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RESEARCHING RIGHT WAY

ABORIGINAL AND TORRES STRAIT ISLANDER HEALTH  
RESEARCH ETHICS: A DOMESTIC AND INTERNATIONAL  
REVIEW.

OCTOBER 2013.



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# 1. INTRODUCTION

Aboriginal and Torres Strait Islander communities have had a chequered history with research practices in Australia. Since the first Europeans landed on the shores in 1788, Aboriginal cultures and lifestyles were scrutinised through a 'lens' that allowed many misconceptions to reinforce themselves into negative stereotypes, without developing a broad understanding of Aboriginal cultures and beliefs. Early research in Australia included negative race-based research practices such as eugenics and scientific racism, which sought to prove that Aboriginal people were mentally and physically inferior human specimens to Europeans. Memories of these times have been ingrained in the psyches of successive generations of Aboriginal and Torres Strait Islander peoples and more recent examples of poor research practices have contributed to the degrees of distrust that developed towards researchers and research institutions.

Since these early days, there has been a development of positive trends including the preparation of ethics principles and guidelines to improve ethical frameworks for research. Much of this work has been prepared by and in collaboration with Aboriginal and/or Torres Strait Islander researchers and community members. This has sought to improve both the research relationships and to better represent the cultural views and shared responsibilities required for meaningful research with Aboriginal and Torres Strait Islander communities. There has been a strong desire from Aboriginal and Torres Strait Islander communities to both create and adhere to these additional guidelines that include culturally appropriate ways to work within our communities. This extends to additional protections above what is referred to into the NHMRC *National Statement on Ethical Conduct in Human Research* [1].

The guidelines must be current, readily available and user-friendly to maintain their efficacy for use by communities, individuals, researchers and HRECS. They also need to be flexible enough to cover emerging research trends that may have significant consequences for the people who are involved. This literature review seeks to cover 'good practice' research developments and guidelines concerning ethical research practices for Aboriginal and Torres Strait Islander communities that have emerged over the past decade. It takes a detailed look at the Australian guidelines and notes where they overlap and how they differ.

Furthermore, overseas ethical guidelines will be assessed to see if lessons can be learned from these documents for the Australian guidelines. The countries assessed were New Zealand, Canada and the US including Hawaii. These countries also have large populations of First Nations people who have similar or shared experiences in the way their First Nations populations have been researched, and who show parallels in their movements towards the development of ethical research frameworks.

## 2. STRUCTURE OF THIS REVIEW

### 2.1 DOMESTIC DOCUMENTS

This review looked at inconsistencies between domestic ethics guidelines including the National Statement, Values and Ethics, Keeping Research on Track, GERAIS (AIATSIS), and the Aboriginal Health & Medical Research Council (NSW) guidelines. The review also looked at other documents that provided analysis of inconsistencies and advice for improvements. Throughout the review examples of good practice were identified. These may provide guidance to researchers coming into the Aboriginal and Torres Strait Islander Health research space or to provide examples of how researchers can and should address the principles and values within *Values and Ethics and Keeping Research on Track*.

Section 3.2 provides a summary of inconsistencies between the domestic ethics documents. These inconsistencies may provide useful in addressing confusion in both interpretation and application of the values and principles in the different ethics contexts from the community level to applying for ethical approval, to assessment by Human Research Ethics Committees.

## 2.2 INTERNATIONAL DOCUMENTS

Section four looks at the ethics documents relevant to Indigenous peoples of New Zealand, Canada and the United States. The review highlights the components in health and human research ethics process in each country and then highlights and makes recommendations that could guide changes in our domestic documents

### 3. AUSTRALIAN DOCUMENTS

Aboriginal people are important in a global sense, as the holders of the world's oldest continuous and most sustainable culture. There are around 600 tribal nations throughout Australia, with their own distinct languages and traditions. Estimates of the length of Aboriginal people's occupation of the Australian continent have varied between 40,000 to 100,000 years, although Aboriginal people maintain that they have always been here from the beginning. Torres Strait Island people come from the numerous islands that make up the Torres Strait, above the tip of North Queensland. They are culturally and linguistically distinctive from Aboriginal people.

#### 3.1 ETHICAL GUIDELINES DOCUMENTS CURRENTLY IN USE

Commonly used ethical guidelines for research projects involving Aboriginal and Torres Strait Islander people include the following:

- *The National Statement on Ethical Conduct in Human Research* 77 [1];
- *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* [2];
- *Keeping Research on Track: A Guide for Aboriginal and Torres Strait Islander peoples about Health Research Ethics* [3];
- *Guidelines for Ethical Research in Australian Indigenous Studies* [4].
- *Aboriginal Health and Medical Centre's key principles* [5].

Also covered is a substantial publication from the Lowitja Institute titled *Researching Indigenous Health: A practical guide for researchers* [6].

The following paragraphs will summarise the target groups, research area and principles of each of the documents. This is followed by a section which identifies the similarities and discrepancies between the documents.

##### 3.1.1 THE NATIONAL STATEMENT ON ETHICAL CONDUCT IN HUMAN RESEARCH

The *National Statement* has been developed by the National Health and Medical Research Council (NHMRC)[1]. It functions as the ethical guidelines for all research involving humans and is designed to be used by: any researcher conducting research with human participants; any member of an ethical review body reviewing that research; those involved in research governance; and potential research participants.

The *National Statement* is grounded in four main principles: Respect, Integrity and Research Merit, Justice and Beneficence. These four principles are applied to different research methods or fields, and specific participants. Aboriginal and Torres Strait Islanders are one group of specific participants recognised in this document.

**Respect:** The central principle of the *National Statement* is respect. Respect is described as the acknowledgement that everybody has an intrinsic value. It forms the basis of all human interactions. Research that shows respect abides to the other three principles, has due regard for personal beliefs, welfare, perception, customs and cultural heritage. It takes privacy, confidentiality and cultural sensitivity into account. It also involves the acknowledgement of the autonomy of every individual and where this autonomy is diminished; the research should aim to empower the individual where possible, or protect them if necessary. Respect in the Aboriginal and Torres Strait Islander context means that respectful and active engagement with Aboriginal and Torres Strait Islander communities must be shown in all steps of the research process.

**Integrity and research merit:** Good research is justifiable by the benefits it brings to the individual, community or broader nation. Research should be using appropriate methods that are relevant to its goals, based on previous research, conducted by qualified researchers, with high levels of respect for participants and using appropriate facilities. Integrity is shown by a commitment to development of knowledge and understanding, based on recognised research methods.

In the context of research involving Aboriginal and Torres Strait Islanders as participants this means that research methods should be respectful and acknowledge the cultural distinctiveness of Aboriginal and Torres Strait Islander communities. Evidence of support from the local communities should be given and methodology should engage with local practices. There should be mutual agreement about the different processes in the research project, such as data collection, analysis, reporting and recruitment. Researchers should identify any potential risks associated with the research project and take steps to reduce this.

**Beneficence:** Do no harm; the benefits of participation in research should outweigh potential risks. Research should strive to improve the benefits for the ones involved and the broader community and take the welfare of the participants into account. Researchers working with Aboriginal and Torres Strait Islander participants should advance the interests of these people; show that there is local support for the research and base their findings on local knowledge and wisdom. The potential benefits of the research should be discussed with and agreed upon by the people involved. The realisable benefits should be distributed fairly over the participants and the researchers.

**Justice:** Acknowledging human sameness; fair distribution of burden and benefits of the research; fair recruitment of participants. For researchers working with Aboriginal and Torres Strait Islander participants, the methodologies should provide opportunities to function as equal research relationships. Researchers must not exploit participants, and must make research findings accessible in a clear and timely manner. Aboriginal and Torres Strait Islanders should have equal opportunities to be involved in the process of research where the researched population has a high level of Aboriginal and Torres Strait Islanders; and the research topic is identified as being of specific concern to Aboriginal and Torres Strait Islander people.

The core principle for research with Aboriginal and Torres Strait Islanders, as mentioned in the *National Statement*, is respect for and valuing their cultural diversity.

### 3.1.2 VALUES AND ETHICS: GUIDELINES FOR ETHICAL CONDUCT IN ABORIGINAL AND TORRES STRAIT ISLANDER HEALTH RESEARCH

*Values and Ethics* was first developed in 2003 as a replacement for the *Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research*, which was issued in 1991. *Values and Ethics* was also developed by the NHMRC. It covers ethics in health research conducted with Aboriginal and Torres Strait Islander peoples and has been written for researchers, communities, human research ethics committees (HRECs) and other stakeholders in the research [2].

These guidelines are linked to the *National Statement*, with references to the relevant sections in the *National Statement*. *Values and Ethics* are not meant to be a compliance checklist, but offers a framework of important cultural values common to Aboriginal and Torres Strait Islander communities for researchers to address throughout the design and implementation of their research work.

*Values and Ethics* is based on the importance of trust, recognition and values. It describes six principles important to Aboriginal and Torres Strait Islander communities. These core values have been identified through a national

consultation process including workshops with Aboriginal and Torres Strait Islanders. The six values are: Spirit and Integrity; Reciprocity; Respect; Equality; Survival and Protection; and Responsibility.

Every value is linked to the relevant section in the *National Statement* and for every value, dot points are listed to guide researchers in demonstrating this value in their research proposal.

***Spirit and Integrity:*** Is the over-arching principle. It describes the continuity between past, present and future generations and their cultural inheritance and acknowledges how these are all intertwined. Integrity is about behavior which maintains the coherence of Aboriginal and Torres Strait Islander values and cultures. Researchers are perceived as owing an obligation to the spirit and integrity of our communities; with respect for the diversity of Aboriginal and Torres Strait Islander cultures. Researchers should acknowledge the process of community decision-making rather than focusing on an individual decision.

***Reciprocity:*** Means an equitable distribution of the burden and the benefits of the research and of capacity, resources and special responsibilities. Equitable and respectful engagement with Aboriginal and Torres Strait Islander communities is mandatory. Research should demonstrate intent to work towards progress in health and wellbeing of the local community, based on the needs of the community. The researchers must show willingness to adjust their research based on the needs, aspirations and values of the community. Potential benefits should be discussed with the community, and demonstrate a return or benefit that is valued by the community. Benefits of the project should go beyond the project duration.

***Respect:*** Includes acknowledgement that every individual has the right to be different and has their own values, norms and aspirations. The contribution of each individual should be recognised. Respectful relationships, constituting openness, trust and engagement are as important as scientific rigour. Difference blindness should be minimalised. Research should engage with the values, processes, knowledge and experiences of the community they are researching. Agreements should be made about intellectual and cultural property rights, publication arrangement, protection of individuals and community identity. Researchers should not make the publication of research findings a greater priority than feeding back the findings to the community. The community should be satisfied with the arrangement and decision-making. Decisions on agreements at the outset of a project must be demonstrated.

***Equality:*** Means the equal value of people; includes distributive fairness and justice; and importantly, is not sameness. Valuing knowledge and wisdom is important in interpreting data, avoid mistrust and ensure quality and benefits of research. The distribution of benefit is an essential test for equality. The community involved in the research should be able to understand the research and the distribution of burden and benefits in the research.

Research that does not appreciate Aboriginal and Torres Strait Islander peoples' values may misinterpret data, and create poor research relationships which consequently affect future research projects. Communities should be included in every part of the research process as the marginalisation of Aboriginal and Torres Strait Islander cultures by a dominant society has created myriad inequalities - there should be a research agreement that will assist in supporting equality.

***Survival and Protection:*** Of the Aboriginal and Torres Strait Islander cultures from colonisation and marginalisation, by holding up values-based solidarity, having respect for social cohesion and being committed to cultural distinctiveness. Barriers to research have been created by poor research practices, which can be an obstacle to research today. Research can contribute to the social bonds between families; it should safeguard against discrimination and contribute to the opportunity for Aboriginal and Torres Strait Islanders to enjoy their

cultural distinctiveness. Research should respect the intrinsic values-based expectations and identity of Aboriginal and Torres Strait Islanders, including the balance between collective and individual identity.

**Responsibility:** Aboriginal and Torres Strait Islander people have core responsibilities towards their country, kinship bonds, caring for others and maintaining the balance between the spiritual and the physical world. No harm should be done which would interfere with people complying with their responsibilities. Responsibilities can be shared, so that more people are accountable. Research is ethical when there is a balance between the different responsibilities, and clarity over who has which responsibilities, there is trust and participants are protected. Transparency should be demonstrated in every aspect of the project, ongoing advice from the community should be sought and feedback given back to the community. Agreements should be made regarding publications.

### 2.1.3 KEEPING RESEARCH ON TRACK: A GUIDE FOR ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLES ABOUT HEALTH RESEARCH ETHICS

*Keeping Research on Track* is the translation of *Values and Ethics* into a community guide. It was developed in 2005 by the NHMRC. It is written to provide clear guidelines in health research involving Aboriginal and Torres Strait Islander peoples and was created specifically for Aboriginal and Torres Strait Islander community members and organisations. It primarily aims to empower Aboriginal people to get the most out of research projects, to know their rights and responsibilities and a checklist of what some important considerations may be [3].

It contains the same six values as described in *Values and Ethics*. In addition to the six values, it outlines the research process in eight steps and describes what the rights and the responsibilities of the researcher and the community are, and which questions the community can ask from the researcher.

The six values are described as follows:

- **Spirit and integrity:** A connection between the past, present and future, and the respectful and honourable behavior that holds Aboriginal and Torres Strait Islander values together.
- **Reciprocity:** Shared responsibilities and obligations to family and the land based on kinship networks, also includes sharing of benefits.
- **Respect:** For each other's dignity and individual ways of living. This is the basis of how Aboriginal and Torres Strait Islander peoples live.
- **Equality:** Recognising the equal value of all individuals. Fairness and justice, the right to be different.
- **Survival and protection:** Of Aboriginal and Torres Strait Islander cultures, languages and identity. Acknowledging shared values is a significant strength.
- **Responsibility:** Is the recognition of important responsibilities, which involve country, kinship, caring for others and maintenance of cultural and spiritual awareness. The main responsibility is to do no harm to any person or any place. Responsibilities can be shared so others can be held accountable.

In addition to these values the next eight steps in the research process are described as:

1. Building relationships.
2. Conceptualisation – thinking.
3. Development and approval.
4. Data collection and management.
5. Analysis: looking at the meaning.
6. Report writing.
7. Dissemination – sharing the results.

## 8. Learning from our experience.

For each of these steps the tasks of the researchers and the involvement of the community/organisation are described, including questions to ask the researchers or for the community to ask themselves to keep the research on track.

A list of rights are attached which include the right to say no; to commission research; questions the community need to ask themselves to adjust research so it meets community priorities; and the right to check the researcher's track record.

### 3.1.4 *GUIDELINES FOR ETHICAL RESEARCH IN AUSTRALIAN INDIGENOUS STUDIES*

This ethical guidelines document has been developed by the Australian Institute for Aboriginal and Torres Strait Islander Studies (AIATSIS) [4]. It was primarily developed for research sponsored by AIATSIS, however it is applicable to all research involving Aboriginal and Torres Strait Islanders, and could be used by all researchers conducting research involving Aboriginal and Torres Strait Islander people. The guidelines have been based on the *United Nations Declaration of Rights for Indigenous Peoples*[7].

The guidelines consist of fourteen principles of ethical research:

1. Recognition of the diversity and uniqueness of peoples as well as individuals.
2. Rights of self-determination of Indigenous peoples must be recognised.
3. Recognise the rights of Indigenous peoples to their intangible heritage.
4. Respect, protect and maintain the right to traditional knowledge and traditional cultural expression.
5. Indigenous knowledge, practices and innovations must be respected, protected and maintained.
6. Consultation, negotiation and free, prior and informed consent are the foundations for research with or about Indigenous peoples.
7. Responsibility for consultation and negotiation is ongoing.
8. Consultation and negotiation should achieve mutual understanding about the proposed research.
9. Negotiation should result in a formal agreement for the conduct of a research project.
10. Indigenous people have the right to full participation appropriate to their skills and experiences in research projects and processes.
11. Indigenous people involved in research should benefit from the research and not be disadvantaged by it.
12. Research outcomes should include specific results that respond to the needs and interests of Indigenous people.
13. Plans should be agreed for managing use of, and access to, research results.
14. Research projects should include appropriate mechanisms and procedures for reporting on ethical aspects of the research and complying with these guidelines.

The application of every principle is discussed.

### 3.1.5 ABORIGINAL HEALTH AND MEDICAL RESEARCH COUNCIL OF NEW SOUTH WALES (AH&MRC)

#### *GUIDELINES FOR RESEARCH INTO ABORIGINAL HEALTH KEY PRINCIPLES*

This document was prepared in order to guide researchers undertaking research into the health of Aboriginal people and assist them in the preparation of applications to the AH&MRC Ethics Committee; and to guide AH&MRC Ethics Committee members in making decisions about applications for ethical approval of individual research projects [5].

## KEY PRINCIPLES

### 1. THE RESEARCH MUST DISPLAY NET BENEFITS FOR ABORIGINAL PEOPLE AND COMMUNITIES

This should indicate the particular problem that the research is addressing and explain specifically how the research can contribute to overcoming the problem. All risks have been identified and assessed; and there will be a net benefit after taking into account known negatives and potential risks.

The benefits for the research may be for Aboriginal health in general or simply for the health of those Aboriginal people and communities that are participating in the project. In working with Aboriginal people in communities and organisations in the development of a research proposal, researchers should provide information and advice about the usefulness of the research to the community.

### 2. ABORIGINAL COMMUNITY CONTROL OF RESEARCH

There must be Aboriginal community control over all aspects of proposed research including the design and conduct of the research, ownership of data, interpretation of data, and the reporting and publication of findings from research affecting the health of Aboriginal people.

Aboriginal community consent is considered necessary for the collection and use of health and health-related community information if any one of the following factors apply: the experience of Aboriginal people is an explicit focus of all or part of the research; or data collection is explicitly directed at Aboriginal peoples; or Aboriginal peoples, as a group, are to be examined in the results; or the information has an impact on one or more Aboriginal communities; or Aboriginal health funds are a source of funding.

At all stages of the research, Aboriginal people and communities participating in, or directly affected by the research will be fully informed about, and agree with, the purposes and conduct of the project. It goes beyond either involvement or consultation and requires an acknowledgment that Aboriginal people have the right to make decisions about research affecting them. This principle also covers details such as community permissions, obtaining formal consent, Aboriginal ownership of data and the publication of findings, confidentiality and privacy.

### 3. CULTURAL SENSITIVITY

Cultural requirements will vary between Aboriginal communities. Researchers should ensure that they have considered the following matters in terms of the process of the research: the decision-making processes in each community; ensuring that all members of the community affected by the research have been properly consulted and informed (eg. family groups, gender issues, etc); adequate time frames for consultation and conduct of the research; and that questionnaires and survey forms are culturally appropriate.

### 4. REIMBURSEMENT OF COSTS

In seeking the co-operation of Aboriginal communities and local community controlled agencies, researchers should reimburse participants for any cost incurred which relates, directly or indirectly, to the research project. Such costs could include telephones, transport, freight, gas and water, accommodation, supervision costs and wages of assistants and interpreters. There should be no imposition upon the Aboriginal community controlled health sector to be involved in processes that are not adequately funded or resourced.

### 5. ENHANCING ABORIGINAL SKILLS AND KNOWLEDGE

When possible, Aboriginal people and especially local community members should be employed in research projects. This will improve the quality of communication and the researchers understanding of the community.

Wherever possible, there should be arrangements for the training and development of Indigenous research workers.

### 3.1.6 RESEARCHING INDIGENOUS HEALTH: A PRACTICAL GUIDE FOR RESEARCHERS

The Lowitja Institute, Australia's National Institute for Aboriginal and Torres Strait Islander Health Research, completed and published this title, which was originally undertaken by the Co-operative Research Centre for Aboriginal Health (CRAH) from 2003-9. *Researching Indigenous Health: A practical guide for Researchers* is a substantial contribution to the discussion around appropriate ethics for health research in Aboriginal and Torres Strait Islander communities [6]. It contains ten chapters which cover three specific focal points:

#### PART A: INDIGENOUS HEALTH RESEARCH IN CONTEXT

- Setting the scene for research
- Principles in Indigenous health research
- Indigenous frameworks and methods

#### PART B: DOING RESEARCH THAT MAKES A DIFFERENCE

- Relationships in Indigenous health research
- Using research for change
- Building capacity through research

#### PART C: DESIGNING AND MANAGING A SUCCESSFUL RESEARCH PROJECT

- Setting the research question
- Planning the project
- Collecting, managing and interpreting data
- Methods for reporting and dissemination

Forming part of the introduction is the following list of points to draw awareness to and ensure good research practices in Aboriginal and Torres Strait Islander health:

- Respect for Indigenous values, knowledge and worldviews.
- Awareness of the history and relationship between the Indigenous world and the world of research.
- Knowing how developments in Indigenous research in recent decades have changed accepted practices.
- Developing, conducting, reporting and using research in ways that lead to practical outcomes and health equality for Indigenous people.
- More Indigenous people and communities controlling what, why, how and when research is done, and how it is used.

This book is an important resource for researchers as it provides numerous case stories, tips and advice to ensure successful and respectful research. It also contains an extensive bibliography to link researchers with further information.

There are further resources available that describe good research practices, and two that were raised on several occasions during the 2013 national 'Researching Right Way' consultations included the South Australia Health and Medical Research Institute (SAHMRI) Accord [8] and the Aboriginal Medical Services Alliance Northern Territory (AMSANT) guidelines[9]. The Lowitja Institute has also produced two papers that deal specifically with questions around genetic research:

- Kowal, E., Rouhani, L. & Anderson, I. 2011, *Genetic Research in Aboriginal and Torres Strait Islander Communities: Beginning the Conversation*, The Lowitja Institute, Melbourne [10].
- Emma Kowal and Ian Anderson 2012. *Genetic Research in Aboriginal and Torres Strait Islander Communities: Continuing the Conversation*. Lowitja Insitute, Melbourne [11].

### 3.1.7 EXTRA: TEN PRINCIPLES RELEVANT TO HEALTH RESEARCH AMONG INDIGENOUS AUSTRALIAN POPULATION.

Based on their own research experience and well documented experiences of others, Jamieson et al [12] set out 10 principles, of which five are essential to research and the other five are desirable. The principles that are outlined are the following:

#### Essential principles:

1. "Addressing a priority health issue as determined by the community". The community's objectives should stay central in the research, which can be achieved by a close partnership.
2. "Conducting research within a mutually respectful partnership framework". Trusting relationship should be developed and research works best when good rapport is established between the researcher and the community, special focus should be on continuing the research relationship in other research project. It is important to have key persons in the community involved in the research and to know how the local community operates.
3. "Capacity building is a key focus of the research partnership, within sufficient budget to support this". Researchers should take 'unexpected' circumstances into account when creating the budget, such as engagement requiring longer time, cancelling of trip, high staff turnovers that causes higher costs for salaries. It is important to employ Indigenous staff on the project and have a commitment to train Indigenous researchers and support their research career.
4. "Flexibility in study implementation while maintaining scientific rigour". Implementations of interventions should have a big focus on community involvement and interventions are most effective, sustainable and accepted when they are community based. This requires flexibility in the research protocol.
5. "Respecting communities' past and present experience of research". The past experiences of Indigenous Australians must be recognized, researchers should expect and accept communities to say "no" to research at any point during the research and communities have the right to expect good research to be done in their communities.

#### Desirable principles

6. "Recognising the diversity of Indigenous Australian populations". This diversity needs to be considered especially when research involves more locality and language groups.
7. "Ensuring extended timelines do not jeopardise projects". Aboriginal health research might need more time due to more complex of ethical approval, including the need for community support letters. It might take more time due to community events, weather, difficulties with recruiting or researchers might have to wait in turn until previous research in the community is finished first.
8. "Preparing for Indigenous leadership turnover". Aboriginal leaders are put under a lot of pressure and therefore there is high indigenous leader turnover, researchers should account for this by not solely basing their research contacts on a couple of leaders, or build strong relationships with the leaders.
9. "Supporting community ownership". Projects can only be sustainable when the community has sufficient input in and ownership over the project. Through advisory committees and Indigenous staff.

10. “Developing systems to facilitate partnership management in multicenter studies”. Equitable and transparent processes still need to be in place when multicenter studies are conducted, to ensure the wellbeing of the community.

**Comment:**

These principles are based on what the authors themselves have experienced through their work in the field of Aboriginal Health research, but also based on what becomes clear from literature on what works and does not work in Indigenous health, in Australia and overseas. They are easy to understand, practical and clearly based on research experiences of what works and what does not. For researchers in the field, these 10 principles might be easier to follow than the six values on the *Values and Ethics document*.

## 3.2 INCONSISTENCIES BETWEEN THE DOCUMENTS

The themes are generally consistent and overlapping. However, the AHMRC documents gave a particular emphasis to the following points which had not been particularly addressed by the other guidelines documents: reimbursement of expenses that community members may have incurred in order to participate in research activities (such as phone or transport costs); that the rights of self-determination for Aboriginal peoples must be recognized; that the responsibility for consultation and negotiation is ongoing throughout the whole research project and this must be demonstrated.

### *Differences in background and rationale for guidelines*

- The different documents base their reasoning for the principles and the need for ethical guidelines on varying backgrounds. *Values and Ethics*, *Keeping Research on Track* and the AH&MRC guidelines are created as a response to a history of damaging unethical practices of research being conducted on Aboriginal and Torres Strait Islander people, with almost no benefits for the local communities [2, 3]. These three guidelines are developed to *prevent* these unethical practices in health research involving Aboriginal and Torres Strait Islanders. On the contrary, Jamieson et al [12] take a more positive approach, in which they aim to *promote* ethical practices in research among Aboriginal populations by describing principles based on best practice from their own experience and what is extensively described in the literature. The AIATSIS guidelines take a different approach altogether and are based on a human rights framework. The United Nations declaration on the rights of Indigenous people [7] is the base for this framework and it is described what rights Aboriginal and Torres Strait Islander people have and how this should be applied in research [4]. Finally, the NHMRC *National Statement* starts from more general 'western' concepts of ethical research, reflected in the four principles of research merit and integrity, respect, beneficence and justice and applies these principles to Aboriginal and Torres Strait Islander research.

### *Differences in principles*

- These different approaches lead to a different focus in the principles. All of the guidelines discuss the importance of community engagement and involvement, agreements, equal and fair distribution of benefits and burden of the research, the need for respect for the distinctiveness of Aboriginal and Torres Strait Islander cultures and the importance of consent. However, where *Values and Ethics* emphasizes community engagement and involvement in every aspect of the research, it does not go as far as to discuss community control and ownership of every aspect of the research. This is done in the AH&MRC and AIATSIS guidelines and the 10 principles discussed by Jamieson et. al [4, 12, 13]. A simple search for the words "ownership" and "control" in the *Values and Ethics* documents results in no matches in the actual discussion of the principles. The AH&MRC guidelines highlights the importance of community control. Ensuring community control and ownership are central to these guidelines, as also becomes clear from the emphasis on letting the community decide on the research and the AH&MRC ethics committee positioning itself as an advisory organ [13]. Based on the Human rights of self-determination, the AIATSIS guidelines also emphasize the importance of community ownership and the rights of communities to control research that is conducted in their communities. Jamieson et. al [12] also emphasize that research shows that projects are most accepted, effective and sustainable when there are high levels of community ownership and control over the project. Based on this observation it might be fair to say that the *Values and Ethics* guidelines are too conservative in their position regarding community involvement, ownership and control.
- In line with these observations made considering community control, is the observation that the AIATSIS and AH&MRC guidelines and the Jamieson paper discuss that research should be responding to the needs of the local community, determined by the local community. This bottom up approach is in contrast with the top

down approach described in the three NHMRC guidelines, in which there is no mention of communities deciding the research agenda, but is only discussed that research should be appropriate for the community, should not harm the community and should “advance the interest of Aboriginal and Torres Strait Islander Peoples” [1]. Again, the NHMRC guidelines are more conservative on the issue of allowing communities to control research.

- The AH&MRC guidelines are strong on the issue that only communities themselves can approve what research is going on in their communities, whereas the NHMRC *National Statement* states it is enough to have someone that is familiar with the culture and practices of Aboriginal and Torres Strait Islanders, or someone that has networks with Aboriginal and/or Torres Strait Islanders and is familiar with the research practices. So the HRECs according to the *National Statement* do not even have to ask advice, nor include an Aboriginal and/or Torres Strait Islander person, but for the AH&MRC guidelines this is essential.
- Even though *Values and Ethics* and the NHMRC *National Statement* are closely related and they both refer to each other, there are discrepancies in their wording of the principles and where they place certain important aspect of Aboriginal Health research. This can be slightly confusing as they basically discuss the same principles, but give them different names or the same names, such as respect. Both documents discuss respect, but they do not cover the same, for example *Values and Ethics* include the assessment of risks and benefits in the principle of respect, but in the *National Statement* this is placed in “Beneficence”. “Integrity” in the *National Statement* means a commitment to development of understanding and knowledge, based on rigorous research methods, however, “integrity” in *Values and Ethics* is about the maintenance of coherence of past, present and future Aboriginal and Torres Strait Islander values and cultures.

#### *Target group*

- It is clear from the language used in *Keeping Research on Track* that it is developed for communities. It gives clear outlines on what the community can and should do in every step of the research. This document clearly shows that Aboriginal people and community do not have to be passive participants, but they can be actively involved in research and determine the research conducted on their lands and communities. This differs from the other guidelines, because the other guidelines, such as the AIATSIS, Value and Ethics and AH&MRC guidelines all focus on what the researcher should do to ensure research is conducted in a correct way.

#### *Philosophical versus pragmatic*

- There is a difference in the level on which the different documents are written, *Keeping Research on Track*, AH&MRC guidelines and the ten principles by Jamieson et al are pragmatically written, whereas the NHMRC *National Statement*, *Values and Ethics* and the AIATSIS guidelines are more philosophical and discuss the principles in more detail, whereas the other documents place more emphasize on practical application of ethical principles. Especially *Keeping Research on Track* is highly pragmatic by including a clear step-by-step research guide, in which the tasks of the researchers and the involvement of the communities are outlined in every step. The AH&MRC guidelines are more pragmatic for example because they outline when community consent is needed, this is missing in the *Values and Ethics* document. Additionally they give practical examples of equal distribution of burden (reimbursing costs) and benefits (enhancing skills in the community through training).
- The more philosophical nature of *Values and Ethics*, AIATSIS guidelines and NHMRC *National Statement* is also illustrated by the extensive summary given on the background of the guidelines. Especially *Values and Ethics* spends nine pages on describing the historical and philosophical background of the guidelines and the development of the guidelines. Even though these introduction are shorter in the AIATSIS guidelines and the NHMRC *National Statement*, and all three documents describe the application of the guidelines, they miss

practical examples of how to actual do that and tend to use more vague words such as “ensure”, “discuss”, “be aware” and “understand”.

#### *Differences in word use and lay out*

- In line with *Values and Ethics* being more philosophical, this document is also more wordy than any of the other documents. The wording is complex and not easy to understand in a first read. *Keeping Research on Track* is a lot easier to read and has a more attractive layout, with its use of a colourful background, less text on a page and bigger character size. Wording is simpler and concepts are explained in an easier and more straightforward manner. The AH&MRC guidelines are also shorter, more to the point with less elaborate explanations of the different principles. Paragraphs are short and a lot of use of dot points, which makes the document clear and well-organized. AIATSIS guidelines also work with listings of how to apply the principles and works with commands, which gives it an easy flow to read.

#### *Other differences*

- *Values and Ethics* refers to the *National Statement*, but the paragraphs mentioned do not align anymore with the updated *National Statement*.

## 4. INTERNATIONAL ETHICS GUIDELINES

This section of the review covers some of the significant international ethics documents that have been created within the last decade. They all have a specific focus on good research practice for First Nations groups, and the scope of this literature review includes New Zealand, Canadian and American guidelines.

### 4.1 NEW ZEALAND

Maori people are the Indigenous people of New Zealand. In the 2006 census, there were an estimated 620,000 Maori in New Zealand, making up roughly 15% of the national population. In addition there are over 120,000 Maori living in Australia. Maori are active in all spheres of New Zealand culture and society, with independent representation in areas such as media, politics and sport.

Disproportionate numbers of Maori face significant economic and social obstacles, with lower life expectancies and incomes compared with other New Zealand ethnic groups, in addition to higher levels of crime, health problems and educational disparity. Socioeconomic initiatives have been implemented aimed at closing the gap between Maori and other New Zealanders. Political redress for historical grievances is also ongoing [14].

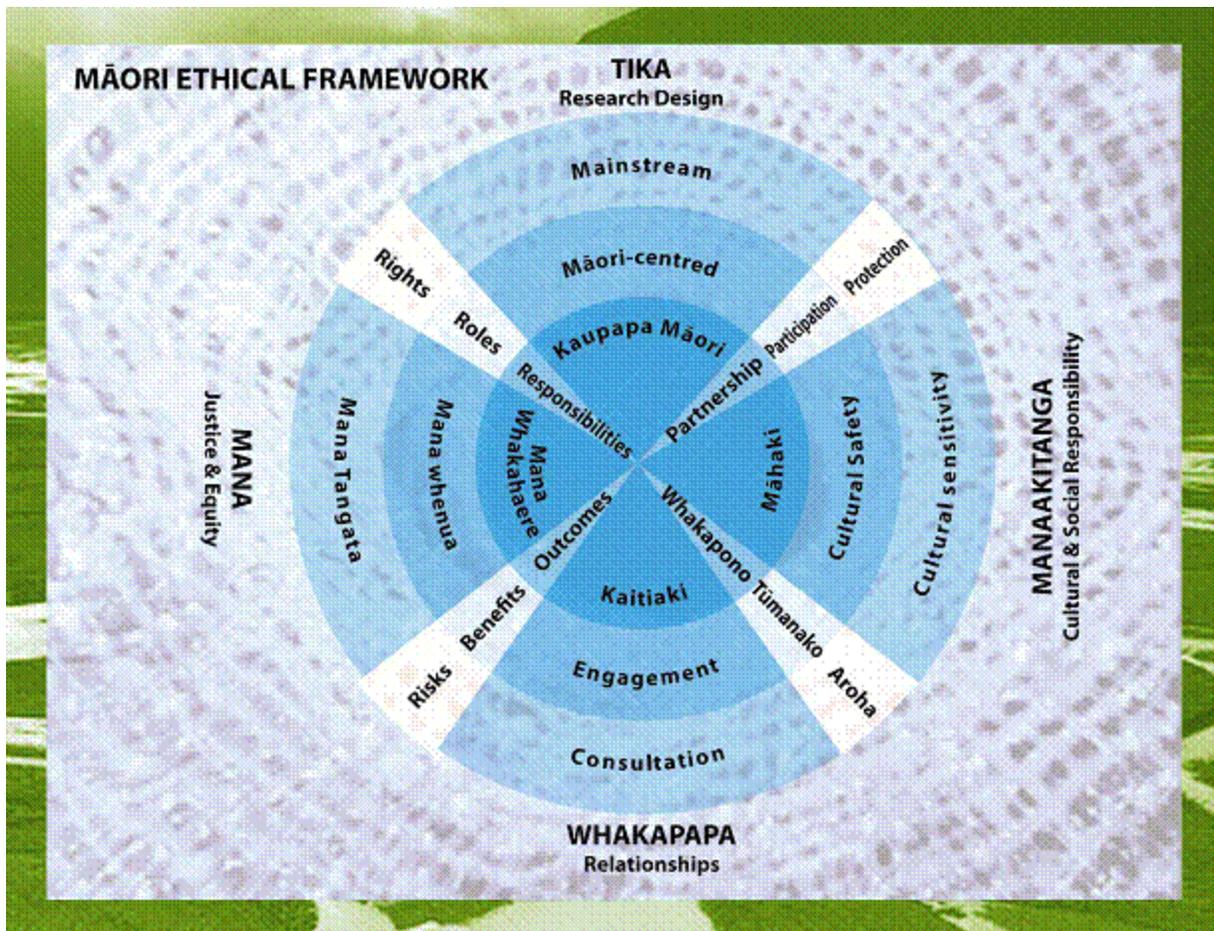
Several documents of interest for this literature review have been identified, which are *Te Ara Tika – guidelines for Maori research ethics: A framework for researchers and ethics committee members* [15]; *Guidelines for researchers on health research involving Maori* [16], and *Nga Ara tohutohu rangahau Maori – guidelines for research and evaluation with Maori* [17].

#### 4.1.1 TE ARA TIKA

The Health Research Council of New Zealand has developed ethical guidelines for Maori research ethics [15]. These guidelines are based on Maori traditional values (matauranga Maori) and tikanga (the right way for Maori to do things), which are locally specific practices and values to preserve justice and equity (mana). Western ethical principles are integrated into these Maori values, through the principles of the Treaty of Waitangi: partnership, participation and protection. *Te Ara Tika* sets out to explain key ethical concepts for Maori; support decision-making around Maori ethical issues; identify ways to address Maori ethical concerns; and clarify kaitiaki (guidance/advocate) roles of Maori ethics committee members. It recognises the importance of justice and reciprocity for identifying and sharing benefits equally and the different roles, responsibilities and relationships the different parties have.

It is acknowledged that Maori ethics committee members have a dual role in the committee. Firstly, they have the same responsibilities and sit alongside the other committee members. Secondly, they have the responsibility to advocate for Maori ethical issues and ensure Maori values are protected. They have to be brave, competent and capable (kaitiaki).

Key ethical concepts for Maori are summarised in the 'Maori Ethical Framework' (taken from *Te Ara Tika* [15]):



The four main Maori ethical values which are based on tikanga are: tika, manaakitanga, whakapapa and mana. For every principle three parts are described, progressing from minimal standard to good practice to best practice. All principles are linked to the rights, roles and responsibilities connected to the Treaty of Waitangi, the principles of the Treaty, the continuum of risks, benefits and outcomes and the Maori values of faith, aspirations and awareness.

#### WHAKAPAPA (RELATIONSHIPS):

Whakapapa is used to explain the source and the purpose of any topic/purpose (kaupapa). Why relationships have formed and how they are progressed over time. Quality of relationships and structures or processes established to support the relationships:

##### Minimum standard - Consultation:

Aroha (protective awareness) and risks - consultations should protect against the risk of engaging in the research and allow for constructive discussion on the proposed project and how Maori are protected in it. It serves as a place to draw up research agreements, including: stating that samples will only be used for a specific purpose; mechanisms to report results back to appropriate parties; allow issues regarding the research scope and agenda to be discussed. A list of questions that should be asked are given.

##### Good practice - engagement:

Tumanako (aspirations) and benefits. Positive engagement with Maori will ensure that the research focuses on tumanako Maori and holds tangible benefits for the Maori community. Relevant questions are listed.

**Best Practice - kaitiaki:**

Whakapono (hope) and outcomes. Empowering Maori to take a Kaitiaki role ensures that tangible outcomes are realised for Maori. A relationship of transparent, good faith, fairness and truthfulness (Whakapono). The development of governance roles in every research aspect for Maori.

**TIKA (RESEARCH DESIGNS)**

What's right and what's good in any particular situation? In research this refers to the validity of the research and whether the design of the research is successful in achieving its goals. Respectful relationships with Maori and mana whenua (regional authorities) are always essential.

**Minimum standard - mainstream:**

Protection and rights. Mainstream research that may or may not have direct relevance for Maori and has Maori participants. Rights and interests of Maori participants should be protected and recruitment methods should be considered.

**Good practice - Maori-centred:**

Participation and roles. This research has a higher level of participation for Maori participants in various roles, such as researcher, mentor, and other kinds of involvement of the research process.

**Best practice – Kaupapa Maori framework:**

Partnerships and responsibilities: Kaupapa is research that has been designed, conducted, made up of, and has benefits to Maori.

**MANAAKITANGA (CULTURAL AND SOCIAL RESPONSIBILITY)**

Acting in a way that ensures that the mana (justice and equity) of both parties is maintained. Cultural and social responsibility and respect for persons.

**Minimum standard – cultural sensitivity:**

Protect and ahora, being aware of issues with cultural sensitivity. Access to appropriate advice and concepts of privacy and confidentiality. Level of confidentiality can be negotiated with the community.

**Good practice – cultural safety:**

Participation and tumanako. Through collective participation goals and benefits can be established that are ensured to be culturally appropriate and the implementation will be done in a culturally safe way. Inclusion of Maori values and concepts and use of whanau support.

**Best practice – Mahaki (respectful conduct):**

Partnerships and whakapono. Partnerships are enhanced by trust and faith in each other. Mahaki (respectful conduct) acknowledges the importance of recognising spiritual integrity, Maori philosophy, and processes like whakawatea (realignment) within the research project.

## MANA

Mana relate to equity and distributive justice. Mana is the barometer for relationships with regard to who has rights, roles and responsibilities when considering risks and benefits of the project.

### **Minimum standard - Mana tangata (autonomous individual):**

Risks and rights. Mana tangata (autonomous individual). Individuals that choose to participate have the right to be fully informed about the risks. Consideration should be given to assessing the risk, fairness of distribution of risks and benefits and place of koha (customs). Informed and oral consent.

### **Good practice - Mana whenua (local authority, tribe/kinship group):**

Benefits and roles. Researchers should establish good relationships with mana whenua (regional authority), who have authority over resource management. Provide opportunities for sharing arrangements. Collective consent when the risks for the collective are at least as serious as for the individual.

### **Best practice - Mana whakahaere (sharing of power and control):**

Responsibility and outcomes. Mana whakahaere is sharing the power and control in the research relationship with hapu, iwi or relevant Maori communities who have the responsibility of the outcomes of the project. This represents Maori control within the project, including intellectual property rights, ownership of research data and guardianship responsibilities in relation to the protection and dissemination of information from the research project.

A list of special considerations is provided for genetic research, collection and use of human tissue, interpretation of results, ongoing communication with donors/participants, informed consent, intellectual property and representation. For the latter it provides a table which assists in assessing the appropriateness of Maori consultation. Finally it provides a list of potential benefits of the research process for the researchers, participants, participant communities, Maori and to society. In the appendix an overview of the development of Maori research ethics is provided.

#### **4.1.2 GUIDELINES FOR RESEARCHERS ON HEALTH RESEARCH INVOLVING MAORI**

In addition to the ethical guidelines described above, the Maori Health Committee of the Health Research Council also has produced *Guidelines for Researchers on Health Research involving Maori*. These are guidelines to assist researchers who undertake biomedical, public health or clinical research involving Maori or on issues relevant to Maori health [16]. This includes studies in which Maori are one part of the wider population under study, or form one cohort in the study. The aim of these guidelines is to ensure that research contributes to improving Maori health and wellbeing, and the research process maintains Maori mana (justice and equity, reflected through power and authority).

The New Zealand government has made a commitment to improve Maori health and reduce health inequalities. The goal is to ensure equal access to health services, to build capacity in the Maori health research workforce, to enable Maori to state their health needs, foster collaborations between Maori and researchers; and foster and support Maori health workers. The Treaty of Waitangi should be incorporated and respected in every health research proposal. Collaboration is essential in involving Maori in research, this accelerates development of the Maori health research workforce and provides training and education opportunities for emerging Maori researchers.

The document describes that research should consult with different Maori and Maori organisations from the start. It provides researchers with a list of considerations that should be discussed during the consultations:

- Does the research topic involve Maori as a population group?
- How will this proposed research project impact on Maori health?
- What are the benefits for Maori?
- How will Maori be involved?
- Which Maori groups would be involved in this research project?
- If Maori researchers are involved in the research team, can a Maori researcher be the lead researcher?

The HRC acknowledges that there are different types of Maori health research: Kaupapa Maori research (major Maori involvement, led by Maori); Maori-centred research (major Maori participation) and research where Maori are involved as participants (minor Maori participation). Consultations assist in determining which type of research will be conducted and how extensive the involvement of Maori should be.

The documents give reasons why researchers should consult with Maori and Maori organisations on the different research processes. Starting with the research topic, consultations with Maori helps identify research topics that are relevant to them and helps to understand each other's expectations. Consultations help to identify the most suitable recruitment and research methods. It assists in preventing problems arising from cultural differences. Consultation prevents issues from arising that the researcher would not have seen by himself and it provides local networks for disseminating the research results.

It also helps maximise the benefits of the research, research skills can be developed in the community and researchers can learn about local practices and research methods through mutual mentoring. Dissemination of the results should also be discussed with Maori and Maori organisations, to ensure that this is done in an appropriate way and sharing credit in publications. Permission should be obtained to disseminate the results.

The extent of consultation should be dependent on the scale of the project, the relevance to Maori and the potential for application of the research results. Consultation preferably starts before the research topic is determined and should be ongoing throughout the research process. It is important that positive relationships are built between the researchers and representatives of the research participants, budgets should take this into account. Consultations should preferably extend beyond the project period and result into lasting partnerships between researchers and communities. This results in highly supportive and innovative research projects.

The next section in the document discusses with whom consultations should be sought including Maori health organisations, Maori health research units, Maori health care providers, local Maori representatives (tribe or kinship group authorities, pan-tribal organisations in the urban areas. Special considerations are given for genetic research on Maori and researchers in this area should ensure that close co-operation with Maori is ensured.

The document finishes with a checklist for the consultation process including preliminaries, preparations, face-to-face consultation and post-consultation.

**4.1.3 NGA ARA TOHUTOHU RANGAHAU MAORI – GUIDELINES FOR RESEARCH AND EVALUATION WITH MAORI**  
The *Nga Ara Tohutohu Rangahua Maori Guidelines for Research and Evaluation with Maori* have been developed by the Centre for Social Research and Evaluation [17]. These guidelines are a set of principles which inform the practice of research and evaluation projects involving Maori, Maori communities, organisations, hapu (kinship groups) and iwi (tribes). These guidelines should be used for research and evaluation projects in which: Maori are a significant subgroup of the research sample for a 'general' study; Maori are one of the specifically targeted subject

groups for a particular study; Maori communities, organisations and/or programs are the specific focus of a project; and consultation with Maori, Maori organisations, hapu and iwi is required as part of the design of methodologies and methods for a research or evaluation-related report.

These guidelines consist of six practice principles, for which the principle, rationale, guidelines and supporting advice and commentary are outlined.

#### PRINCIPLE 1: PLANNING FOR MAORI INVOLVEMENT:

Involvement of Maori is essential in ensuring effective research and evaluation practices as participants or key stakeholders. It is also important for ensuring that the project is workable, in the interest of Maori, accurate cost estimates can be made and robust information can be gathered. Projects must start with identifying whether the research will be of interest for Maori and whether consultation/engagement is required from Maori. The level of this engagement should be estimated, a consultation plan should be developed and a budget should be developed in which there is room for consultation. Involvement is a beneficial and essential part of research and evaluation projects involving Maori and should be sought as early as possible.

Maori input could assist with: defining the research topic, setting objectives, developing appropriate methodology, analysing data and presenting findings. To determine relevant external stakeholders to be involved in the study the following things should be taken into account: people affected now and in the future, particular sectors, specific geographical area and pan-Maori organisations and urban authorities.

Maori involvement should be included in the budget and Maori advisors should receive the same fiscal recognition as other advisors. The cost of hosting a research hui should be paid by the researchers and not the local community. Attention should be given to thorough 'desk' research to prevent over-researching of certain topics and areas and communities. Check for existing and recent research on a specific topic, areas and communities.

#### PRINCIPLE 2: ENGAGING WITH MAORI PARTICIPANTS AND STAKEHOLDERS

Culturally appropriate involvement with Maori includes having approved ethics frameworks to ensure best practice. Involving Maori requires meaningful consultations with honest information exchanges and observation and involvement of Maori values and cultural practices. Ethical guidelines should be applied, protocols should be identified and followed, where necessary assistance should be arranged for following the protocols, participants should be allowed to take part in the design, and progress should be reported on Maori-specific requirements. Ethical engagement is important, which means that Maori have actual input in the project. Sufficient time for ethical engagement should be built into the process. Effective work relationships should be built with Maori and key principles and practices of ethical conduct should be abided to.

The objectives of an evaluation should be made clear to the participants, as are ownership issues, who will have access to the research results and who will benefit from them. All aspects of research should be discussed with key stakeholders and Maori participants. Culturally appropriate engagement with Maori requires that researchers engage in hui (ceremonies/seminars), for this it is essential that the team members, or at least one researcher on the team, has knowledge about the local tikanga, mana and cultural knowledge. A list is provided with the preferable characteristics that at least one of the team members should possess when engaging in hui: an empathy towards Maori culture and strong desire to work with Maori; experience and ability to communicate and work effectively with hapu, iwi and Maori organisations; understanding of the reo and tikanga; or have the assistance of someone that does; ability to understand Maori concepts; ability to understand Maori issues and to be able to communicate them; ability to formulate research questions from a mainstream, scientific and Maori perspective. Researchers should be willing to change their research design based on consultations with Maori.

### PRINCIPLE 3: DEVELOPING EFFECTIVE AND APPROPRIATE METHODOLOGIES

Methodologies will be developed in consultation with key Maori stakeholders. Methodologies should be relevant and appropriate for the research topic, the local Maori community and the cultural place. Methodologies should be culturally appropriate and assist in gathering of robust data. Methodologies should be discussed in consultation, space should be made available on the agenda to discuss this, methodologies should be discussed in the information package and notes for the consultation. All reports related to the project should report on discussions with Maori about the methodologies and the changes made to these methodologies.

Researchers should be prepared to change the scope of their research design based on consultations, they should familiarise themselves with Maori research methods and ways of collecting data, methodologies should be modified where appropriate to the local situation. Researchers should not strive for methodological excellence and should take into account the local cultures. It is important to find the right balance between these two. The effectiveness and appropriateness of a certain methodology depends on the local area. Quantitative methods might work just as well for Maori as for non-Maori, only methods of administration might differ because of their socioeconomic issues, such as not owning a phone or literacy difficulties.

### PRINCIPLE 4: PROTECTING KNOWLEDGE

Maori have the right to protect their cultural knowledge and intellectual property, observation of these strategies and processes is important in making research with Maori ethical and appropriate. Maori processes to protect their cultural practices and knowledge during dissemination of results are important and should be protected by the researcher as well. External and internal sources should be used to uncover which processes should be protected and how they should be protected; identify and use appropriate processes based on consultations. Find a representative from the local community to assist in identifying and solving issues related to protection of intellectual property. Strategies to protect intellectual property should be discussed in consultations.

### PRINCIPLE 5: ENCOURAGE RECIPROCITY

All research participants have the right to access the information that is gathered during the research and evaluation project. Information should be made available to Maori participants, in such a form that they can use it for their social and economic development. Validity of the results and reporting should be checked with Maori stakeholders. Appropriate processes, strategies and formats should be discussed in consultations with Maori and used when disseminating the results. Provide all findings in a suitable format and timely manner.

### PRINCIPLE 6: SUPPORTING MAORI DEVELOPMENT

Research and evaluation projects should assist in the Maori social development and economic development. Ethical and culturally appropriate research ensures the gathering of robust data can inform policies that support social and economic development of Maori. Information and data requirements of Maori should be identified through consultation processes, incorporated in the research design and included in final reports.

#### 4.1.4 WHAT AUSTRALIA CAN LEARN FROM NEW ZEALAND'S ETHICAL GUIDELINES

- The New Zealand guidelines appear to be more based on Maori principles than the Australian guidelines. This especially appears to be so because Maori terms and concepts are used in the ethical framework described in *Te Ara Tika*. In addition to Maori concepts and values being the basis for the guidelines, they are integrated with Western principles that go back to the Treaty of Waitangi. This integration makes for a comprehensive framework that is easy to grasp for both Maori and non-Maori researchers.

- *Te Ara Tika* gives more concrete guidelines for ethical research than the *Values and Ethics* document used in Australia. The practical application of the guidelines is ensured by the listing of the minimum standard, good practice and best practice in each of the four main principles. This reduces the freedom of interpretation that Australian researchers experience when working with *Values and Ethics* guidelines<sup>1</sup>. Through this it also acknowledges the wide range of research involving Maori and that complete participation is not always needed. Questions at every level of research guide the researcher to where they're at in relation to the principle.
- *Te Ara Tika* provides a clear description of the distinct role that Maori ethics committee members have, this is something that is not mentioned in Australian guidelines. *Te Ara Tika* provides a list of potential benefits for different stakeholders involved in the research. This is something that the Australian guidelines could incorporate as well, since equal sharing of benefits is seen as an important part of ethical research, but what potential benefits are for different parties is often unclear [2].<sup>2</sup>
- *Te Ara Tika* finishes with a timeline that shows the development of the ethical guidelines for health research involving Maori, this could be something to incorporate in the *Values and Ethics* guidelines as well. Instead of having the background written out in the first introduction, provide a clear timeline.
- Consultations and engagement with Maori receive a lot of attention in these guidelines. The guidelines for researchers on health research involving Maori provides a list of considerations for the consultations, a checklist for consultations and why, who and when to consult. These guidelines acknowledge that the need and form of consultation varies for each project [16]. This is important in Australia as well, where research with Aboriginal and Torres Strait islanders takes many forms and is done on many levels.

*Nga Ara Tohutohu Rangahau Maori* also highlights that consultation is the basis for ethical research with Maori. It gives very practical and concrete instructions for consultations; stating that ethical consultation starts before the research topic is identified. It gives Maori people real input, it does not leave room for interpretation [17]. This could be done in *Values and Ethics* as well.

- *Nga Ara Tohutohu Rangahau Maori* describes how important it is to make space in the budget for consultation and time in the planning phase. This is something that is missing in *Values and Ethics*. If consultations and engagement are an essential part in effective and ethical health research for Aboriginal and Torres Strait Islanders, it should be made a priority in ethical guidelines and funding and government agencies should ensure that consultations are budgeted for.
- *Nga Ara Tohutohu Rangahau Maori* highlights the importance of thorough desk research. This could be incorporated in Australian guidelines as well, to prevent Aboriginal and Torres Strait Islanders from being over-researched.
- Researchers should have knowledge about Maori ways of doing research [15, 17]. The same goes for Australian researchers and this should be mentioned in the guidelines. Kaupapa Maori is research by and for

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<sup>1</sup> As mentioned in the consultation workshops

<sup>2</sup> As mentioned in the consultation workshops

Maori and is mentioned often in the guidelines as best practice. Even though such research practices also exist in Aboriginal and Torres Strait Islander communities<sup>3</sup>, these are not mentioned in the ethical guidelines.

- Just as in the AIATSIS guidelines, *Nga Ara Tohutohu Rangahau Maori* has a focus on ensuring that research protects processes, knowledge and intellectual property of Maori [4, 17]. In *Values and Ethics* it is only mentioned that these should be respected. In *Nga Ara Tohutohu Rangahau Maori* it is emphasised that researchers should take extra effort to protect these things, through consultations and seeking advice on how to do this.
- Finally, *Nga Ara Tohutohu Rangahua Maori* gives an interesting list of characteristics that a research team member should own to be able to engage in culturally appropriate and effective consultation with Maori [17]. This is an interesting feature to include in an ethics guideline, since it's all about the persons in the research and therefore it is important that they have the right attitude, knowledge and characteristics to ensure good consultations.

In conclusion, the New Zealand guidelines are more practical and less philosophical than *Values and Ethics*. They give more concrete steps and instructions for conducting research with Maori and have a greater acknowledgement for the different types of research that Maori can be involved in. The concreteness of the New Zealand guidelines leave less room for interpretation than the Australian guidelines or they have accounted for different interpretation as shown in the minimum standard, good practice and best practice divisions. Finally, they have a strong focus on consultations and engagement with Maori and describe what real consultation is.

## 4.2 CANADA

### 4.2.1 NATIONAL GUIDELINES

The national guidelines for research involving First Nations, Metis and Inuit are integrated into the general national guidelines for human research in Canada: *Tri-Council policy statement: ethical conduct for research involving humans* [18]. Human dignity is the underlying value of these ethical guidelines, which is expressed in three core values: Respect for persons, concern for welfare, and justice. Chapter nine of this document is dedicated to research involving First Nations, Metis and Inuit, and describes how the three central principles specifically apply to research which involves these groups [19].

Principle	Description and application in research [18]	Application in research involving First Nations, Metis and Inuit [19]
<b>Respect for persons</b>	Every person has a value in themselves. Respect the autonomy of those involved in research, to protect that of those with developing, impaired or diminished autonomy. People are free to choose: this includes getting participants to provide their free, informed and ongoing consent.	Extends to keeping traditional knowledge and passing it through to future generations. Interconnection between humans and the natural world.
<b>Concern for welfare</b>	Welfare is quality of life in all its aspects: physical, mental and spiritual health and economic, social and cultural circumstances. Welfare should be protected, or even promoted through research. Risks should be minimised in the research and be outweighed by benefits. Participants should be	Especially focuses on the collective welfare of the community. In addition, the cultural welfare is important and Aboriginal people think that research should focus on maintaining their culture.

<sup>3</sup> Eg. Yolngu research practices: <http://yalu.cdu.edu.au/healthResources/research.html>

	free to decline or withdraw participation when risks outweigh the benefits.	
<b>Justice</b>	Treating people fairly and equitably: treating all persons with equal respect and an equal distribution of burdens and benefits of research. Everybody should have the same right to participate and receive benefits from research. Inclusion and exclusion of participants should be in line with the research's aims and can't discriminate. The probable power imbalance between the researcher and participant should be taken into account and by no means misused.	A power balance between the researcher and participants. An imbalance may not be misused. Misuse can include things like, misappropriations of sacred songs, stories and artefacts, devaluing of Aboriginal peoples' knowledge as primitive or superstitious, etc. This can be prevented by establishing trustful relationships.

The chapter concerns research involving First Nations, Metis and Inuit Peoples. It starts with outlining the important concepts in this research, which include Aboriginal people, community, Indigenous people, community customs and codes of research practice and traditional knowledge. Self-identification is central in its definition for Indigenous people. It includes the definition for community and acknowledges that an individual can belong to multiple communities.

The rest of the chapter addresses how the guidelines apply to the Aboriginal People of Canada in twenty-two paragraphs.

(9.1) Community engagement in Aboriginal research is required when the research is likely to affect the community in/on which the research is conducted. This includes: research conducted on First Nations, Inuit or Metis lands; recruitment criteria that includes Aboriginal identity as a factor for the entire study or a sub-group of the study; research that seeks input from a community regarding a community's cultural heritage, artefacts, traditional knowledge or unique characteristics; research in which Aboriginality is used as a variable in analysis; interpretations of research that will refer to Aboriginal people. Engagement with communities may bring up certain issues that are not considered by the community and engagement ensures that traditional knowledge is treated fairly, ethically and equitably.

(9.2) The nature of engagement varies per type of research that is conducted; different kinds of research require different levels of engagement and some types of research don't require community engagement. Also the diversity of types of communities make it important not to generalise about community engagement, and take into account that the form the community engagement takes is unique for every community/research partnership. Mutual expectations and obligations should be clarified and recorded in the research agreement. Where the welfare of the community is not affected, informed consent from participants will be sufficient. Research examples of how and when community engagement is required, are provided.

(9.3) When research is conducted on land that is governed by First Nations, Inuit or Metis people, their authorities must be respected and approval for the research must be obtained from these authorities before any participants can be recruited. Even when research is conducted in multiple geographical areas and regional or national approval is given, the final decision still lies with the local community. Authority's approval is no substitute for individual consent.

(9.4) Aboriginal organisations should be recognised as communities and should be represented in ethical review and project oversight.

(9.5) Community engagement processes should be created and documented when approval of research through leadership is not possible.

(9.6) All relevant views in the community should be considered. Especially those of marginalised and/or vulnerable groups which should have the same influence on the research and experience the same benefits.

(9.7) When conducting critical inquiry, i.e. assessing the conduct of public institutions, organisations or individuals that are Aboriginals or exercise power of Aboriginal people, this should be conducted ethically, with respect to cultural norms, protecting the safety of the participants and ensuring the welfare of the larger community.

(9.8) Researchers should be aware of, and adhere to, local communities' codes of research practice. Aboriginal codes of research practice are based on cultural traditions. Researchers should make the effort to become aware of these traditions, taking into account the disclosing of information which might be publically available, available to a specific audience or available only under certain circumstances. Many First Nations communities adhere to the OCAP ethics code: this code asserts ownership of, control of, access to and possession of the research process and the resulting data affecting the community. A possession agreement is important.

(9.9) Institutional ethics approval is still essential for the commencement of the research projects, even when local approval is obtained. When local Research Ethics Boards (REBs) are in partnership with the researcher's institution, ethical review might not be required.

(9.10) When planning to conduct research with Aboriginal people, the researcher should provide an explanation of how they have engaged or intend to engage with the involved community. When no engagement is planned, they should come up with a strong rationale for this. Researchers should provide a formal research agreement; a written decision or oral decision in a group setting, indicating the community engagement; or a written summary of advice received from a culturally informed advisory group.

(9.11) Terms and undertakings of both the community and the research team should be set out in a research agreement, before participants are recruited. It should contain the mutual expectations, tasks and expenses of the community and the research team. The scope of the document is dependent on the level of community engagement.

(9.12) As part of the community engagement, the research should consider collaborative or participatory research approaches. In collaborative research approaches, both parties bring in their own expertise and have their own responsibilities based on this expertise. Collaborative research is a means of facilitating mutually respectful and productive relations. Participatory research involves the active participation of the research participants in data collection, analysing and producing the final product. Participatory research is based on respect, relevance, reciprocity and mutual responsibility.

(9.13) Research should be relevant to community needs and priorities, it should benefit the participating community and extend the boundaries of knowledge. Collaborative research involving Aboriginal communities can make seemingly irrelevant research relevant to the community, because they learn about the issue being studied. Participatory research can assist communities in communicating their needs clearly to authorities. Research can also benefit the community by providing employment and skills. Including Aboriginal people in the research as researchers also increases the capacity to conduct research in the local language. Researchers should provide the community with access to research data, so they can use this for lobbying for funds to aid their community.

(9.14) Research projects should build the capacity in the community through enhancement of research skills, through collaboration with and participation of community members as researchers. Reciprocal learning should take place in which community members are trained in research skills and researchers learn how to conduct culturally relevant research.

(9.15) Engagement should be sought with Elders, who can provide the researchers with essential traditional knowledge that can guide in developing research proposals and interpreting results. Elders can also provide access to community networks.

(9.16) Privacy and confidentiality should be addressed early in the research. No personal information can be disclosed without the consent of the individual. Especially in small communities, there should be extra attention to anonymity - some communities may be easy to identify based on their characteristics and this could lead to stigmatisation of entire communities. In individuals who have suffered trauma, the researchers should ensure that the research does not accidentally re-traumatise these individuals.

(9.17) Researchers should include community representatives in interpreting the data and reviewing research findings before they are published. Continuing communications with the community is essential. The review and approval of reports and academic publications is essential to validate findings, correct any cultural inaccuracies and maintain respect for community knowledge. Reports should be made available to all the groups involved. The community and the researchers should agree on how the collaboration of different parties will be recognised in the publications.

(9.18) Intellectual property rights should be discussed before the research commences and should be included in the research agreement. Anticipated secondary use of data or human material should be discussed beforehand. Rights of marketable results from the collaborative research should be discussed and decided upon.

(9.19) Researchers should seek agreement with the community about the rights and proprietary interests related to human material and associated data. Aboriginal people might request to maintain control over this data, in line with their 'full embodiment' view on life that every part is sacred and cannot be alienated. Research agreements should address: objectives for collection, use and storage of human biological materials; roles and responsibilities regarding custodianship of the data; any future use of these human biological materials and associated data, including material transfer agreements to third parties and any subsequent requirement for community engagement.

(9.20) Researchers should seek engagement with the community from whom the original data is taken: when they want to use it for a second time; when no research agreement is there; when a research agreement doesn't state anything about secondary use; or when data is not publicly or legally accessible.

(9.21) Where the data is obtained from a legally accessible source, then no ethical approval is needed for the use of the data. When, however, the original source of this data can be identified, the researchers should assess the potential risks the research has for the community.

(9.22) When a researcher plans to combine two anonymous data sources that might lead to identification of the source of the data, ethical approval is needed, which can possibly conclude that community engagement is needed.

### **Good practice?**

- This document acknowledges that people can be part of multiple communities and that community is a fluid concept.
- It gives a definition for Indigenous people, which acknowledges that it is based on self-definition.
- This document acknowledges that community engagement is not required in every type of research. It provides a list of when engagement is needed and practical examples of when and how engagement is required.
- It acknowledges that Aboriginal communities are unique and that no rules can be given on how engagement should work, this should be worked out with the local community. Many communities have their own research practices and guidelines and the researcher should take time to get to know these.
- The local practices often adhere to the OCAP ethics code: Ownership, Control, Access and Possession.
- It provides special rules concerning genetics and human biology research.

#### 4.2.2 OWNERSHIP, CONTROL, ACCESS AND POSSESSION

OCAP is a set of principles for research with First Nations people in Canada [20]. These principles are developed in response to colonial research practices that have led to much grievance in First Nations communities. First Nations people feel that they have been researched to death, with many bad research practices occurring including gaining data without consent; not compensating or employing local First Nations in the research; not respecting the human dignity, religious, cultural and spiritual beliefs; not respecting secrecy and misusing research data; leading to marginalisation and discrimination. OCAP is self-determination applied to research.

New research guidelines have emerged that discourage bad research practices and promote more community involvement, consent, negotiations of relationships, respect for Aboriginal cultural and religious beliefs and collective rights of Aboriginal people. However, these guidelines are developed by governments or academic institutions. These guidelines are their own set of rules and often inadequate in addressing the priority issues of Aboriginal people. Mostly they are written in colonial/anthropological wordings and make a strict distinction between researchers and Indigenous people, without acknowledging that First Nations people can and should also control research. However, in many government, academic and research institutions there is still a misconception that Indigenous people lack the capacity to self-govern their communities and should not have the right to do so.

In response to the new guidelines that still are not able to address Indigenous priority issues, a growing number of Indigenous communities and organisations have developed their own research guidelines, ethical review processes and ethical review committees. Several examples of these policies are outlined below. These include the Nuu-chah-nulth Tribal Council Protocols and Principles, the Six Nations' policy regarding conducting research, Sante' Mawio'mi Research Principles and Protocols, Guidelines for ethical Aboriginal research in the Manitoulin area and the Akwesasne Good Mind Research Protocol.

### 4.2.3 LOCAL COUNCIL RESEARCH PROTOCOLS AND PRINCIPLES

In Canada there are many tribal councils that provide programs, services and advice to the groups of bands that are part of the region that the council is serving. Tribal councils are organisations existing of bands that come together voluntarily. Tribal councils are funded by the Canadian government through the Department of Aboriginal Affairs and Northern Development Canada [21]. In 2001-2002 there were 78 Tribal Councils in Canada that were funded by the government [21]. A growing number of communities and councils have created and adapted their own ethical research guidelines.

#### PROTOCOLS AND PRINCIPLES FOR CONDUCTING RESEARCH IN A NUU-CHAH-NULTH CONTEXT

*Nuu-Chah-Nulth Tribal Council Research Ethics Committee (2008)[22]*

The Nuu-cha-nulth Tribal Council governs the area on the western side of Vancouver Island (British Columbia, Canada). This area consists of different communities, family and band groups. This council provides different services to the included nations, it can function as a sounding board for common issues and can oversee issues. The council developed the protocols and principles for research to ensure that research within Nuu-chah-nulth communities is conducted in an appropriate manner, by assisting the researchers in meeting the appropriate protocols. It describes that every community has its own protocols and the researchers must make sure that they identify these protocols; this is done through consultation with the community members.

Research conducted in Nuu-chah-nulth communities preferably partners with the community and must ensure that the research protocols uphold the protection of the community and its resources (which include people and their knowledge). All Nuu-chah-nulth people have the right to participate or refuse participation in research, they should get enough time to think about participation and can withdraw at any time without consequences. Principles for research with Nuu-chah-nulth communities:

- Research that works with two or more Nuu-chah-nulth communities should get approval from the Nuu-chah-nulth ethics committee.
- Purpose should be clearly stated, including benefits for community.
- Risk cannot outweigh benefits.
- Minimal disruption should be caused to the community.
- No deception involved in the research process.
- Individuals in the research process should be clearly identified and all should have their qualifications made clear.
- Data and results should be disseminated to individuals and communities involved in the research in an accessible format.
- Ownership of the data should be made clear and the community should have at least partial ownership and full rights of accessing and using the data.
- It should be clear what is going to happen with the data after the study is finished.

#### **Good practice?**

This document is very short and very comprehensible. It summarises nicely the important ethical points that are mentioned in the national guidelines. Besides ethical guidelines it gives research principles, which can guide the researchers in developing the research within Nuu-chah-nulth communities. It is good that this tribal council has its own principles and protocols and emphasises that each community has their own protocols that the researchers should follow. It is recommended that Aboriginal and Torres Strait Islander communities in Australia develop

research protocols like this as well, to ensure that research conducted in communities is conducted in a safe and ethical way.

The council states that they ‘continue to follow our ancestors’ true self-determination and real self-sufficiency when they lived and thrived on the lands and waters on the West Coast of Vancouver Island. Through the Nuu-chah-nulth Tribal Council, our vision is self-government that promotes strong, healthy Nuu-chah-nulth communities, which are guided by n'aas (Creator) and ha'wiih (hereditary chiefs).’ [23] ‘Having our own research protocols and principles to which outside researchers need to adhere is a good example of self-determination’ [20]. For Aboriginal and Torres Strait Islander communities to have their own research ethics protocols and principles could also be a good way of improving self-determination and ownership of research conducted in their communities.

### SIX NATIONS COUNCIL CONDUCTING RESEARCH AT SIX NATIONS

*Six Nations Council (2009) [24]*

Another example of a local First Nations council having a policy for ethical research is the Six Nations Council [24]. This is a council in Ontario which includes different communities, families and band groups from the Iroquis nations [25]. In this policy the Council acknowledges the importance of research and the benefits it can bring to the communities. It also emphasises that research only has benefits when it is conducted based on mutual respect, understanding and trust.

The policy states that the Council has the authority to accept and refuse research being conducted in their communities, depending on whether the research is based on ethical principles and it contributes to preserving the integrity of their Indigenous knowledge. It is the Council’s responsibility that the communities enjoy the benefits of the research and are protected against any harm from research. The Six Nations Council has an ethics committee that assesses whether proposed research is appropriate, based on the ethics committee terms of reference.

A set of principles for research within Six Nations territory is outlined:

- All research conducted in the area should have approval from the Ethics Committee in the form required by the Committee.
- Research should adhere to the Tri-Council policy statement and be based on good-practice and respect the integrity of Indigenous knowledge.
- Culture and members of Six Nations should be protected from harm and abuse.
- Where practical, Aboriginal researchers should be recruited and trained.
- Research has to respect community life, norms and customs.
- The well-being of participants should be respected, including their autonomy and confidentiality. These can only be breached when breaking this would hold no harm for the participants and the participants are fully aware of this.
- Participants have to provide free, prior and informed consent and furthermore it highlights the importance of written consent and how this should be obtained from participants prior to the research. Written consent doesn’t need to be provided when the researchers explain the reasons to the Ethics Committee, which could include that the research has a minimal risk to the subject, written consent is not practical, research does not involve therapeutic intervention. Subjects will receive information after the research is conducted.
- Research data should not be sold, transferred or reused without permission from the Ethics Committee.

The Six Nations Council has its own ethics committee to which researchers should apply for approval by sending in research proposals. Research can be terminated by the ethics committee when ethical principles are breached. The committee can bring out public announcements regarding the research going on in the Six Nations region, and release reports regarding research in the Six Nations region to keep the communities informed. Researchers should update the committee on the outcomes of the research upon completion, and when the project lasts for more than a year, researchers should provide the committee with an annual report. Before publishing the results the researchers should get approval from the committee where applicable, and make changes according to the concerns of the committee. Researchers have to provide the committee with copies of the outcomes.

### **Good practice?**

This is a very straight forward policy for research conducted in the Six Nations region. It is clear that research can only be conducted in the region once ethical approval is obtained from the ethics committee. Ethical research means that it is based on mutual respect, understanding and trust and preserving the integrity of Indigenous knowledge of the Six Nations' people. The council has its own ethical research policy and takes control over this which shows the importance to them that research is conducted in an ethical fashion, and reflects ownership, responsibility and self-determination [20].

### **MI'KMAW RESEARCH PRINCIPLES AND PROTOCOLS**

*Mi'kmaw Ethics Watch (2000) [26]*

The Mi'kmaw ethics committee concerning Mi'kmaq people was established by the Sante' Mawio'mi (Grand Council) in 1999. This committee researched issues related to research with Indigenous peoples and established its research principles and protocols based on the outcomes of this. The protocols and principles were disseminated to the different Mi'kmaq communities for review.

Principles described in the document firstly consider cultural knowledge. Mi'kmaq people are guardians and interpreters of cultural knowledge. Cultural knowledge is connected to land and tradition and is collectively owned, discovered, used, taught and guarded. Community have their own control over their knowledge and knowledge can have traditional owners. Research inquiring into this knowledge has to be approved by the Mi'kmaw Ethics Watch and belongs by Mi'kmaq people and must be returned to them. The Sante' Mawio'mi has authority over the research and how the Watch is composed. The Watch has control over all research processes and should conduct fair and timely review of research going on in the Mi'kmaq communities.

The next section of the documents considers the obligation researchers have when conducting research that will enter the public domain, in Mi'kmaq communities and protocols for research in these communities. Everybody involved should be treated equally, Mi'kmaq people should not be treated as mere participants or informants, and there should be an attempt to impart new skills into the community. There should be respect for local culture and for the highest research standards. Researchers should educate themselves on local culture and research protocols and should provide the local community with a detailed description of the research process in their own language, including details on how the research is funded and who is involved (and their qualifications). Consent and information should be provided in their own language and be both oral and written.

Mi'kmaq people should not be forced to participate. They have the right to decline or withdraw from the research at any time, without consequences. When participants are younger than fourteen, consent should be obtained from their parents or guardians. Participants should be informed on their anonymity and confidentiality in the research and the consequences when this cannot be assured. Information should be provided on the possible risks and benefits from participating in the research. Participants should be informed about each research step along

the way and on the distribution of the results. Mi'kmaq participants should be included in the interpretation and conclusions based on the results, to ensure accuracy and sensitivity. To empower Indigenous voice and skills, researchers should consider a variety of research processes.

The following section describes the obligations for the Mi'kmaq Ethics Watch: the Watch will consist of local community representatives that are chosen by the community. The community decides on the level of authority and the representatives should work collaboratively. The Watch operates on the basis of the self-determination of every community and should consider the risks and benefits that the research entails for the community and the rights of both the individual and the collective. The Ethics Watch should consider intellectual property rights and nothing can be distributed or used without the permission of the Watch.

No genetic information shall be collected from Mi'kmaq people unless it benefits them. The Watch will educate communities and individuals on research and issues, concerns, benefits and risks related to it. The Watch will consider disciplinary actions against researchers that do not comply with the guidelines and protocols. Context of the research will be considered and power and control related to the research. The Watch will encourage researchers to consult with Mi'kmaq people about the results and interpretation of these results.

### **Good practice?**

Just as with the other First Nations Council protocols, this Mi'kmaq protocol is a good way for the Mi'kmaq people to have control over the research, to show self-determination and protect its own people from harm that can be caused by unethical research [20]. An important point of the protocols are the focus on skills development in the community when research is conducted, and the focus of empowerment through considering different research methods, other than quantitative methods. The observation that consent and information should be provided in both English and Mi'kmaq (and in both written and oral form) is an important one.

### **Example of good practice**

A good practice example of research conducted in the Mi'kmaq communities was a study to increasing the understandings of the gaps, barriers and successes/solutions in mental health services in Mi'kmaq communities [27]. The study was initiated by the local health directors in the thirteen Mi'kmaq communities, who invited researchers to undertake study in their communities. Approval was obtained from the thirteen community chiefs, the university ethics board and the Mi'kmaq Ethics Watch. The health directors recruited participants, the researchers conducted the data collection and analysis and discussed this with the health director during the analysis. One of the health directors is the co-author of the paper. The study gave useful insights in the gaps and barriers to success in mental health services in Mi'kmaq communities.

### **AKWESASNE GOOD MIND RESEARCH PROTOCOL**

*Akwesasne Research Advisory Committee (1996) [28]*

Akwesasne community is located in an area where a lot of environmental research is conducted. This research often overlapped and did not benefit the community. To deal with this problem the Research Advisory Commission was established in 1994, as part of the Akwesasne Task Force on the Environment. The task of this commission is to develop and review proposals which affect the people of Akwesasne and to ensure that the proposed research benefits the people.

The commission developed a set of guidelines and protocols for the research conducted in the Akwesasne region. The main aims in developing these guidelines were to establish what good research at Akwesasne would be, and to

develop a philosophy and ethics of community based research which are community specific. The primary aim of the protocol is to ensure the development of good relationships between researchers and the community. The goal is sharing of respect, equity and empowerment.

The review process conducted by the ethics commission should be seen as a guide to promote collaboration built on mutual trust and co-operation. Scientists should recognise the importance of community empowerment, control of the research process and ownership of data and information. The commission ensures that research benefits the community and that burden and benefits are equally shared among the community and the researchers: Akwesasne people should be provided an opportunity to be involved in the research and decision-making, and be empowered through training and education. Proposed research should protect environmental, natural and cultural resources.

The three main principles on which the Akwesasne Good Mind Research protocol is built are:

- Skennen (peace) – which is the active striving of humans for the purpose of establishing universal justice, unifying people on the path of righteousness.
- Kariwio (good mind) – while working towards peace, a good mind develops. A good mind means a good way of thinking, people using their purest and most unselfish mind.
- Kasastensera (strength) – when working for peace and a good mind, strength is developed. Strength flows from the power of the good mind to use rational thinking and persuasion to channel the inherent goodwill of humans to work towards peace, justice and unity.

From these principles, behaviours that flow are:

- **Respect** – both parties should have an understanding of each other's social, political and cultural structures. Communications must work both ways to create a good research agreement.
- **Empowerment** – Sharing of power, which is the result of a good research agreement created by both parties. Each party feels their needs are being met and their credibility increases. Authorship must be shared between both parties.
- **Equity** – Sharing of resources. Finance, money, cultural knowledge, networks, personnel and political/social power and other commodities need to be shared. Equity needs to be reviewed constantly throughout the whole process of research.

**A Good research agreement:** promotes collaboration based on trust and co-operation. It will result in sharing resources, power and mutual understanding. It will ensure research that is culturally sensitive, relevant and beneficial to the participants and community.

The protocol describes what researchers should include in their application for ethics approval from the commission. It ensures that the researchers seek permission and collaboration from the Ethics Committee as early as possible in the research. Things that need to be included in the application are: statement of the problem; intent/benefit to Akwesasne people; method; confidentiality; disposition of the data; risks; funding/budget; cultural sensitivity training; empowerment; intellectual property rights and review of product or research results; data ownership/archive.

The commission has the right to withdraw approval for a project, deny researchers the right to conduct research in Akwesasne community and withdraw consent to use or release information and/or prevent publications of data.

**Good Practice?**

The people of Akwesasne took control of research-caused problems in their community by establishing a Research Advisory Committee and developing protocols related to research. This way the people of Akwesasne took ownership of the research that happened in their community and could protect the environment, the people and the culture against researchers marching in and out. They took control in their own hands and created their own guidelines to which researchers have to adhere.

An important point in these guidelines is the mutual obligation that both the researcher and the community have. Many guidelines only focus on the obligations the researchers have, but communities have certain obligations as well. Both researchers and communities should share their commodities equally among each other when they're in a partnership based on a good research agreement. Both parties should be considering the other's background, instead of just the researcher considering the community's background. Finally in the definition of empowerment, there should be sharing of power and both parties should have equal say in research and decision-making.

### **Example of research in Akwesasne**

A study was conducted on the health effects of toxicants exposure of young adults in the region [29]. Indigenous people are more prone to the adverse health effects of toxicants in the environment due to their cultural practices, in which the land has an important meaning. Toxicant exposure therefore does not just have adverse effects on health, but also on cultural identity. The following study was conducted in close partnership with the local community, which is an example for how the guidelines are used in practice. The partnership started during another study and this study was able to build on that partnership and relationships that were already built. There were sponsors that would support projects in the Akwesasne community.

A meeting was organised between the researchers and the community to discuss what projects could be run in the community. There were three driving forces: what kind of projects the sponsors want to support, what the community wanted and needed and the expertise of the researchers. They found a project that fitted all of these needs. Getting to know each other was important and cultural sensitivity training was attended by the researchers, who also attended community events. The researchers showed understanding towards the long decision-making process in the local community. This consensus was important to identify appropriate research questions, methodologies, evaluation strategies and to select effective means for dissemination and education.

The project trained local community members as part of the project. These local members were trained in skills related to the project such as different data collection methods. Having the local community members actively involved in the research was important to the development of the measurements, because they gave unique insights based on their local knowledge. The local knowledge was also essential in recruiting participants, which was reflected by the recruitment rate of 65% (which is high for studies with hard-to-reach populations). Local expertise was used for the development of the effective community outreach and education programs. There was a local community member who had experience with a similar project in the community and he became director of the program, which was developed based on his local knowledge. Local partners were also made co-authors on the papers.

### **GUIDELINES FOR ETHICAL ABORIGINAL RESEARCH**

*Aboriginal Health Research Review Committee (Manitoulin area; 2003) [30]*

This manual helps to assist in identifying research that is useful and empowering to the local Aboriginal community. The manual was developed as a response to the feeling that Aboriginal communities were 'researched to death' without receiving any benefits from the research. By developing a vision and ethical research guidelines

for health research conducted in the Manitoulin District, to which researchers must adhere, good ethical research can be conducted.

The vision described in this document states that all the research should be owned by local First Nations communities and organisations and should add to local decision making and development of local health programs. Research should never harm the community. It should adhere to relevant guidelines and the local community's mission. Community empowerment through research can be established through:

- Research designed to directly benefit the community.
- Respect the diversity between and within communities.
- Produce documents which are useful for communities and agencies.
- Respect that the collected data is owned by local communities and agencies.
- Respect traditional Aboriginal knowledge and culture.
- Build local capacity for research.
- Research topic should fit into a local strategic plan for research and/or be directly relevant to local communities.

The Aboriginal ethical research guidelines are based on the seven grandfather teachings of:

- Respect – for the diversity in spirituality, beliefs and values. Look at health in a holistic way: participants should know the outcomes of the study; be clear on what happens with the data; spend time with participants; ensure mutual understanding; appropriate approaches; not rushing; and respecting participant's individuality. Do not ask intrusive questions. Approach the project holistically, because humans are interconnected with the environment and animals.
- Wisdom – Appreciate silence, appreciate wisdom of Elders and children, appreciate someone's humor.
- Love – Have kindness in research, have vision and think ahead, sharing and generosity: benefit to the community, benefit to future generations, is it what ancestors wanted, does it reflect love for future generations and caring about their survival.
- Honesty – A trust basis must be developed in the research with the community and individuals, researchers should visit the community often to establish this. There should be honesty in the relationship between the research team and the community members, individuals should feel (and be) part of the team and their contributions should be acknowledged.
- Bravery – It takes courage to participate in and conduct research. When you participate in research you reveal aspects of your life and it takes courage to stand by this and be part of change.
- Humility – Get rid of preconceived expectations, do not be intrusive with questions, ensure that it is the right time to conduct the interview, acknowledge the contribution of the participant and remember that participants are **helping** the researcher.
- Truth – Responses are given in the hope of benefitting everybody, therefore the truth comes out. The truth translates into action and benefit from research without causing harm.

The document also includes the Tri-Council Policy Statement ethical guidelines and emphasises that researchers also still need to adhere to these national guidelines.

Furthermore, the reviewing process is described and consists of two steps: ethical review and research review. The ethical review looks at whether the research is ethical, based on different guidelines. When this is passed, the research review is undertaken. This review looks at whether the proposed research fits in with the community's research agenda and priorities and whether it ensures that benefits are maximised for the community.

The document finishes with strategies for forming a community-based research steering committee. Some communities might already have policies in place for this, but for the communities that don't have that, these guidelines give them some strategies to achieve this.

#### 4.2.4 ETHICAL TOOL KIT: BUILDING HONORABLE AND EQUITABLE RELATIONSHIPS

An ethical tool kit is developed as a guideline in developing partnerships and relationships for social and health services in First Nations, Inuit or Metis communities [31, 32]. It provides guidelines for the design of local ethical frameworks based on local culture, moral and ethical values. This tool kit is especially developed for the development of relationship in the development of an intervention. It 'serves as a safety measure, respecting the integrity and needs of the community/organisation and holding government agencies and outside funders to accountability standards throughout the period of the evaluation'.

The tool kit starts with a framework for the development of a programs and services ethics committee (PSEC) in the community or organisation that will be involved in the intervention. PSECs have to make sure the intervention development, implementation and evaluation is conducted in an ethical way and herein are protecting the interest of the community. A list of people that should be on a PSEC is provided as are examples of PSECs. Additional questions are stated to assist in creating the PSEC. A list of goals of PSECs is provided and an example of a local PSEC mission statement is given.

The tool kit further describes how PSECs should create their own ethical guidelines and evaluate whether a proposed intervention of policy fits in with their local, cultural values, norms and ethics. Different issues related to funding practices are provided with some ideas of what kind of issues the PSEC can come across. This includes funding allocation, under-resourcing, and the timeframe related to funding, which sometimes does not align with the timeframe of the proposed intervention. It is described how PSECs can conduct assessments and develop recommendations and how to assess risk and determine levels of risk. This section provides example questions for the process of risk assessment. In addition, it provides 'guiding ethical questions' for different issues: programming, funding practices, client rights and workers. It finishes with a list of four recommendations that can be done after the assessment process is finished.

The document ends with internal and external factors for success, which are: collective support, political stability, leadership and champions, government readiness and co-operation, collaboration and reconciliation.

In addition to this document of the tool kit, there is a website (<https://ethicaltool.kit.ca/>) with very useful information and resources to guide social and health services, governments and researchers in the development of 'honorable and equitable relationships' [31]. This website contains the tool kit and an elaboration of its goals, development, purpose, benefits and references. In addition, it provides material for training PSEC members and for training the trainer including powerpoints and also documentaries: '*Child welfare, the state as parent*' and '*Do you find this unethical, partner*'. These documentaries serve to better understand the challenges First Nations, Inuit and Metis communities and organisations face, with the goal of producing a collective voice from front-line workers about the reality of serving their people in the best ways possible.

#### 4.2.5 RECOMMENDATIONS BASED ON CANADA

In Canada the national guidelines for research involving First Nations people are embedded into the general ethics guidelines for health research. It describes how the three principles of ethical health research should be applied in a First Nations context. A couple of recommendations for the Australian guidelines can be made based on the *Tri-Council policy statement: ethical conduct for research involving humans*.

- The chapter about research involving First Nations, Metis and Inuit starts off with some definitions of central concepts in Aboriginal research, including community and Indigenous. The Australian guidelines do not have these types of definitions. A definition for community might be especially important, because this word is used a lot when talking about Aboriginal and Torres Strait Islander research. Community is defined as ‘a collectivity with shared identity or interests that has the capacity to act or express itself as a collective’. The boundaries of communities are fluid, organisations are communities as well and an individual is part of mutual communities.
- Just as in the Australian guidelines, these guidelines emphasise the importance of community engagement. However, in their description they are a bit more elaborate. The Canadian guidelines acknowledge that not every type of research requires community engagement and provides a list of requirements when research involving First Nations, Metis and Inuit people requires community engagement. To make it even clearer the guidelines also provide a list of examples of when and how community engagement was and was not used. It is recommended that the Australian guidelines also make this distinction and provide practical examples of how and when community engagement is needed.
- The Canadian guidelines stress the variation in different First Nations, Metis and Inuit communities. It describes how different communities have different local cultural and religious beliefs with which the researchers have to become familiar. The differences also imply that there can be no set of rules for community engagement that applies to all the communities. Australian guidelines should also acknowledge the variation in Aboriginal and Torres Strait Islander cultures and emphasise that there is no one-size-fits-all approach, but that researchers should invest time in familiarising themselves with the local belief systems.
- The Canadian guidelines acknowledge the OCAP ethical principles, which are used by many local communities in applying self-determination to research. It states that researchers should take the OCAP guidelines into account. These OCAP guidelines should influence Australian Aboriginal and Torres Strait Islander research ethics as well.
- In addition to acknowledging the variety of Aboriginal communities and the importance of OCAP, the guidelines also focus on how many Tribal and community councils have their own policies, protocols and guidelines regarding research conducted in their communities. The national guidelines state that researchers should adhere to these local policies as well, in addition to the national guidelines. The national guidelines of Australia should also acknowledge that these kind of local protocols exist.

In addition to these national guidelines, many local councils, communities and organisations have created their own research guidelines based on OCAP, to which researchers who want to conduct research in their community should adhere. Councils also take their right to control research in their communities by having the authority to refuse, interrupt or stop research that is undertaken in their communities, when it is not in line with the local protocol, culture or religious beliefs.

- Having their own guidelines and protocols and taking their right to refuse, interrupt or stop research in their communities, Canadian Aboriginal communities enjoy real self-determination in the research. They take control and ownership over the research that is conducted in their communities. It is recommended for Australia, where communities are as diverse as in Canada, that local community councils take their right for self-determination into their own hands and to establish similar protocols and guidelines.
- An ethical tool kit is developed to assist Canadian Aboriginal communities in developing such guidelines [31]. A similar tool kit could be developed for Australian Aboriginal and Torres Strait Islander communities.
- The Mi'kmaw Research Protocols and Principles highlight the importance of skills development in the community and community empowerment [26]. It states that this should especially be done through

adopting other research methods besides quantitative methods, such as qualitative and participatory methods. This could be included in the *National Statement* in Australia as well.

- The Mi'kmaw Protocols also emphasise that consent forms and information disseminated to the community should be written in both English and Mi'kmaq [26]. Writing this information in the local language, or in such a way that all the community members who are involved will understand, is important. It is therefore recommended that the Australian guidelines focus on this as well.
- Just as the *Nga Ara Tohutohu Rangahau Maori* [17], Scnarch, in the paper on OCAP, also mentioned that some individuals might not have the right skills to conduct research which involves Indigenous people. And that some people 'don't get it' [20]. This is an interesting notion and might be worth looking into for Australian research involving Aboriginal and Torres Strait Islander peoples.

## 4.3 AMERICAN INDIAN GUIDELINES

American Indian people are the First Nations people of North America. They have numerous distinct tribal groups and hold sovereignty and treaty rights over some of their land. They are a distinct minority in their land, comprising less than one per cent of the population of the USA, but have made important steps in creating diverse Indian organisations and tribal councils to represent their people's aspirations.

### 4.3.1 GUIDELINES FOR RESEARCHERS

The American national principles that govern research practices are from *The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research* [33]. Similar to the Australian *National Statement*, the three principles that researchers must address in their ethics applications are: Respect for People, Beneficence and Justice. However, the American First Nations Peoples have similarly found that they needed further guidelines to encourage culturally appropriate research methods to be undertaken in their communities. However, less new work has been released within the last ten years and within the scope of this literature review. There are recommendations to refer communities to the ethics guidelines produced by Canada, and for communities to set their own standards for acceptable research practices based on this body of work. There does not appear to be a national framework or guidelines for ethical research with American First Nations people that exists in the other countries that are covered in this review. However, there has been more localized work produced which contains similar content toward having ethical standards in place.

The Northern Plains Tribal Epidemiology Center (NPTEC) has published *Guidelines for Researchers* [34]. These guidelines have been developed for use by researchers who submit research applications to the Aberdeen Area Tribal Chairmen's Health Board (IHS). The Aberdeen Area Indian Health Service reviews all research activities in Iowa, North Dakota and South Dakota. NPTEC and IHS teams have significant health research experience within American Indian and Alaskan Native (AI/AN) communities.

The NPTEC Guidelines highlights the following considerations in two strands: Researcher Sensitivity and Researcher Responsibility.

#### **Research in AI/AN Communities Researcher Sensitivity:**

- Ensure understanding and good communication.
- Respect tribal culture and traditions.
- Respect tribal sovereignty and self-determination.
- Respect concerns and opinions of community.
- Respect local research priorities and needs.

- Respect individuals, families, and communities.
- Respect human participants' rights and dignity.
- Exclude over-studied populations from participation.
- Demystify research.
- Be accessible.
- Provide feedback and findings in a timely manner.
- Respect a tribe's right to decline participation.
- Respect the autonomy and decisions of the tribe.

Researchers must be sensitive to the local culture, traditions, research priorities, and lifestyle of AI/AN communities. Furthermore, researchers must be responsible and accountable to the tribal government where the research is being conducted, as tribes are sovereign nations.

#### **Research in AI/AN Communities Researcher Responsibility:**

- Communicate and coordinate with tribal leaders.
- Negotiate tribal and community consent to participate.
- Maximize benefits and minimize risks.
- Protect human participants and sensitive data.
- Comply with informed consent process.
- Obtain service unit director, tribal, IHS research committee and IRB approval.
- Do not begin research until all approvals are obtained.
- Share results of the research with the tribes.
- Protect participant and tribal identity.
- Build capacity within the community.
- Comply with the agreed-upon protocol specifications.
- Comply with tribal and IHS publication clearance.

#### **Good Practice?**

The strength of this document comes from its comprehensive supporting appendixes: this includes a guide to developing a protocol checklist for ethical projects, tips to build procedures and methods, and a variety of sample submission. Also attached are sample submissions to inform researchers about the most effective way to prepare their applications for ethics clearance.

#### **4.3.2 KAHNAWAKE SCHOOLS DIABETES PREVENTION PROJECT CODE OF RESEARCH ETHICS (REVISED 2007)**

This report, which was updated in 2007, has been published by the Kahnawake Schools Diabetes Prevention Project (KSDPP) [35]. Its key principles have been separated into the following sub-headings: Principles, Obligations of the Partners, Obligations of Community Researchers, Obligations of Academic Researchers, the Rights of the Community and Participants, the Collective Rights of the Community, and the Rights of Participants, which have been listed below:

##### **Principles**

- The Kanien'kehá:ka and the philosophy of the Kanien'kehá:ka must be respected.
- The academic researchers and the professional responsibilities of the academic researchers must be respected.
- The research must respect and include Indigenous methodologies, incorporating the strengths, knowledge, experiences, and culture of the community.

- The community is an equal partner in all aspects of the research. Continuous consultation and collaboration must characterize the partnership.
- The research must be relevant and beneficial to the community.
- The research must provide opportunities for the involvement of community researchers and utilise community resources.
- Meaningful community capacity-building must be incorporated into all aspects of the research process.
- All research must undergo the Review and Approval Process for Ethically Responsible Research.
- Ethical approval must be granted from all partners before research begins.
- Active, free and informed consent must be obtained from all participants.
- Research must ensure confidentiality and anonymity of individuals, organizations, and communities unless these parties choose to be named when the results are reported.
- Research analyses, interpretations and results must be presented to and discussed by all partners to ensure accuracy and avoid misunderstanding.
- Reports and summaries must be returned in a language and format that is comprehensible to the community.
- Research results must be presented to the community before being disseminated in the public domain.
- All partners must be involved in making decisions about the publication and dissemination of the research.
- A partner has the right to dissent concerning the interpretation of the research results. A differing interpretation of the results must be fully explained and agreed upon through the consensual decision making process.
- The community retains ownership, control, access and possession of all data collected (as guardian of the data, the community must continue to ensure confidentiality and anonymity of individuals, organizations, and communities).
- Academic researchers must keep a copy of data to meet their institutional responsibilities. (All future use of this data must comply with all the above- mentioned principles).

### **Obligations of the Partners**

- To ensure Kanien'kehá:ka culture and values are embodied in the research process, while maintaining the scientific integrity of the research.
- To represent the interests of the community and to be an ambassador of wellness by promoting the objectives of daily physical activity, healthy eating habits and positive attitudes to the community.
- To provide ongoing recommendations, to inform the planning, implementation, and evaluation of intervention activities.
- To collaborate with researchers to provide ongoing recommendations concerning the research.
- To be involved in knowledge translation with other communities and organizations at the local, national and international levels.
- To be in possession and to safeguard the data after the completion of the research components of the KSDPP.
- To be involved in the Review and Approval Process for Ethically Responsible Research Obligations of Community Researchers
- To maintain the integrity of the partnership and a relationship of trust, the well-being of the community is always the first priority in any decision about research.
- To work with researchers to ensure mutual understanding of the strengths, knowledge, experiences and culture of the community.
- To facilitate exchanges between researchers and the community to ensure the integrity of the project.
- To promote the vision of KSDPP within the community, as well as nationally and internationally.

### **Obligations of Community Researchers**

- To maintain the integrity of the partnership and a relationship of trust, the well-being of the community is always the first priority in any decision about research.
- To work with researchers to ensure mutual understanding of the strengths, knowledge, experiences and culture of the community.
- To facilitate exchanges between researchers and the community to ensure the integrity of the project.
- To promote the vision of KSDPP within the community, as well as nationally and internationally.

### **Obligations of Academic Researchers**

- To develop cultural awareness of the community.
- To do no harm to the community.
- To collaborate with the community in the research design, implementation, data collection, data analysis, interpretation and the dissemination of results.
- To ensure that the research is relevant and beneficial to the community and in agreement with the standards of competent research.
- To promote creation and dissemination of knowledge through written publications, and oral presentations. This includes the documentation of the undertaking of the project, and of the results.
- To ensure that the community has opportunities to participate in all aspects of the research.
- To enhance community capacity by providing community members ongoing opportunities for active participation in the research.
- To train and mentor aboriginal and non-aboriginal students with preference to aboriginal students.
- To ensure that the research undergoes the Review and Approval Process for Ethically Responsible Research.
- To respond to community requests for information after the research project ends.

### **The Rights of the Community and Participants**

Research must respect the rights and dignity of the community and the people involved in the research.

#### **The Collective Rights of the Community**

- To know why the research is being carried out.
- To know the objectives, methods and potential results of the research.
- To know how the research will benefit the community.
- To know if and how the research could potentially harm the community.
- To be involved in the Review and Approval Process for Ethically Responsible Research.
- To be given the opportunity to be involved in all aspects of the research process.
- To know that the research will respect the KSDPP Code of Research Ethics.

#### **The Rights of Participants**

- To ask the researcher questions about the research at any time.
- To contact the selected KSDPP ombudsperson if they have any concerns about a research project.
- To know that participation in the research is voluntary.
- To know that they can refuse to participate in the research and still be entitled to benefit from KSDPP and KSDPP related activities.
- To know that they can withdraw from participating in the research at any time and still be entitled to benefit from KSDPP and KSDPP related activities.

### **Good Practice?**

The strength of these guidelines comes from the way that it has been set out, firstly to describe the principles to which the researcher must adhere to, and then the list of obligations that each stakeholder needs to respect during the process of undertaking or participating in research in AI/AN communities. It acknowledges that there are both academic and community researchers, and spells out the obligations of project partners which is not a clear theme in *Values and Ethics*. By holding projectpartners/ funders as well as researchers accountable for ethical research, it sends a message that there is a shared obligation for both to ensure that ethical processes are followed.

## 5. CASE STUDIES: POSITIVE EXAMPLES CONCERNING ETHICAL RESEARCH WITH ABORIGINAL AND TORRES STRAIT ISLANDERS IN AUSTRALIA.

A literature study was conducted on how the ethical guidelines described in *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* and *Keeping Research on Track: a guide for Aboriginal and Torres Strait Islander peoples about health research ethics*. This literature research aimed to find published peer-reviewed papers that explicitly mentioned the use of and/or adherence to the ethical guidelines. Accordingly, a database search was conducted in Scopus using the following search string: TITLE-ABS-KEY ('*Values and Ethics* ' ) OR ('*Keeping Research on Track* ') AND (Aboriginal OR 'Torres Strait' OR Indigenous) AND Australia. This search resulted in 28 hits.

Results were consequently scanned on whether the publication described new research. All publications that were discussion papers were excluded. Only papers that were published after 2003 were included, because *Values and Ethics* was published this year. This resulted in nine papers which were found eligible. An additional strategy was browsing the 'research ethics' section on the Australian Indigenous HealthInfoNet website. This section provides an overview of guidelines and organisations on Aboriginal and Torres Strait Islander research ethics and it also has a list of publications addressing ethics related to Aboriginal and Torres Strait Islander research<sup>4</sup>.

The same selection process was used as for the Scopus papers. Five papers were found eligible, however, four of them had already been identified through the Scopus search, therefore only one additional paper was found in the HealthInfoNet database. One additional paper was obtained after a tip from an expert in the field who attended one of the consultations. Two other papers were identified from a reference list of another publication. A total of thirteen papers describing the application of ethical guidelines in their research were identified and are described below. For every publication it is described what the aim for their research was and how they addressed each of the six central values of *Values and Ethics*. The results are described in the following table:

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<sup>4</sup> <http://www.healthinfonet.ecu.edu.au/health-infrastructure/ethics/publications/specific-topics/research-ethics>

<b>Author and year</b>	<b>Aim of research</b>	<b>Reciprocity</b> <i>Demonstrate return (benefit) to the community that is valued by the community, equitable distribution of resources.</i>	<b>Respect</b> <i>Trust, openness and engagement. Respecting other's values and the diversity. Acknowledge contribution of everybody.</i>	<b>Equality</b> <i>Acknowledge equal value of people, their knowledge and skills. Fair distribution of burden and benefits.</i>	<b>Responsibility</b> <i>No harm, protection of participants, maintenance of trust and transparency.</i>	<b>Survival and protection</b> <i>Protection of culture, value and identity from erosion, marginalisation.</i>	<b>Spirit and integrity</b> <i>Respecting the continuing and coherent culture of Aboriginal people.</i>
Hing, Breen and Gordon (2010) [36]	Undertaking a household survey on gambling in Aboriginal communities in Queensland. Extensive consultation was conducted (150 one-on-one face-to-face meetings); local research assistants were trained and conducted the survey. Community events were organized around the survey, community donations were made, follow-up activities were organised.	Research was conducted on an acknowledged public health problem in the community (gambling) and raised awareness for this problem and provided education and health promotion. Questionnaire was modified after consultation with the community, questions were deleted and added to make it sensitive to the community's needs. A donation was made to the community, research data is owned by the local health organisation and could be used to lobby for funding, local research assistants were employed.	There was continuing consultation with the community to ensure all processes were appropriate, flexibility was required. Community owns the research data, in the way that the researchers have to get permission from the Mayor if they want to publish anything.	Equality came forward through the consultation and the local wisdom was valued as much as the researcher's knowledge and their advice was followed in many aspects of the research, such as adapting survey question, logos for the awareness week, prizes for winners at the art competition and working out what kind of health promotion material would be most suited. The benefits of the research streamed back into the community by creating employment, donating money and developing health promotion and educational material.	Harm was reduced by ensuring anonymity and confidentiality of the survey participants. Special safety procedures had been installed for the research assistance (e.g. carrying walkie-talkies and training in handling stressful situations). Trust was built and maintained through extensive consultations with community members and ongoing explanation by the researchers of what they were doing and why. Communication was maintained in between community visits.	Researchers went through extensive length to get to know the community. They visited often and were involved in a range of community activities. This helped in understanding the community and their priorities. Understanding the background of the community was important in understanding the role of gambling and getting to know the structure of the community in terms of families was essential for tailoring the survey in a sensitive manner. Eg. the majority of the community is from the Stolen Generation, therefore questions about dependent children might bring up fears about removals and might mean that people do not want to answer or may provide socially desirable answers.	Consultations improved decision-making based on the values of the community and therein maintaining the spirit and integrity throughout the research. This improved the design implementation and interpretation of the research results.
Mooney-Somers and Maher (2009) [37]	The Indigenous Resiliency project aims to develop and conduct research on what protects young Aboriginal	Young people and health service staff are trained in research methods through workshops in which they	Interview schedules and other materials were developed in the workshops attended by the peer researchers and the	The local knowledge and skills that the ground researchers had was seen as just as valuable	The local researchers were also trained in how to talk about the sensitive issues that	Culture was maintained by using local methods and knowledge in developing the materials	Family connections were discussed in the interviews, acknowledging the

	and Torres Strait Islander youth against blood-borne viruses and sexually transmissible infections, through bringing university-based researchers, health services and young Aboriginal people together. It aims to build research capacity, assess the STI and BBV resilience in Aboriginal youth and decrease risk for STI and BBV. The project took place in three locations (Townsville, Redfern and Perth) and is unique at each location so as to be appropriate to the local priorities and issues.	also designed the interview schedules. These local researchers conducted the data collection, analysis and dissemination. Each workshop was tailored to the relevant priorities of the local population. Through this, research skills were developed in the community, young people gained jobs and were invited to sit on boards and advisory committees. Community belonging grows by being active in community organisations. Improvements in self-esteem and confidence. The local health service was promoted through the interviews conducted by staff and young people wearing a badge from the service. New partnerships between the health service and other organisations developed through this project.	health service staff. This ensured that it was based on local knowledge, methods and values. The value and contribution of the ground researchers is highly valued and acknowledged. Shared ownership of the research outcomes was ensured through an Australian Steering Committee, made up of two representatives from the three locations and research partner and independent Aboriginal researchers.	as the research knowledge that the university based researchers had.	were the topic of this research (BBV and STI). Transparency and trust was built and maintained through developing all the material involved in this research in the training workshop.	used in the research. In the interviews cultural sensitivity was ensured through starting the interview by talking about where the interviewee and his/her family are from, this way the researcher and the participants can get to know each other.	importance of this. Local methods and knowledge were used to develop researcher materials. The Australian Steering Committee ensured oversees and advices on cultural matters.
Kingsley, Phillips, Townsend and Henderson-Wilson (2010) [38]	Healthy Country, Healthy People project. Improving understanding of the connection between Country and health of Victorian Aboriginal People.	Aboriginal people were allowed an opportunity to assist in the project, for example through co-authoring academic journal articles. Results were made available to all participants and the project resulted in the creation of books and a DVD describing the importance of Country to Victorian Aboriginal people, which can guide future researchers in this area.	Qualitative methods were chosen to improve involvement of Aboriginal people in the research and allow for building of stronger relationships. Co-authorship of Aboriginal community members on academic papers.	Mutual understandings were created through involvement of different Aboriginal parties, including Elders, communities, policy makers and park rangers.	Feedback was given continuously to the community. Participants were protecting by removing all identifying information from interviews, and they had the chance to read the verbatim transcription of their interview. The results (in form of a thesis) were made available to all participants.	A reference group was established during the start of the design phase of the study and approval was requested from Elders and Traditional Custodians.	Community approval was sought for everything that was going to be written about them.
Couzos, Lea, Murray and	NACCHO Ear Trial. Randomised controlled trial	The trial was initiated and controlled by Aboriginal	Research agreements were established with James Cook	Research agreements between NACCHO and	Research priority and research questions		Outcomes of the trial were measured in line

Culbong (2005) [39]	for treatment of chronic suppurative otitis media. Comparing the standard treatment to a new treatment. Measured biomedical outcomes, but also school outcomes and quality of life. Trial was run by NACCHO.	organisations. Eight local ACCHOs were involved in the research, local Aboriginal Health Workers were trained to follow the trial protocol, made possible thanks to extra funding that was sought for this purpose. Benefits of the trial were direct (due to using normal treatment instead of a placebo and raising awareness for treatment during the trial) and delayed by improving service and treatment delivery). Services were improved through workforce support, equipment provided during the trial, health worker training and local partnerships between public health nurses, school and other community structure and creating lasting relationships between research bodies. Benefits from the research lasted due to building on existing infrastructures and workforce. Some ACCHOs extended their ear health services by introducing mobile services.	University, including the financial administration of the project at the university - control over the trial and research processes stayed with NACCHO. Research was built on existing relationships between NACCHO and local ACCHOs. There was no risk to the participants, because they receive treatment as usual. Consent forms were written in plain English and AHWs were trained to explain the forms using visual flipcharts.	local ACCHOs.	were discussed and approved in national NACCHO workshops of Aboriginal community representatives. Community was made aware of the project through pamphlets. Leadership was at local ACCHOs, personnel were committed to the outcomes of the trial and there was a lot of continuing communication between ACCHOs and NACCHO.		with Aboriginal holistic view of health and included not only biomedical outcomes, but also school outcomes and quality of life. The planning of the project lasted three years due to the collaborative nature.
Cusack, de Crespigny and Wilson (2013) [40]	Understanding the experience of Aboriginal people living in north-west suburbs of Adelaide with over the counter (OTC) analgesics. Learning about their understanding, selection and experience of barriers in accessing useful information.	Participants were given an easy to read information sheet with pictures and a brief education session about OTC analgesics. A subsequent safe medication information session was given in return.	Verbal consent was given.	A local Elder worked with the research team and offered guidance and community consultation and liaison. He was further involved in recruiting participants, data collection, analysis, interpretation and participant feedback,	Confidentiality was maintained through not taping the interviews. Results were discussed with the Elder, providing a reflective analysis. After the first round of analysis, this was verbally presented to the community and	Research was conducted in collaboration with Aboriginal Health Council of South Australia. Consent was given verbally. Interviews were not taped. Participatory action research was used and qualitative data collection was done	A local Elder worked with the team and offered cultural advice. The Elder ran the focus groups.

				reflection on the findings and formulating the report and recommendations.	their feedback was sought. Feedback was used in further analysis and this was again presented to the community for feedback. Community also provided feedback for the report and the recommendations.	through focus groups and one-on-one interviews.	
Devitt, Cass, Cunningham, Preece, Anderson and Snelling (2008) [41]	Improving Access to Kidney Transplants (IMPAKT) Understanding the nature of barriers to kidney transplants for Aboriginal people. Assess impact of medical and socio-demographic status on the likelihood of being suitable for kidney transplant. Evaluate appropriateness, accessibility and effectiveness of education programs, identify systemic barriers to transplantation, examine the effect of current deceased-organ allocation algorithms upon Aboriginal patients' access to kidneys and to collaborate with service providers to improve their service provision.	Research team engaged with local ACCHOs, who provided feedback on the project, prior to and during the research. Research team adjusted their plans based on this feedback.	<p>Researcher had put in extra effort to develop information sheets and consent forms in plain English format that were site specific. Information consent forms included information about the interview, and sought permission to use the participants' words in publications. Permission was asked to record the interview.</p> <p>Interviews with Aboriginal people were constructed as a life story narrative, to make it appropriate, recognisable and engaging for Aboriginal patients. More sensitive questions were saved for when rapport was established.</p>	An Aboriginal health researcher was employed on the project, who systematically engaged with relevant Aboriginal and Torres Strait Islander communities.	Contact was sought with all local ACCHOs in writing to inform them about the study and invite them to give feedback on the proposed research. An introductory presentation was given to a group of nephrologist, hospital renal staff and ACCHO staff in which they could give feedback and ask questions about the research. ACCHOs were invited to develop a local reference group from which feedback was asked during the research. Participants were kept up-to-date about the research through a quarterly newsletter.	NACCHO provided a support letter for the project.	Aboriginal health researcher was included in the research team. In the consent form special attention was given to issues with keeping voices of the deceased, which is not appropriate in some Aboriginal cultures, therefore participants could indicate whether they wanted their interview recording to be destroyed afterwards.
Isaacs, Pepper, Pyett, Gruis, Waples-Crowe, Oakley-Browne (2011) [42].	Improve mental health services for Aboriginal men.	Conducting training on the basics of counseling for social and emotional wellbeing (SEWB) programs. Let participants read the findings to avoid misinterpretation. Acknowledging everyone's contribution in publications.	<p>Participants read the findings to avoid misinterpretations. Everyone's contribution is acknowledged in the publications.</p> <p>Researchers gradually built trust with the community by attending various events in the community (such as</p>	Partners were identified in the local communities and partnerships were formalised. ACCHO support was obtained. Formal support from cultural advisors was obtained.	Area of research was identified and confirmed through consultation with Koori community/Aboriginal experts in the field. Research was introduced in the community by a research promoter,	Familiarity with Aboriginal history and culture through attending community events, visiting museums, spending time with a community in South Australia and receiving training in cultural competence.	A cultural advisor was appointed in each of the three communities to guide the researcher in his research and help him establish contacts and trust with the communities.

			<p>NAIDOC celebrations and funerals) under the guidance of a cultural advisor.</p> <p>Participants were recruited in the study through snowball sampling.</p>		<p>with plenty of experience of such research.</p> <p>VACCHO provided the researcher with support from Aboriginal and non-Aboriginal supervisors.</p>		
Hing, Breen, Gordon and Russell (2013)[43]	Large sample of Aboriginal and Torres Strait people inquiring into gambling behavior and help-seeking behavior.	Local people were employed as research staff; they were trained in administering the survey, safety procedures etc. Data was collected at community events, at these events public education and promotional material on gambling was provided. Every survey contained an information card for the gambling helpline.	Research methodologies were developed during consultation and meetings with community leaders, Elders, study communities and Aboriginal organisations.	Employing local research personnel and developing methodologies in consultation with Aboriginal stakeholders.	Consultations to develop the survey were undertaken and methodologies developed in consultation with different Aboriginal stakeholders.	Prior to publishing the paper, consent was obtained from the community leaders and others involved. Questions were removed from standardised surveys when during the consultations it became clear that they were not appropriate.	
Knight, Comino, Harris and Jackson-Pulver (2009) [44]	Gudaga: An Eight year birth cohort study starting in 2005 to describe birth outcomes, health development and health services used by children and their mothers living in outer area of south-western Sydney.	Exchange between four different groups involved in the project. Aboriginal health organisations provided expertise and experience to the project and received feedback. Local Aboriginal health care professionals received capacity building and feedback from the project and provide local knowledge and expertise. The local Aboriginal community (including local mothers who were employed as project officers) had an opportunity for input, capacity building and training and provide expertise, wisdom, local knowledge and encouragement to the	Respect and trust was built with the local Aboriginal land council through previous collaborations. Trust was also built with other local organisations, which helped in providing the thank-you gifts for example. The holistic view on health of Aboriginal people was respected through having questions in the questionnaire being developed on the four dimensions of wellbeing (spiritual, cultural, emotional and social). Trust and openness was promoted by the employment of local Aboriginal mothers who conducted questionnaires.	<p>Local Aboriginal mothers with young children were employed to conduct the questionnaires every six months. They were selected because of their local knowledge.</p> <p>The local mothers and project officers identified the issues that were included in the research.</p> <p>Regular meetings with the local Aboriginal land councils were conducted to receive their feedback.</p> <p>The expertise and knowledge of the local Aboriginal Health Workers were sought.</p>	<p>At each contact point with the participating mothers the project officer ensured that there was a culturally safe environment.</p> <p>All participating mothers were given the contact details of the local health service's ethics committee and were informed about the researcher's contacts with the local Aboriginal Land council and they could contact these organisations if they had any concerns about the research.</p>	The name of the project (Gudaga) means healthy baby in the local Aboriginal language and was proposed by the local Aboriginal Health Workers. The logo for the project was designed by a local mother. The staff wore a shirt with this logo and the gifts given to the mothers and children had this logo as well.	The project respected the importance of family bonds in Aboriginal communities by asking questions about the family and other people supporting the mother and the baby. In cases where the grandmother took care of the baby, she would decide whether or not the baby should stay in the study.

		participants of the project. The participants received a thank-you health pack, photos of their child and a health and development assessment for their child at 1, 3 and 5 years.		Local expertise was valued as much as academic skills.			
Wise, Massi, Rose, Nacarrow, Conigrave, Bauman and Hearn (2012) [45]	SmokeCheck. To build the capacity of Aboriginal health workers (AHWs) and non-Aboriginal health workers who work with Aboriginal communities in NSW to deliver evidence-based best practice smoking cessation interventions. Development of culturally specific resources.	Aboriginal Health Workers received a one-day training workshop containing information about the impact of smoking on the health of Aboriginal Australians, including history, smoking rates, and health effects. Treatment and health promotional theories informing Smokecheck were also discussed.	The project was based on demands of AHWs and the need for training in communities that are usually too small or remote to receive training.  Meetings with communities were only undertaken on the terms of the community. The resources and flexibility of the project allowed for this.  Respect for Aboriginal culture was expressed by having the training especially focused on Aboriginal smoking and its effects.	The project was based on the input of the Aboriginal health workers.  The chief investigator of the project was an Aboriginal researcher, the rest of the team were both Aboriginal and non-Aboriginal, who all had experience with research in Aboriginal communities and services.	Feedback from participants was sought after workshops to ensure quality of the workshops.	The workshop was culturally specific by talking about the effects of smoking on Aboriginal people, using the 'stages of change' model to engage Aboriginal clients in conversation about where they are in their quitting attempt. The Aboriginal health workers were central in the approach and formulated questions to help their clients develop awareness of the effects of smoking.  The workshops were presented by Aboriginal and non-Aboriginal people who both had extended experience in this field.	Attention was given to the past, present and future burden of smoking on Aboriginal people.
Lehmann, Arumugaswamy, Slsbury, Finucane, Stokes, Monck, Jeffries-Stokes, McAullay, Coates and Stanley (2008) [46]	The goals of this project were to identify causal pathways of otitis media (OM) in Aboriginal communities, by investigating avoidable risk factors for Aboriginal and non-Aboriginal children in the Kalgoorlie-Boulder area of Western Australia.  Understanding how these risk factors arise and interact in the complex causal pathways in order to develop effective	The community was concerned about the negative impact of OM on the wellbeing and school performance of their community. One of the participating Aboriginal health services did not have ear, nose and throat treatment available so the project ENT specialist provided this service for free during the project.  The health service was supported in obtaining	Obtaining support from the community was a first priority and formal collaborations were established.  All stakeholders were involved in the planning process and were updated regularly during the project.  Researchers participated in local social activities to get to know the local community.	The co-ordinator of the local health service was listed as a chief investigator on the first grant application and other Aboriginal investigators were part of the project later on.  Aboriginal health workers and nurses were employed on the project as research assistants.  All contributions of Aboriginal and non-	Information about the study was disseminated through TV, radio, newspaper articles and face-to-face discussions. Community members, both Aboriginal and non-Aboriginal provided input in the design of the study, the content of information sheet, consent forms and questionnaires.  Manuscripts were	The investigators piloted the questionnaire and sampling of specimens on themselves to be able to explain what type of discomfort the children would experience.  The study was monitored by the board and members of the involved Aboriginal health services.  A full-time local research assistant was employed, the community had asked	To response to past research practice which had been damaging to the community, ethical research was emphasised in this study. The study was conducted to reduce present and future negative impact of OM on the community.

	intervention strategies.	<p>funding for an Ear Health Worker. Parents and children were offered transport to ENT clinics.</p> <p>AHWs and nurses were trained in research skills.</p> <p>Children were offered hearing screening during the assessment and this is still in place, even though the project is not running anymore.</p> <p>Consultations with local committees on the results of the projects were being undertaken during the writing of this publication and will work towards developing appropriate interventions.</p>		<p>Aboriginal investigators were acknowledged, and different investigators presented the findings at national and international conferences.</p> <p>They all had equal training opportunities.</p>	<p>submitted to the community for feedback before publication. Community was kept up-to-date through a newsletter.</p>	<p>this person to work on the project and she and the rest of the Aboriginal staff provided cultural security.</p>	
Weston, Brooks, Gladman, Senior, Denley, Silove, Whyman, Kickett, Bryant, Files and the Aboriginal Community Advisory Committee (2009) [47]	Community Safety Research Project (CRSP). Violence prevention in western NSW; promoting open and honest discussion about violence.	<p>The focus of the project was established through conversations between the chief investigator and the CEO of the Aboriginal Health Corporation. The CEO of the AHC consulted the community and determined the specific focus.</p> <p>Aboriginal collaborators were offered seminars about the importance of the research and implementation processes.</p> <p>Community workers were trained in psychological effects of trauma, grief and loss; research methods.</p>	<p>There was space for open and honest discussion with the community because their priority of addressing violence was appointed as a priority in the research.</p> <p>The Aboriginal CI on the project introduced the other non-Aboriginal CIs to the community.</p>	<p>The priority of the research was defined by the community and the community took the driving position in the development of the research project.</p> <p>Community had input, coordination and participation in every aspect of the research.</p> <p>Research processes are explained to local communities in seminars, informal gatherings and by door-knocking.</p>	<p>Results of an initial qualitative research were presented to the community through newsletters, feedback sessions and conference presentations. All results were de-identified.</p>	<p>Two committees were developed: Chief Investigator's Group and the Aboriginal Community Advisory Committee (ACAC). The latter consisted of local community members who ensured safety for participants by overseeing and advising on all aspects of the project. They also promoted the research among the community.</p>	<p>An Aboriginal Community Advisory Committee was implemented to ensure the cultural appropriateness of the project.</p>

<p>Kildea, Barclay, Wardaguga and Dawumal (2009) [48]</p>	<p>Creating an internet-based resource containing Aboriginal cultural knowledge regarding pregnancy and childbirth, for health professionals working with Aboriginal people. It records stories of Maningrida women in Arnhem Land.</p>	<p>Research objectives were based on the priorities of the communities and were flexible during the research when new priorities emerged.</p> <p>Local stories were saved for later generations.</p> <p>During data collection, the circumstances of the women were taken into account and the researchers would wait until the women's own priorities were met before data collection was conducted.</p> <p>A vehicle was hired by the project, which enabled the women to go hunting or collect materials for art and crafts.</p>	<p>The research topic was initially brought in by the main researcher, who had worked in the community for years and were later refined through discussions with community members, while research methodologies were also discussed.</p> <p>Formal agreements were made about intellectual property, ownership and acknowledgement on publications.</p> <p>Rapport and relationships were built through being involved in the hunting and art activities of the women.</p>	<p>Co-researchers were both retired senior Aboriginal health workers, they guided the research processes through the use of local knowledge.</p> <p>The participatory action research (PAR) team included local Aboriginal women, health workers, health care practitioners and the three researchers. Participating women were well respected in the community.</p>	<p>Feedback on the research focus and methodology was sought in the community.</p> <p>Feedback and drafts of materials were cycled at every stage of the research project to the PAR team and the critical reference group.</p> <p>Transcriptions were read out to the participants to ensure that the right information was presented and they received permission for the use of it.</p> <p>Field notes were discussed with the Aboriginal co-researchers to ensure correct understanding.</p>	<p>Formal agreements were made about intellectual property, ownership and acknowledgement on publications.</p> <p>Women from different local language groups were involved in the PAR team, to ensure local representation.</p> <p>A critical reference group was also established to ensure that the cultural and community information that was documented was correct.</p> <p>All the transcription and stories about to be published on the website were read to the participants to ensure that no taboos would be documented. Also that no information was spread that was not supposed to be</p>	<p>Local knowledge was used to guide the research project.</p> <p>Local stories were recorded and saved for the future.</p> <p>Consent was obtained from every women and their families to show their photo after they passed away.</p>
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