further reading - Page One of Two

In addition to the material discussed at 2.0 and 5.0 of this Booklet, there are quite a few texts about the history of research with Aboriginal and Torres Strait Islander Peoples, current good practice for such research, and the associated ethical challenges. For some examples see:

Dodson M, Williamson R: Indigenous peoples and the morality of the Human Genome Diversity Project. J Med Ethics 1999, 25:204–208.

Doreen Mellor and Terri Janke (2001) VALUING ART, RESPECTING CULTURE – NAVA: Protocols for working with the Australian indigenous visual arts and craft sector valuing art, respecting culture

Evans M, Miller A, Hutchinson P & Dingwall C. "De-Colonizing Research Practice: Indigenous Methodologies, Aboriginal Methods, and Knowledge/Knowing", in Oxford Handbook of Qualitative Research. Patricia Leavy (ed.) New York: NY, Oxford University Press, 179-191, June 2014.

Indigenous Art Code

Kowal E: Genetic research in indigenous health: significant progress, substantial challenges. MJA 2012, 197:19–20.

Kowal E, Rouhani L, Anderson I: Genetic Research in Aboriginal and Torres Strait Islander Communities: Beginning the Conversation. In Lowitja Institute. Australia's National Institute for Aboriginal and Torres Strait Islander Health Research; 2011 http://www.lowitja.org.au/lowitja-institute-publishing.

Martin, K.L. (2008). Please knock before you enter: Aboriginal regulation of Outsiders and the implications for research and researchers. Teneriffe, Brisbane; PostPressed

Martin, K. (2003). Ways of Knowing, Being and Doing: A theoretical framework and methods for Indigenous and Indigenist research. In K. McWilliam, P. Stephenson & G. Thompson (Eds), Voicing Dissent, New Talents 21C: Next Generation Australian Studies. (pp.203-214). St Lucia, Qld: University of Queensland Press.

Rigney, L.H., 2006. Indigenist research and Aboriginal Australia. In Indigenous Peoples' Wisdom and Power. Bodmin, UK: Ashgate Publishing Limited, pp. 32-50.

Terri Janke and Company First Peoples: A Roadmap for Enhancing Indigenous Engagement in Museums and Galleries, Australian. Museums and Galleries Association, 2018 Page 17 of 20 v3.9 | October 2020

vi) When images/recordings of Aboriginal or Torres Strait Islanders who might be deceased are to be shown publicly, a forewarning is required.

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15.0 Australia Council for the Arts, Indigenous Cultural Protocols

Further reading - Page Two of Two

van Holst Pellekaan S: Human Genome Diversity: ethics and practice in Australia. Human Evolution 2004, 19:131–144.

West, R., Stewart, L., Usher, K. & Foster, K. (2012). Through a critical lens: Indigenist research and the Dadirri method. Qualitative Health Research, 22(11):1582-1590.

At the time of writing the NHMRC was conducting a public consultation/review of Australia's Indigenous research ethics arrangements. It is anticipated that the outcomes of this process will be publicly available later in 2020.

In September 2020, the Australian Council released new guidance with regard to New Protocols on First Nations Cultural and Intellectual Property.

This material sets out 10 principles to inform the respectful use of First People artistic work. The ten principles are:

Principle 1 – Respect

Principle 2 – Self-determination

Principle 3 – Communication, consultation and consent

Principle 4 – Interpretation

Principle 5 – Cultural integrity and authenticity

Principle 6 – Secrecy and confidentiality

Principle 7 – Attribution

Principle 8 – Benefit sharing

Principle 9 – Continuing cultures

Principle 10 – Recognition and protection

It then uses case studies to apply the principles to real areas of scientific endeavours, such as:

- o Visual arts
- o Music
- o Writing and literature
- o Dance
- o Theatre
- o Multi-art forms
- Emerging and experimental arts
- o Events-based projects.

In practice, these guidelines apply to use of the artistic creations of First People in research. They also apply when such work is used in support of research (such as artwork on the cover of a research outputs). See Commentary Inset 6 for more.

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16.0 Research ethics review

As was noted at 2.0 and 5.2 of this Booklet, Griffith University research with Aboriginal and Torres Strait Islander people or communities must be reviewed by the GUHREC.

Such research must comply with the National Statement (2007 updated 2018), the Indigenous guidelines issued by the NHMRC and the Code Ethics issued by AIATSIS.

The application for research ethics review for such a project must:

- i) discuss which sources of advice have been consulted (see 5.0);
- ii) outline how the six principles from the <u>Ethical conduct guidelines</u> have been addressed (<u>see</u> 6.0);
- iii) discuss what consultation has occurred with the relevant communities or Peoples, what
 - additional consultation is planned, and how both of these have informed the design of the project and will inform the conduct of the project (see 8.0);
- iv) outline the anticipated benefits of the project and what benefit will flow to the communities/Peoples (see 9.0);
- v) share the initial consideration of the authorship of the outputs arising from the research (see 10.0);
- vi) discuss how research data and materials will be managed (see 11.0); and
- vii) identify whether any of the potential issues discussed at 12.0 to 15.0 of this Booklet apply to the project and outline how these will be addressed.

Hints & Tips

Some things to consider when first considering a research project with Aboriginal and Torres Strait Islander Peoples or issues:

- 1) Is the research project or topic considered significant or otherwise important to the communities who will participate?
- 2) Have/will the communities have meaningful input into the design, conduct and monitoring of the project?
- 3) What is the project's anticipated impact on individuals and/or communities participating in the research?
- 4) Is the project extending, enhancing or supporting existing services or structures within the community?
- 5) Will the project disrupt the community in any way? If yes, how this will be minimised/managed.
- 6) What are the short and long-term benefits for the community or individuals within the community?
- 7) What are the risks of the project to Aboriginal and Torres Strait Islander people, the community, or individuals participating in the project?

An Indigenous research project is unlikely to receive ethics clearance if the above matters have not been addressed or unless a strong rationale is provided why any unaddressed item is not relevant for the specific project.

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17.0 First Peoples in other countries

The principles and guidelines discussed in this booklet are intended specifically for research involving the participation of Australian Aboriginal and Torres Strait Islander Peoples or issues.

Nevertheless, this booklet may provide useful prompts for research with other First Peoples. When a project involves the participation of another First Peoples, researchers should determine what principles and guidance material exists in that jurisdiction.

When conducting research with First People in another jurisdiction, Griffith University must determine if there is any guidance available for research with those First People.

Griffith University researchers who conduct work with other First Peoples must respect those principles and guidelines and adhere to the guidance provided by the <u>other booklets of the Griffith University-REM</u>. Refer to <u>Booklet 39 of the Griffith University-REM</u> for more about research that is conducted in other jurisdictions.

Essential Reading: Denzin NK, Lincoln YS, Smith LT (Eds) *Handbook of Critical and Indigenous Methodologies*, Sage Publications: California, 2008.

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Contacts

There are a number of resources available to assist researchers formulate an appropriate response to a question or challenge about the design and/or conduct of a project. This includes the Griffith University Research Ethics Manual and the Human Research Ethics Information Sheet Series. These documents are available from the URL below.

Research students – The first point of contact for research students for advice on any research ethics matter is always your supervisors.

REAs – All academic elements of the University have been asked to appoint at least one member of academic staff as a Research Ethics Advisor. REAs are a local contact for advice, information and suggestions. The contact details of all the current REAs can be found on the URL below.

Office for Research – Staff in the Office for Research (see below) are available to advise with the process of lodging an application or other administrative matters, procedural or policy questions. However, you will be asked what advice you have sought or received already (e.g. consultation with the REA for your area).

Manager, Research Ethics and Integrity

Tel: (07) 373 54375

research-ethics@griffith.edu.au

Policy Officer, Research Ethics and Integrity

Tel: (07) 373 58043

Research Ethics Systems and Support Officer

Tel: (07) 373 5 2069

On the ethics web site you will find:

https://www.griffith.edu.au/research/research-services/research-ethics-integrity/human

- The other booklets of the Griffith University Research Ethics Manual
- The Griffith University Human Research Ethics Information Sheet Series

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- Either downloadable copies of, or links to, the various application forms
- Contact information for the Research Ethics Advisers (REA) and other contacts
- Educational and other resource material
- Useful external links



Griffith University is commercialising the GUREM through licenses to other universities and research institutions. Consequently, Griffith University staff are asked not to send copies of any booklet to persons external to Griffith. For further information please contact the Office for Research (see above).