

TE ARA TIKA

Guidelines for Māori Research Ethics:

**A framework for researchers and
ethics committee members**

Pūtaiora Writing Group

Maui Hudson

Moe Milne

Dr Paul Reynolds

Dr Khyla Russell

Dr Barry Smith

"In preparing this document on behalf of Pūtaiora¹, the Pūtaiora writing group wish to acknowledge the support and encouragement of the National Ethics Advisory Committee (NEAC) and, in particular, the input of Dr Polly Atatoa-Carr, the Health Research Council of NZ (HRC) and Ngā Pae o te Maramatanga, University of Auckland"

¹ Pūtaiora is the name used for meetings held by the Māori members of ethics committees

Guidelines for Māori Research Ethics: A framework for researchers and ethics committee members

Me whakatika te matatika ki roto i te tikanga kia tika ai

Introduction

This document outlines a framework for addressing Māori ethical issues within the context of decision-making by ethics committee members. It draws on a foundation of tikanga Māori and will be useful for researchers, ethics committee members and those who engage in consultation or advice about Māori ethical issues from a local, regional, national or international perspective.

Context

Research contributes to the broader development objectives of society. Ethics has a specific role in guiding key behaviours, processes and methodologies used in research. International Codes of Ethics such as the Nuremburg Code (1947), the Helsinki Declaration (1964), the Belmont Report (1979) and, more recently, the UNESCO Universal Declaration on Bioethics and Human Rights (2005) shape the changing ethical standards and professional expectations for researchers.

These codes have often developed in response to examples of research that resulted in adverse outcomes/experiences for participants and their communities. Despite formal processes and Codes of Ethics there is ongoing evidence of unethical research practice which highlights the importance of the researcher's own credibility, trust, honesty and integrity vis-à-vis the research project and participants.

Over the years Māori have contributed to the critiques of research practice and advocated the inclusion of tikanga Māori as part of formal ethical decision-making processes [appendix one]. There are a range of models of Māori research ethics which guide researchers and ensure that *tikanga* (protocols and practices) and cultural concepts are acknowledged [appendix two].

The Treaty principles of partnership, participation and protection provide a framework for identifying Māori ethical issues in terms of; rights, roles and responsibilities of researchers and Māori communities; the contribution that research makes towards providing useful and relevant outcomes; and addressing inequalities. All research in New Zealand is of interest to Māori, and research which includes Māori is of paramount importance to Māori

In a research context, to ignore the reality of inter-cultural difference is to live with outdated notions of scientific investigation. It is also likely to hamper the conduct of research, and limit the capacity of research to improve human development².

² National Health and Medical Research Council (2003). Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research. Canberra: 24.

Tikanga

The primary indigenous reference for Māori values and ethics are the creation stories which highlight specific relationships deemed fundamental to the sustainability of life. These relationships are embedded as 'kawa' and provide the foundation for the establishment of 'tikanga'.

Ethics is about values, and ethical behaviour reflects values held by people at large. For Māori, ethics is about 'tikanga' – for Tikanga reflects our values, our beliefs and the way we view the world³.

Tikanga are locally specific practices that aim to enhance these relationships and ensure the preservation of mana. As the environment changes or new situations arise, tikanga are enacted or adapted to provide context-specific responses. Kawa and tikanga provide the primary interface for accessing repositories of cultural knowledge and experience that can be used to inform ethical deliberations. Tikanga also provides a framework through which Māori can actively engage with ethical issues and consider the effect research may have on their values or relationships.

Purpose

Articulating the ethical dimensions of tikanga as they relate to particular research proposals is a necessary step to support Māori members of ethics committees to fulfil their kaitiaki responsibilities. It should also be of assistance to ethics committees in the course of the ethical deliberations and researchers more generally as a guide to Māori ethical understandings and perspectives. It will improve the capacity of key personnel within the system of ethical review to respond more appropriately to Māori issues and, in doing so, enhance Māori communities' confidence and trust in the decisions made by both institutional and Health and Disability ethics committees. In summary, this framework has four main objectives:

- to explain key ethical concepts for Māori
- to support decision-making around Māori ethical issues
- to identify ways to address Māori ethical concerns
- to clarify the kaitiaki roles of Māori ethics committee members

There have been consistent messages about the dual responsibilities of Māori ethics committee members. As defined by the Operational Standard, the Māori ethics committee member sits alongside other members of the committee to implement the principles of ethical review. In addition, whanau/hapu/iwi expect Māori members of ethics committee to act as kaitiaki by understanding Māori ethical concerns, advocating for Māori ethical issues, and protecting Māori interests.

³ Te Puni Kokiri (1994). Health sector ethics: Nga tikanga pono wahanga hauora: Mechanisms for Māori into ethical review, Wellington N.Z. : Ministry of Māori Development.

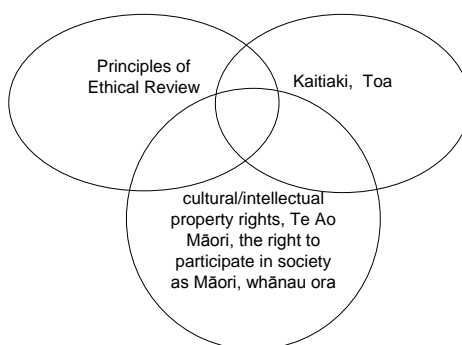


Figure 1: The roles and responsibilities of Māori ethics committee members

Background to the Guidelines and the Framework

The framework presented in this guideline recognises the broad range of ethical issues identified in previous documents, particularly in the context of health research. The main principles are drawn from tikanga Māori and its philosophical base of mātauranga Māori, but also integrate understandings from the Treaty of Waitangi, indigenous values and western ethical principles.

This framework aims to focus the ethical deliberation towards a more constructive critique of research in terms of not only its ability to identify risks but its potential to enhance relationships through the creation of positive outcomes for Māori communities. Concepts of justice and reciprocity are important for identifying tangible outcomes for all parties and supporting more equitable benefit sharing

The framework also advocates for constructive relationships and acknowledges the roles, relationships and responsibilities each party has in the process of engagement. The framework considers that both the research design and the cultural and social responsibility of the researchers have an immediate influence on the likely outcomes of the research project and should be considered during ethical deliberations.

The Māori ethics framework references four tikanga based principles (**Whakapapa, Tika, Manaakitanga, and Mana**) as the primary ethical principles in relation to research ethics. Other ethical concepts and principles are located within this framework and the ethical issues within each segment are identified and cross-referenced to the Operational Standard⁴.

Each segment is divided into a 3 parts that identify progressive expectations of ethical behaviour. The outer quadrant relates to what has been termed minimum standards. The **minimum standards** are expected to have been met by researchers before ethics committee members consider ethical approval for the research project. The middle quadrant refers to **good practice** which indicates a more Māori

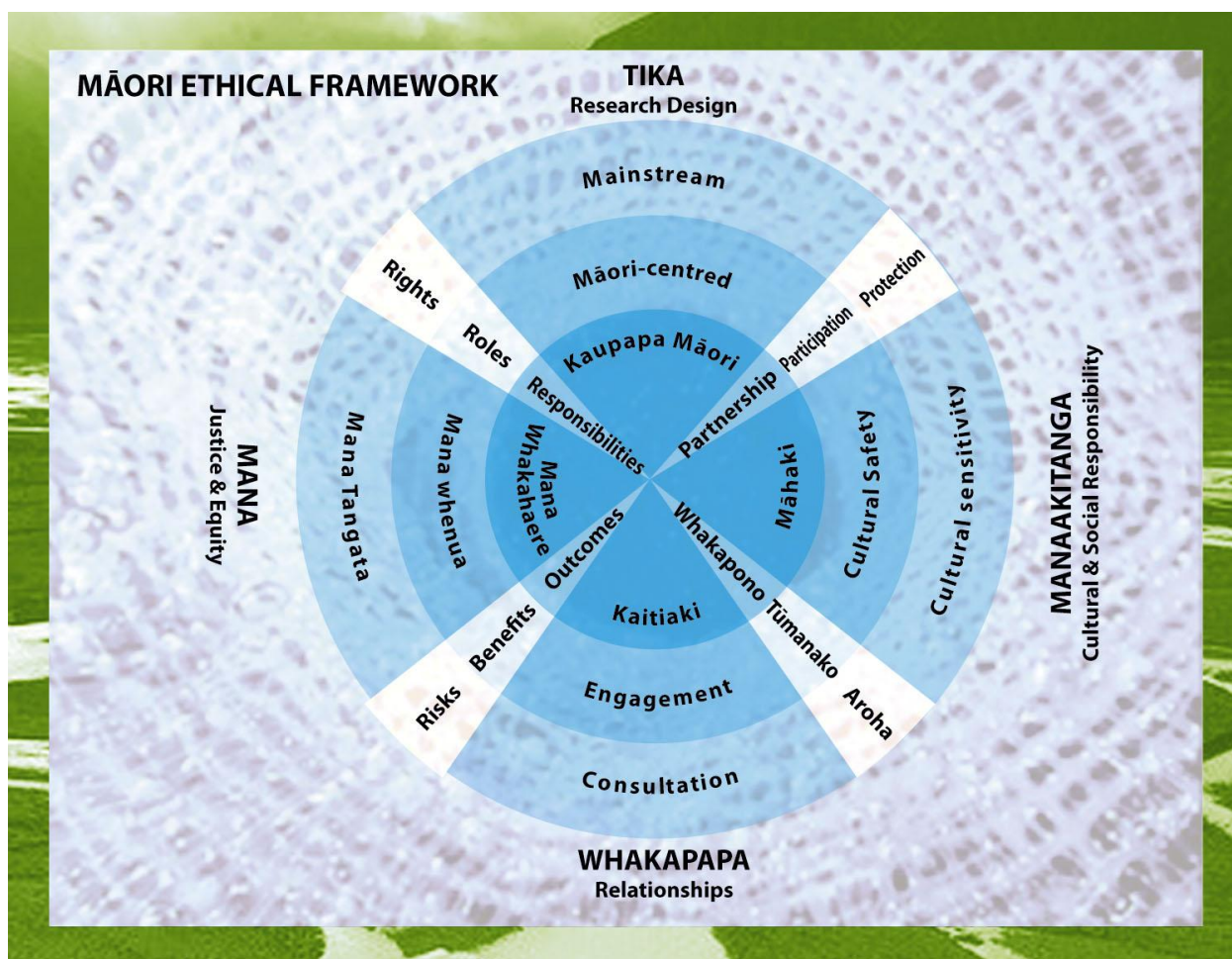
⁴ Ministry of Health (2006). Operational Standard for Ethics Committees. Wellington, New Zealand, Ministry of Health.

responsive approach to the research project. **Best practice** extends the ethical consideration to align with expectations of behaviour within Te Ao Māori.

The axis between the segments provides further opportunity to link the ethical issues to the rights, roles and responsibilities associated with the Treaty of Waitangi, the principles themselves (partnership, participation and protection), a risk/benefit/outcome continuum, and the Māori values of whakapono, tumanako and aroha.

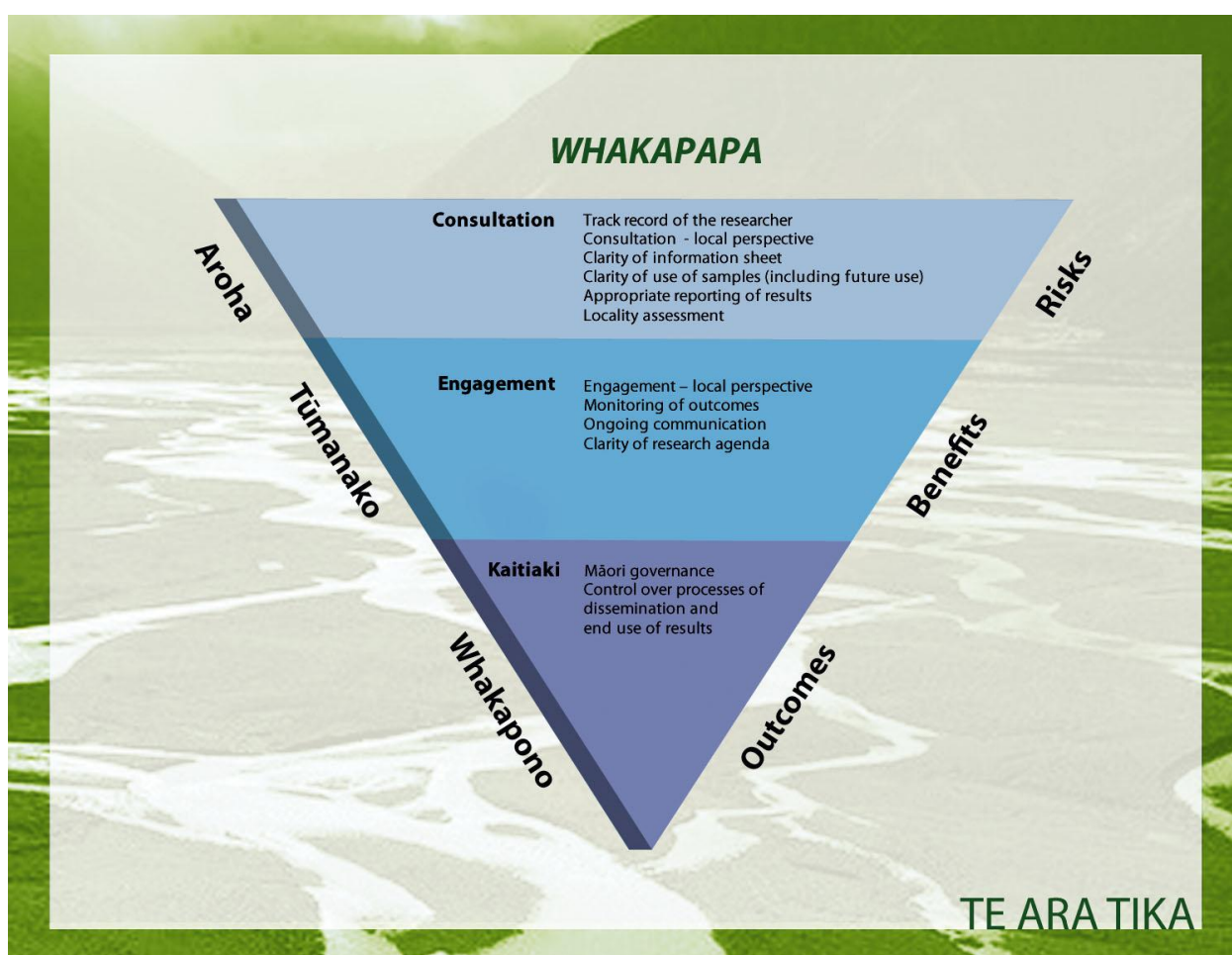
The process of ethical review can be thought of in terms of TAPU and NOA. The concept of 'Kia Tūpato' (to be careful) becomes the starting point for considering the value or potential benefit of a research project. Kia āta-whakaaro' (precise analysis) and 'kia āta-korero' (robust discussion) of the practical/ethical/spiritual dimensions of any project is necessary to provide a foundation to 'kia āta-whiriwhiri' (consciously determine) the conditions which allow the project to 'kia āta-haere' (proceed with understanding).

**TAPU → Kia tūpato → Āta – whakaaro → Āta – korero →
Āta - whiriwhiri → Āta – haere → NOA**



Whakapapa – He aha te whakapapa o tēnei kaupapa?⁵

Whakapapa is used to explain both the genesis and purpose of any particular kaupapa. Whakapapa is an analytical tool for not only understanding why relationships have been formed but also monitoring how the **relationships** progress and develop over time (mai i te whai ao ki te ao mārama). Within the context of decision-making about ethics, whakapapa refers to quality of relationships and the structures or processes that have been established to support these relationships. In research, the development and maintenance of meaningful relationships between researcher and research participant forms another axis of consideration for evaluating the ethical tenor of a research project and its associated activity.



Minimum standard: Consultation

An element of “**aroha**” or “aro ki te ha” involves acknowledging the essence of the environment within which a person operates. In a traditional context, a person going fishing or diving might be cautioned with the phrase “Kia aroha ki a Tangaroa”. Within this guideline we use the notion of aroha as the protective element, a basic caution relating to the **risks** of engaging in research and to consider ways in which they might be mitigated. **Consultation** [2.2.37, appendix 8.381-382] ensures that

⁵ What is the genesis of this project?

there has been a constructive critique of the proposed project and its potential impact on Māori. It also provides an opportunity for the community to consider the track record of the researcher. Consultation assists with the development of clearly written information sheets which specify that samples will only be used for the purpose for which they are taken [2.2.33], provide a mechanism for reporting back results to appropriate parties [Appendix 8.386] and allow issues regarding the research scope and agenda [2.0.23; 2.7.82] to be discussed. These are considered minimum requirements and should be reflected in the locality assessment and section F of the ethics application.

Questions which should be asked include:

- *Is the information sheet written with clarity and with no exaggerated claims or understatement of risks?*
- *Is there clarity around potential future use of the samples or data?*
- *Does the reporting back of results reach its intended audience?*
- *Is there evidence of local consultation?*
- *Does the researcher have a good track record?*

Good Practice: Engagement

We encourage researchers to move beyond consultation and look to substantial and positive **engagement** with Māori communities. This will ensure that Māori participation in the research project aligns with their '**tūmanako**' (Māori aspirations) and tangible **benefits** are derived. Where research is clearly Māori centered and displays a focus on generating answers to questions that are of particular relevance and importance to Māori then additional features in the research protocol will be expected in terms of cultural safety and research design.

Question of relevance include:

- *What is the evidence for engagement with Māori and what was the shape, time scale and extent of this?*
- *How has the consent issue been dealt with and is the mode of informed consent suggested appropriate?*

Best Practice: Kaitiaki

A best practice level of 'relationship' empowers Māori to take a **kaitiaki** role within the research project with a view to ensuring that tangible **outcomes** are realised within Māori communities. A relationship displaying transparency, good faith, fairness and truthfulness is captured in the concept of '**whakapono**' and the whakatauki (proverb) "kia u ki te whakapono me te aroha tetahi ki tetahi" (hold fast to the truth with respect for each other). Where research is framed by tenets of kaupapa Māori the above sets of requirements will be augmented by clear evidence that implications of using this methodology is transparently manifested right across the application and in all additional and supporting documents. Of particular relevance here will be the development of mechanisms for Māori to have a

governance role in the planning, development and execution of research as well as monitoring [Appendix 8.378] the project through its life cycle. The dissemination of results from the project will be focused on matters of relevance to Māori with information directed to an end use that shows clear benefits for Māori.

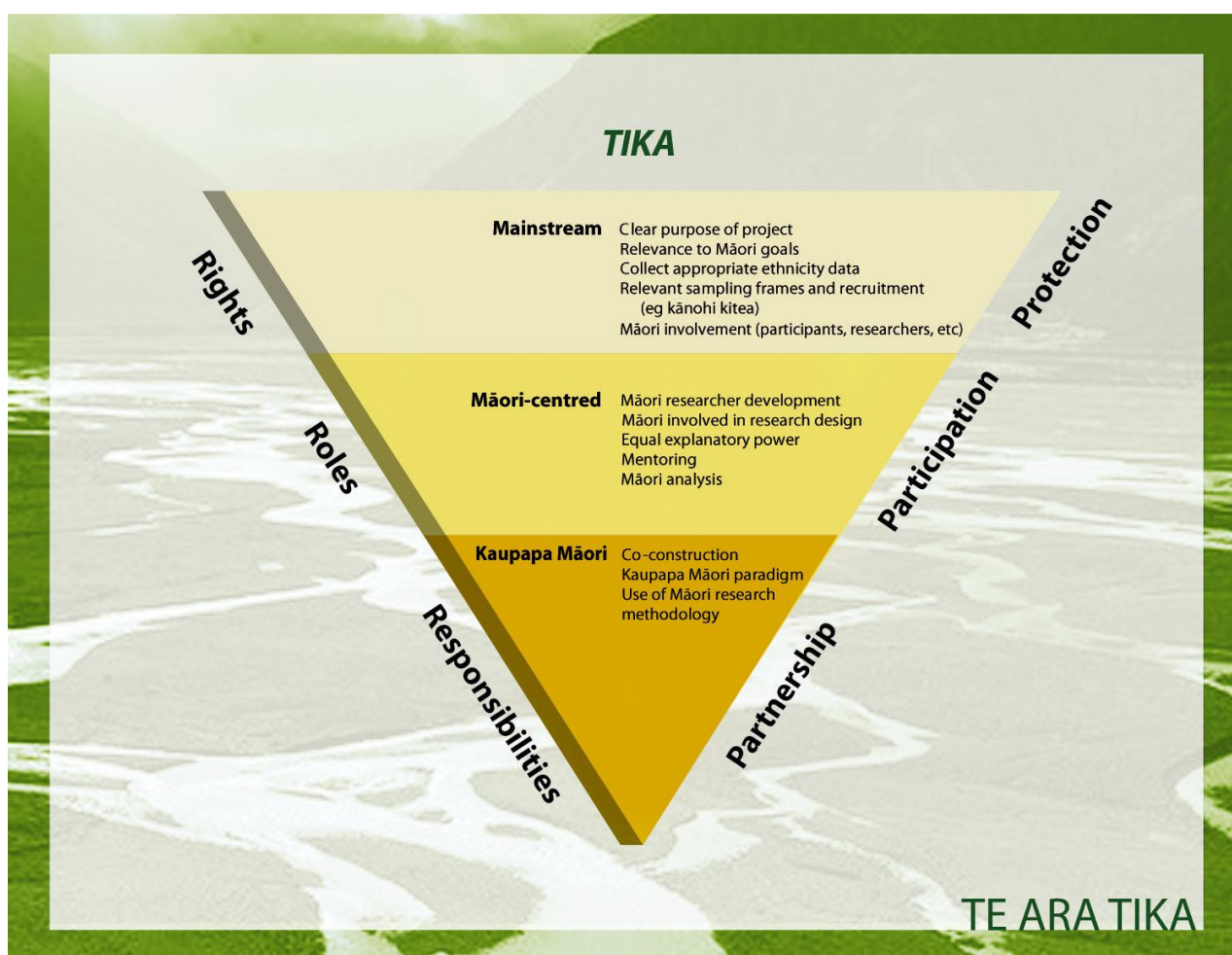
Questions of relevance include:

- *Is the use of kaupapa Māori research approach evidenced right through the application document?*
- *What degree of meaningful input have Māori had in influencing the shape of the research?*
- *Are Māori participants and their iwi, hapu and Whanau the prime recipients or contributors of results?*
- *What mechanisms are in place to optimise benefits to participants along the attendant benefits appropriately targeted?*
- *Is there an adequate monitoring mechanism?*

TIKA – Me pehea e tika ai tēnei kaupapa?⁶

Tika provides a general foundation for tikanga and in the Māori context refers to what is right and what is good for any particular situation. In the context of this framework we relate it to the **validity of the research** proposal [2.4]. The design of a research project is a critical determinant in whether the research is successful in achieving proposed outcomes, benefiting participants and communities, and bringing about positive transformative change.

Respectful relations with Māori and mana whenua are vital in all research projects, whatever approach the research team decides to use. There are a continuum of approaches to research, each with varying degrees of responsiveness to Māori which reflect the responsibilities, roles, rights of researchers and Māori communities. In this framework approaches to research design (Kaupapa Māori, Māori-centered, and Mainstream: for further information see appendix 3) are considered in relation to the Treaty principles of partnership, participation and protection.



⁶ How will the project proceed correctly?

Minimum standard: Mainstream

A **mainstream** approach refers to research that may or may not have direct relevance to Māori and where Māori engage as research participants. In these situations researchers are expected to **protect** the **rights** and interests of Māori although there is little real involvement in the research process or outcomes. Using this research approach, a number of factors need to be considered when designing the research project including defining the purpose of the project [2.4.57, 2.6.73] and its relevance to Māori goals, [2.7.82, Appendix 8: 383]. If Māori are involved as participants [2.6.74] then it is important to consider the recruitment methods (is kanohi-ki-te-kanohi/face to face recruitment appropriate?) the sampling frameworks and whether it is relevant and appropriate to collect ethnicity data [2.4.57]. In this regard the collection of ethnicity data may not be of primary use to the research proposal itself but can provide valuable baseline data for other researchers or Māori communities.

Questions which should be asked include:

- *In what way does this research project impact on Māori?*
- *How will Māori be included in this project? Is this appropriate and respectful?*
- *Do I need to consult with Māori for this project? If so, how do I do that?*

Good Practice: Māori-centered

Research designs that give Māori a greater level of **participation** within the research process are encouraged. Māori-centered research involves Māori as significant participants in various **roles**, including research team and participants, and possibly analysis and outcomes. Issues to be considered when using this research approach include Māori involvement in research design [2.5.66, 2.0.23], the role of mentors and Māori researcher development [2.6.73], use of sampling frameworks that allow equal explanatory power [2.4.57] and Māori involvement in analysis [2.4.57, 2.0.23].

Questions of relevance include:

- *How will Māori be involved in this project? As researchers, participants, advisors?*
- *How will this research project benefit Māori in all of the above?*
- *Is there adequate participation of Māori in different stages of the research project, including research design, analysis and dissemination of the results?*

Best Practice: Kaupapa Māori Framework

This approach to the research design acknowledges the importance of **partnerships** and the **responsibilities** of Māori to ensuring the project delivers its intended outcomes to Māori communities. Use of a **kaupapa Māori framework** to develop research that is designed by, conducted by, made up of, and benefits, Māori is promoted. We encourage research that frames Māori kaupapa as the primary interest of the project, involves Māori as co-constructors of the project [2.3.56], supports kaupapa Māori theory [2.4.61] and uses Māori research methodologies as appropriate [2.0.23, Appendix 8:383].

Questions of relevance include:

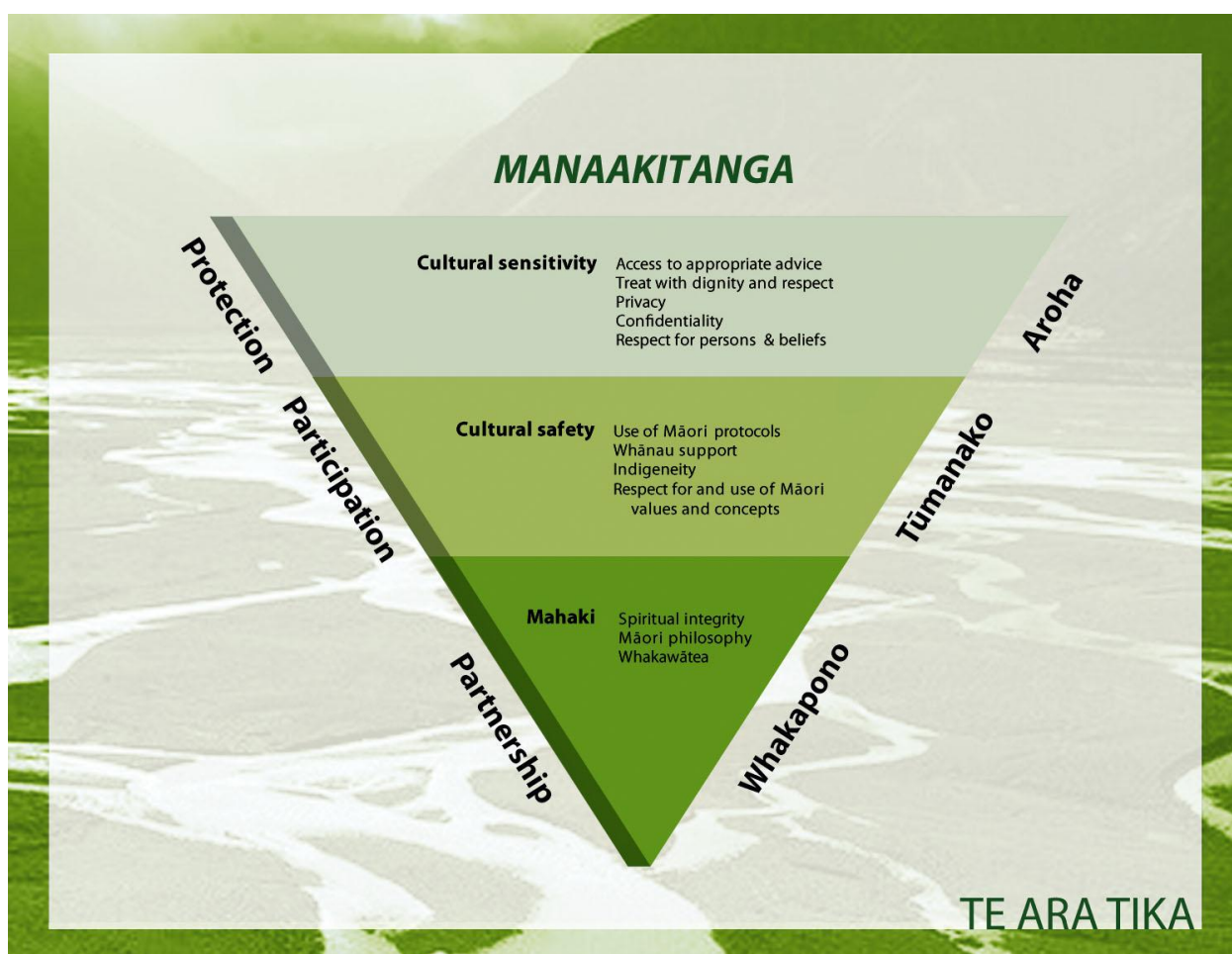
- *Who defined the research problem?*
- *For whom is the study worthy and relevant?*
- *Who says so?*
- *What knowledge will the community gain from this study?*
- *What are some likely positive outcomes from this study?*
- *What are some possible negative outcomes?*
- *How can the negative outcomes be eliminated?*
- *To whom is the researcher accountable?*
- *What processes are in place to support the research, the researched and the researcher?*⁷

Note: The TIKA segment is what contextualises the Māori ethics framework to research. The framework may have utility in other areas (eg. environmental, assisted reproductive technology) by adapting this section.

⁷ Smith, L. T., *Decolonizing methodologies: Research and Indigenous peoples*, New York: Zed Books, 1999, p.173.

Manaakitanga – Mā wai e manaaki tēnei kaupapa?⁸

The concept of manaakitanga encompasses a range of meanings in a traditional sense with a central focus on ensuring the mana of both parties is upheld. In this context it is associated with notions of **cultural and social responsibility [2.7]** and **respect for persons [2.1]**.



Minimum Standard: Cultural Sensitivity

The minimum standard for manaakitanga acknowledges a persons inherent dignity [2.7.77] and responsibility people have to act in a caring manner towards others. The responsibility to **protect** and care for people with **aroha** and be aware of issues of **cultural sensitivity** comes to the fore. In this context it includes access to appropriate advice (eg. Kaumātua, advocate) [2.1.24-26, 2.7.77] and respect for concepts of **privacy and confidentiality [2.3]**.

Concepts of privacy and confidentiality are altered when the individualised notion of autonomy is removed. Information is shared to provide support and increase the transparency and accountability between members of the community. While recognising the appropriateness of privacy and confidentiality to safeguard any

⁸ Who will ensure respect is maintained?

harmful effects from disclosure of information, in many situations, the level of confidentiality can be negotiated with communities and participants. This may simply involve participants consenting to be named as part of the study and giving them the opportunity to remove or de-identify particular comments from the final report.

Questions which should be asked include:

- *Are the participants being treated with dignity and respect?*
- *Will the participants have access to appropriate advice?*
- *Is privacy and confidentiality being applied appropriately?*

Good Practice: Cultural Safety

A better standard of manaakitanga or cultural & social responsibility can be achieved by recognizing, in addition to the issues above, the importance of collective **participation** in establishing the goals and benefits (**tūmanako**) [2.7.82, 2.6.73, appendix 8.384] of a research project and its **culturally safe** implementation [appendix 8.384]. This is enhanced by considering the inclusion of Māori values and concepts [1.5.14, 2.0.23, 2.5.66, 2.7.79-81, appendix 8.384] indigenous values and concepts, and allowing for the use of whanau support [2.0.23, 2.7.77] and appropriate Māori protocols [appendix 8.384].

Questions of relevance include:

- *Are Māori values or concepts used within this research project?*
- *How will Māori protocols be observed as part of the research project?*
- *Are whanau able to support participants within this project?*

Best Practice: Māhaki

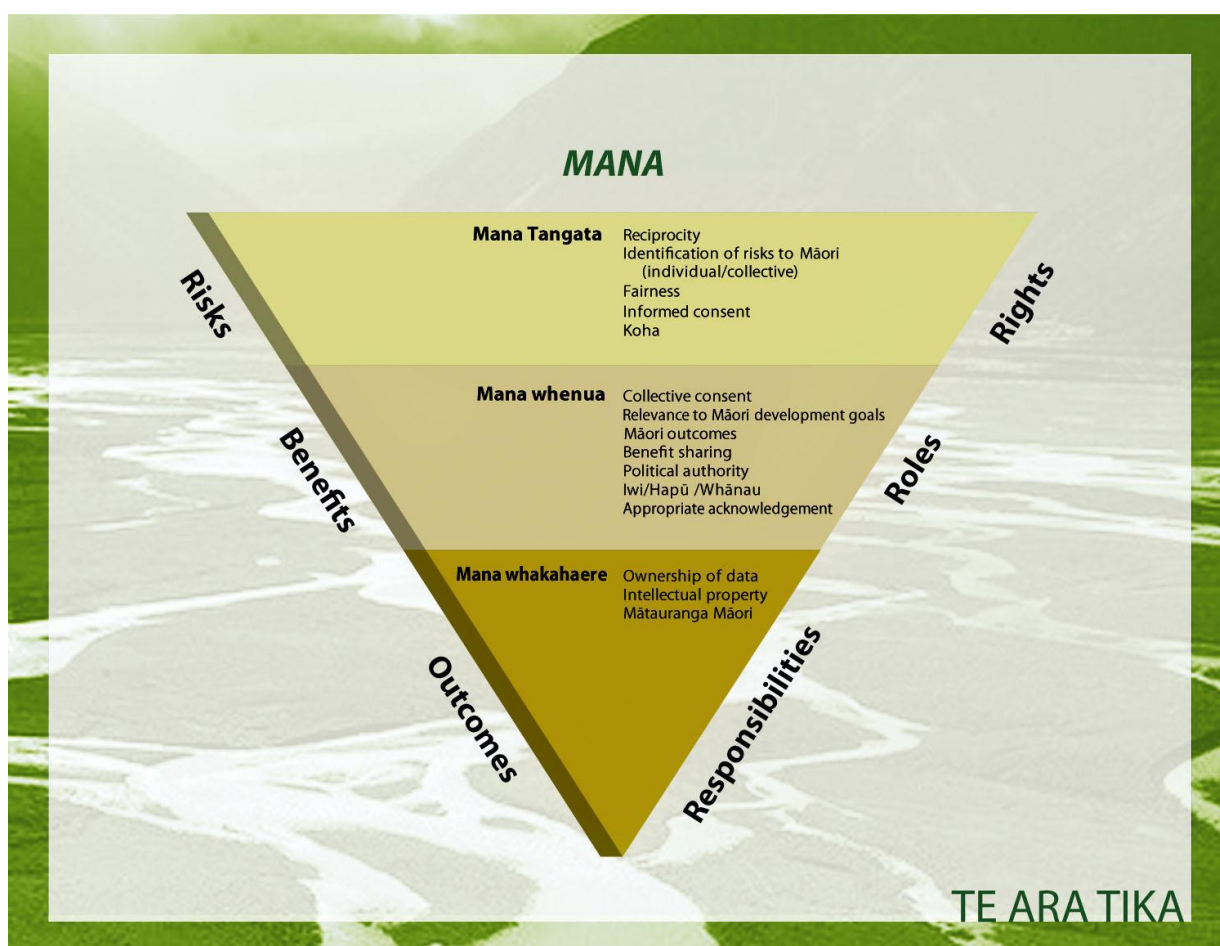
Manaakitanga is fully realized in the context of relationships. Here mana akiaki empowers **partnerships** whose quality is enhanced by the level of the parties' faith and trust in each other (**whakapono**). Extending beyond cultural safety, levels of respectful conduct (**māhaki**) acknowledge the importance of recognizing spiritual integrity [2.0.23], Māori philosophy [appendix 8.384], and may include processes like whakawātea within the research project.

Questions of relevance include:

- *Are kaumātua required to guide the research team?*
- *How will researchers ensure the safe application of protocols?*

Mana – Kei a wai te mana mō tēnei kaupapa?⁹

Mana in a Māori context refers to power and authority bestowed, gained or inherited individually and collectively. In the context of this framework mana relates to equity [2.6.73] and distributive **justice** [2.6]. Mana acts as a barometer of the quality of relationships by acknowledging issues of power and authority in relation to who has rights, roles and responsibilities when considering the risks, benefits and outcomes of the project.



Minimum standard: Mana Tangata

Mana Tangata, in the context of this framework, refers to individuals that choose to participate in research and their **right** to be appropriately informed of **risks** to their individual or collective mana. As such consideration should be given to the identification of risks (individual/collective) [2.0.23, 2.5.64-72], fairness in terms of their distribution [2.6.73] and the place of koha [2.2.43, 2.7.85-86]. Providing clear understanding of the requirements for informed consent [2.2], and recognising the place of oral consent in some Māori settings [appendix 8.384] is integral to demonstrating respect for the mana of Māori participants.

⁹ Who has control over the project?

Questions which should be asked include:

- *How open/transparent has the process of consultation been?*
- *How honestly and fully have the potential or real risks involved in this research been explained?*
- *How equitable will the results be for Māori*
- *Are the ideas behind koha understood?*
- *Is there evidence of:*
 - *Equitable outcomes for Māori?*
 - *Minimization of harm?*
 - *Fairness by appropriate inclusion of Māori*
 - *Engagement with the most appropriate groups to deliver favourable research outcomes.*

Good Practice: Mana Whenua

Mana whenua are iwi and hapu who are recognized as having rights to occupy and a primary **role** discerning **benefits** and making decisions around resource management and research being done in their rohe pōtae or tribal area [2.0.23, 2.3.55, appendix 8.384]. Researchers should be establishing meaningful relationships with mana whenua at the research design/conceptual stage to ensure the research provides outcomes for Māori [2.6.73, 2.7.82, appendix 8.384] and provides opportunities to explore benefit sharing arrangements [2.6.73]. Recognising the mandated authority of hapu and iwi [2.0.23, 2.3.55, appendix 8.384] acknowledges the role they have in dealing with issues around consent. It may be appropriate to recognise ethical requirements for 'collective consent' [2.2.40-41; 2.3.56; 2.6.23; 2.7.78] in circumstances where risks to the collective are at least as serious as those to the individual participant.

Questions of relevance include:

- *Who will benefit from the research and how will this be evidenced?*
- *Have the contributions of mana whenua been acknowledged?*
- *Is there evidence of mana whenua goals, aspirations, development, or expectations?*
- *How will these be measured and by whom?*
- *Where will the research be developed, undertaken, and with whom?*
- *Has there been engagement with mana whenua and in what capacity?*
- *To whom must the researchers report besides your funders/institution?*
- *What and where is the relevance to/for Māori in their ongoing development in this research?*
- *Does the research include the achievement of Māori goals as an outcome?*

Best practice Mana whakahaere

In regard to research **mana whakahaere** refers to the sharing of power and control in the research relationship with hapu, iwi or relevant Māori communities who assume the **responsibility** for the **outcomes** of the project. This presupposes engagement with Māori as mana whenua or tangata whenua. Mana whakahaere represents Māori control within the research project and includes acknowledgement of iwi intellectual property [appendix 8.384], their knowledge systems (Mātauranga

Māori) [appendix 8.384], ownership of research data [2.0.23, 2.3.55, appendix 8.384] and guardianship responsibilities in relation to the protection and dissemination of information from the research project.

Questions of relevance include:

- *Is there evidence of engagement in a meaningful relationship with mana whenua, tangata whenua (or Mataawaka) as Tangata Tiriti or Iwi researchers?*
- *How does this application protect Māori Intellectual property?*
- *Has consent been gained to access/use of Mātauranga Māori*
- *How is data ownership guaranteed under mana whakahaere?*
- *Whose intellectual property will/does this research become?*
- *Has Mātauranga Māori contributed to the research and how is this evidenced?*
- *Who will own the data produced/collected/generated during the research?*

Special ethical considerations

This section outlines areas of special ethical consideration.

1. Collection and Use of Human Tissue

The body is considered tapu by Māori and Indigenous people generally. Researchers involved in health or medical research that involves the body, or any part of the body, such as organs, blood, hair, saliva and/or other tissue, must do so in a respectful manner. The collection of human tissue is particularly sensitive when it involves the use of a deceased person's tissue.

2. Genetic research

Genetic research is an area of prime sensitivity for Māori because of the association with whakapapa. Communities are also concerned about new technologies and research in areas such as genetic engineering, the creation of transgenic life-forms, and human genome research investigating human variation and diversity by in indigenous populations.

Researchers should be aware of the following issues:

Informed Consent

Concerns have been expressed about the nature and specificity of the consent. In particular, explicit consents should be sought for;

- Ongoing storage in tissue banks
- The establishment of cell lines
- Tissue being sent overseas
- Use within genetic studies
- Future use

Māori favour the recognition of both individual and collective consents as some ethical issues can be usefully considered and consented to by an individual and other ethical issues require community engagement. A collective is likely to be involved in early decisions about the appropriateness of the study while an individual can decide once the study has begun whether or not they will to participate¹⁰. This means that two forms of consent are required for research involving human tissue and/or genetic samples. Firstly, that of an appropriate community/collective for the study to take place (via consultation) and secondly, those of individual Māori participating in the study.

On-going Communication with donors/participants

Beyond the initial consent process, it is also important to provide a communication channel so that donors and their families are able to find out what

¹⁰ Hudson, M. (2009). Think Globally, Act Locally: 'Collective Consent' and the Ethics of Knowledge Production. *International Social Science Journal*. Accepted for publication.

has happened to their tissue and for which research projects it has been included. This provides a mechanism for donors/participants to vary or withdraw their consent both for the actual study and future studies (if so consented).

Interpretation

Early genetic research focused on identifying single genes responsible for specific familial disorders. However, radical technological advancements such as high throughput testing and genome-wide scanning techniques have made it possible to examine complex conditions influenced by multiple genes and environmental factors to determine population susceptibility. The association of genetic or biological susceptibility to disease with ethnicity is problematic for population based research. Due care should be taken when conducting ethnic specific analyses, particularly in genetic studies, as there is always the potential for community disruption, stigmatisation, stereotyping or undermining either through research processes or outcomes¹¹. Care needs to be taken to avoid such harms through the use of incorrect terminology, for example 'Māori genes'.

Intellectual Property

Māori continue to assert their cultural and intellectual property rights through a range of mechanisms; the Treaty of Waitangi (article two: protection of taonga), the United Nations Declaration on the Rights of Indigenous Peoples, the Waitangi Tribunal (Wai 262) and the Mataatua Declaration (an affirmation of kaitiakitanga in relation to the intellectual property rights of Māori).

Of particular concern to Māori is research that involves the use of traditional plants and other natural resources. Specific concerns for Māori arise from the claiming of intellectual property over natural and cultural properties, and the exclusionary nature of these IP provisions. Traditional uses should never be impacted by IP patents.

Opportunities for the sharing of new intellectual property with Maori communities should be facilitated particularly where Maori analyses have contributed to the development of the intellectual property.

¹¹ Hausman, D. (2008). Protecting groups from genetic research. *Bioethics*. Vol 22(3), pg 157-165.

Representation

Māori ethics committee members, along with their respective colleagues need to assess the appropriateness of consulted parties and determine whether there are other potential organisations that should have been part of the engagement process. The table below identifies some criteria for assessing the appropriateness of the representative body.

	Mana Whenua / Tangata Whenua	Institution-based group (DHB/University)	Other consultation group (eg Mataawaka)	Health professionals (eg ECART counsellors)
Who are they				
Expertise/key interest areas				
Level of engagement in selection of Māori members				
Level of participation in consultation process				
Use of evaluation techniques eg risk assessment tool, checklist				
Relationships with other groups eg DHB representative				
Current process for feedback, discussion, reporting				
Capacity to engage in consultation, eg time, resources, expertise				
Willingness to engage with ethics committee				

Table 1: Assessing appropriateness of Māori consultation

Benefit Sharing

Equity and justice are ethical principles underpinning the importance of benefit-sharing. Research will also have a range of outcomes and part of the ethical deliberation is to consider the nature of the outcomes (risk versus benefit, short versus long term) and their relative distribution (researchers, participants, communities, society). Researchers will legitimately benefit from being involved in research but consideration should be given to how participants and their communities might also benefit from participation.

Benefits to researchers

- Status and reputation
- Qualifications (Masters and PhD theses)
- Personal advancement
- Increasing networks

Benefits to participants

- Access to interventions
- Opportunity to share experiences
- Koha
- Acknowledgement in publications
- Copies of reports

Benefits to participant communities

- Research capacity – research skills, understanding research processes
- Access to interventions
- Collection and protection of existing intellectual property
- Knowledge advancement
- Copies of reports
- Sharing of new Intellectual Property

Benefit to Māori

- Community development eg. health promoting events
- Researcher development eg. qualifications, research experience
- Knowledge advancement eg. research outputs, wānanga
- Development of mātauranga Māori

Benefit to society

- Knowledge advancement eg. research outputs, wānanga
- Inclusiveness and diversity within the research system

Implementation

This framework helps to clarify key ethical concepts for Māori and in doing so supports decision-making around Māori ethical issues. It does not replace ethical deliberation but enhances the process by framing Māori ethical issues in a way that aligns to the expectations of Māori communities. The Māori ethical framework should be used in conjunction with the Operational Standard and the majority of the concepts and issues identified within the Māori ethical framework can be referenced back to the Operational Standard. To gain a fuller appreciation of Māori ethical concepts, issues and concerns, additional training should be undertaken. Ideally this will also occur as part of the orientation process for new ethics committee members.

Appendix 1:

Timeline of developments in Māori research ethics

Date	Hui/Publication
1991	Ngahua Te Awekotuku, he tikanga whakaaro
1993	First International Conference on the Cultural and Intellectual Property Rights of Indigenous Peoples (Whakatane)
1993	Māori Working Group on Health Sector Ethics established by the Ministry of Health
1994	Te Ara Ahu Whakamua, Māori Health Decade Hui
1994	Health Sector Ethics: Nga tikanga pono wahanga hauora
1996	Pū Tai Ora first meeting held
1996	Hui Whakapiripiri, Wellington (HRC)
1997	Hui Whakatipu/piripiri, Whaiora Marae, Otara, Auckland (HRC)
1998	Te Oru Rangahau Māori Research Conference, Palmerston North
1998	HRC produces Guidelines for Researchers on Health Research Involving Māori.
1998/1999	Pū Tai Ora – tikanga Māori, Māori ethical principles, training/education.
1999	Linda Smith, Decolonising methodologies
1999	Te Puni Kokiri publishes <i>Evaluation for Māori: Guidelines for Government agencies</i> (Te Puni Kokiri, 1999).
2000	Pū Tai Ora meeting
2001	Fiona Cram, Rangahau Māori: Tona tika tona pono – The validity and integrity of Māori researchers
2002	Kiri Powick, Nga Take Matatika mo te mahi Rangahau Māori. Māori research ethics: a literature review of the ethical issues and implications of kaupapa Māori research and Research involving Māori for Researchers, Supervisors and Ethics Committees
2002	Pū Tai Ora wananga at Te Herenga Waka Marae, Victoria University, Wellington
2003	Fiona Cram, Preliminary discussions with Key Māori informants
2003	Hirini Moko Mead, Tikanga Māori: Living by Māori values
2004	Andrew Sporle & Jonathon Koea, Māori Responsiveness in health and medical research
2004	Mātauranga Tuku Iho Tikanga Rangahau, Ngā Pae o te Māramatanga hosts a Traditional Knowledge and Research Ethics Conference in Wellington
2004	Maui Hudson, He Matatika Māori: Māori and Ethical Review of Health Research.
2004	Rachel Robson, Māori framework for ethical review of health and disability research: Scoping report to the National Advisory Committee on Health and Disability Ethics
2004	NEAC, the HRC and Ngā Pae o te Māramatanga establish a collaborative relationship to facilitate development of a Māori Framework for health and disability research ethics.
2005	Pū Tai Ora hui, themes discussed include Māori members' role, quality of consultation/representation, need for consensus/consistency, frameworks/models for decision-making on Māori ethical issues, need for more information in a number of areas.
2006	Completion of NEAC contracted stocktake on how the central issues in New Zealand and other countries have so far been addressed (Kennedy & Wehipeihana, 2006).

2006	Hui Whakapiripiri, discussed Ngai Tahu ethics, Rod Lea effect, ethical issues for Māori, role of Māori EC members
2006	Pū Tai Ora hui, meeting of the Māori and Pacific members of the Health and Disability Ethics Committees
2007	Pū Tai Ora hui, meeting of the Māori and Pacific members of the Health and Disability Ethics Committees
2007	Meeting of NEAC, HRC and Ngā Pae o te Māramatanga, agreed new project plan and next steps in project
2008	HRC updates its 1998 Guidelines for Researchers on Health Research Involving Māori (Health Research Council, 2008).
2008	Mason Durie, 9 th Global Forum on Bioethics in Research. The Ethics of Indigenous Peoples and Vulnerable Populations
2009	Maui Hudson & Khyla Russell, The Treaty of Waitangi and Research Ethics

Appendix 2

Operational Standard – Additional issues for Māori

Main principles	Additional issues for Māori
Respect for persons	Respect for Māori collectives – whānau, hapū and iwi
Informed consent	Gaining consent of collectives
Privacy and confidentiality	Collective ownership of information
Validity of research proposal	Kaupapa Māori and Māori-focused methodologies
Minimisation of harm	Minimising harm to te taha whānau (family and community), te taha hinengaro (emotional wellbeing and state of mind), te taha wairua (spirit), te taha tinana (the body or physical self)
Justice	
Cultural and social responsibility	Cultural diversity, koha (donation, present or gift)
Compensation for research participants	

(Operation Standard for Ethics Committees, Ministry of Health, 2006)

Appendix 3
Māori ethical frameworks

Kaa Williams	Te Pa Harakeke o te Tangata
Manuka Henare	Koru of Māori ethics
Hugh Kawharu	Te noho kotahitanga
Hirini Moko Mead	Tikanga tests
Linda Smith	Kaupapa Māori practices
Mason Durie	Rangahau painga
Stephanie Palmer	Homai te waiora ki ahau

Appendix 4:
Characteristics of Māori research

Characteristics	Research Involving Māori	Māori-Centred Research	Kaupapa Māori Research
Description	Research where Māori are involved as participants or subjects, or possibly as junior members of a research team; Research where Māori data is sought and analysed; Research where Māori may be trained in contemporary research methods and mainstream analysis.	Research where Māori are significant participants, and are typically senior members of research teams; Research where a Māori analysis is undertaken and which produces Māori knowledge, albeit measured against mainstream standards for research.	Research where Māori are significant participants, and where the research team is typically all Māori; Research where a Māori analysis undertaken and which produces Māori knowledge; Research which primarily meets expectations and quality standards set by Māori.
Examples	Analysis of ethnic differentials in disease rates; genetic study of familial cancer.	Longitudinal social science study of Māori households.	Traditional study of cosmology; study of cultural specific aspects of determinants of health.
Control	Mainstream.	Mainstream.	Māori.
Māori Participation	Minor.	Major.	Major, possibly exclusive.
Methods/tools	Contemporary – mainstream.	Contemporary – mainstream and Māori.	Contemporary – mainstream and Māori.
Analysis	Mainstream.	Māori.	Māori.