

Te Ara Tika
Guidelines for Māori research ethics:
A framework for researchers
and ethics committee members

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

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**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 (Māori protocols and practices) 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 Nuremberg Code (1947)², the Helsinki Declaration (1964)³, the Belmont Report (1979)⁴ and, more recently, the UNESCO Universal Declaration on Bioethics and Human Rights (2005)⁵ shape the changing ethical standards and professional expectations for researchers.

These codes have often been developed in response to examples of research that resulted in adverse outcomes and/or 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-vis⁶ the research project and participants.

Over the years Māori have contributed to the critiques of research practice and advocated for the inclusion of tikanga Māori as part of formal ethical decision-making processes (Appendix A). There are a range of models of Māori research ethics which guide researchers and ensure that tikanga and cultural concepts are acknowledged (Appendix B).

The Treaty of Waitangi 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 development⁷.

² The Nuremberg Code (1947). The Nuremberg Code is made up of ten ethical principles that govern human experimentation <http://ohsr.od.nih.gov/guidelines/nuremberg.html>.

³ Helsinki Declaration (1964). World Medical Association Declaration of Helsinki: Ethical principles for medical research involving human subjects. Adopted by the 18th WMA General Assembly, Helsinki, Finland, June 1964, and amended by the 59th WMA General Assembly, Seoul, October 2008.

⁴ Belmont Report (1979). National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research,

⁵ UNESCO Universal Declaration on Bioethics and Human Rights (2005). United Nations Educational, Scientific and Cultural Organisation (UNESCO) (2005).

⁶ *In relation to*

⁷ 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 (primary values) 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 world⁸.

Tikanga are locally specific practices that aim to enhance these relationships and ensure the preservation of mana (justice and equity, reflected through power and authority). 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 (guardian/advocate) 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, and
- 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 Ministry of Health's Operational Standard for Ethics Committees (2006)⁹ the Māori ethics committee member sits alongside other members of the committee to implement the principles of ethical review.

⁸ Te Puni Kokiri (1994). Health sector ethics: Nga tikanga pono wahanga hauora: Mechanisms for Māori into ethical review, Wellington, New Zealand, Ministry of Māori Development.

⁹ Ministry of Health (2006). Operational Standard for Ethics Committees. Wellington, New Zealand, Ministry of Health.

In addition, whānau/hapū/iwi (family/kinship group/tribe) expect Māori members of ethics committee to act as kaitiaki by understanding Māori ethical concerns, advocating for Māori ethical issues, and protecting Māori interests.

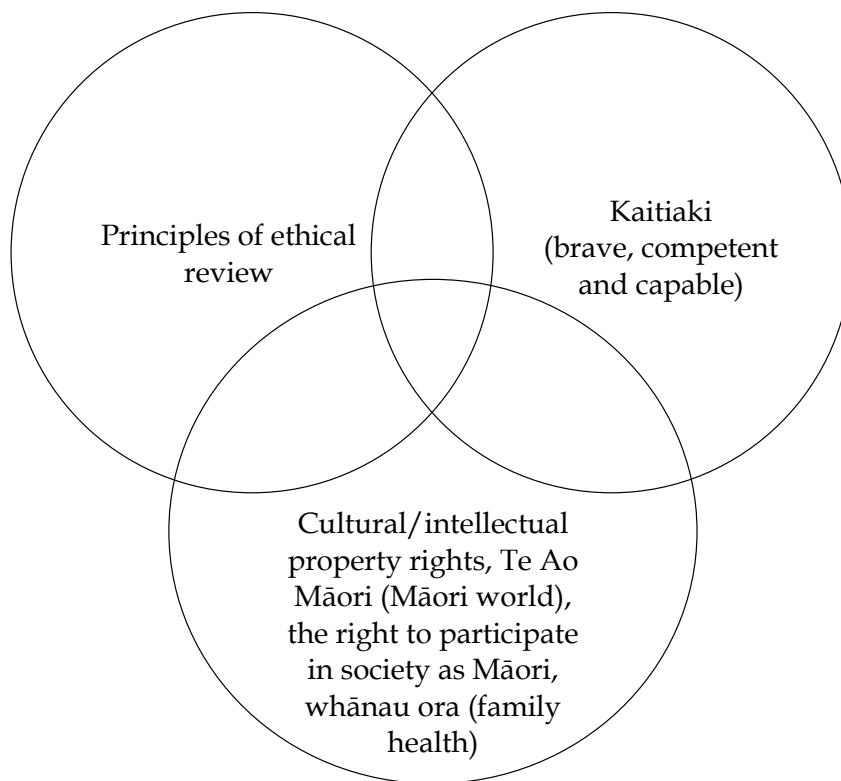


Figure 1: The roles and responsibilities of Māori ethics committee members

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 (traditional knowledge), 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.

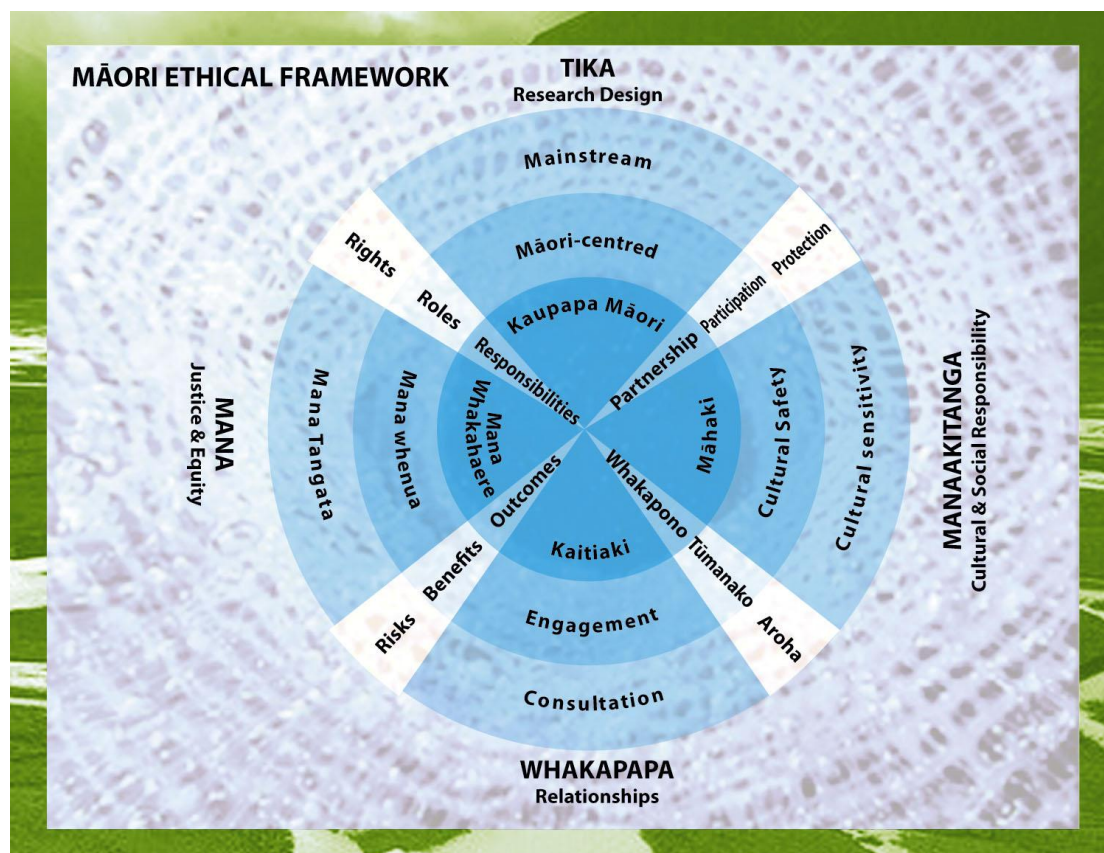


Figure 2: Māori ethical framework

The Māori ethics framework references four tikanga based principles (whakapapa (relationships), tika (research design), manaakitanga (cultural and social responsibility), and mana (justice and equity) 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 Ministry of Health's Operational Standard for Ethics Committees¹⁰.

Each segment is divided into three 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 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 (faith), tūmanako (aspirations) and aroha (awareness).

¹⁰ Ministry of Health (2006). Operational Standard for Ethics Committees. Wellington, New Zealand, Ministry of Health.

The process of ethical review can be thought of in terms of tapu (restricted) and noa (unrestricted). 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*

*RESTRICTED → careful consideration → precise analysis →
 robust discussion → determine these conditions →
 proceed with understanding → UNRESTRICTED*

Whakapapa – He aha te whakapapa o tēnei kaupapa?¹¹

Whakapapa is used to explain both the genesis and purpose of any particular kaupapa (topic/purpose). 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.

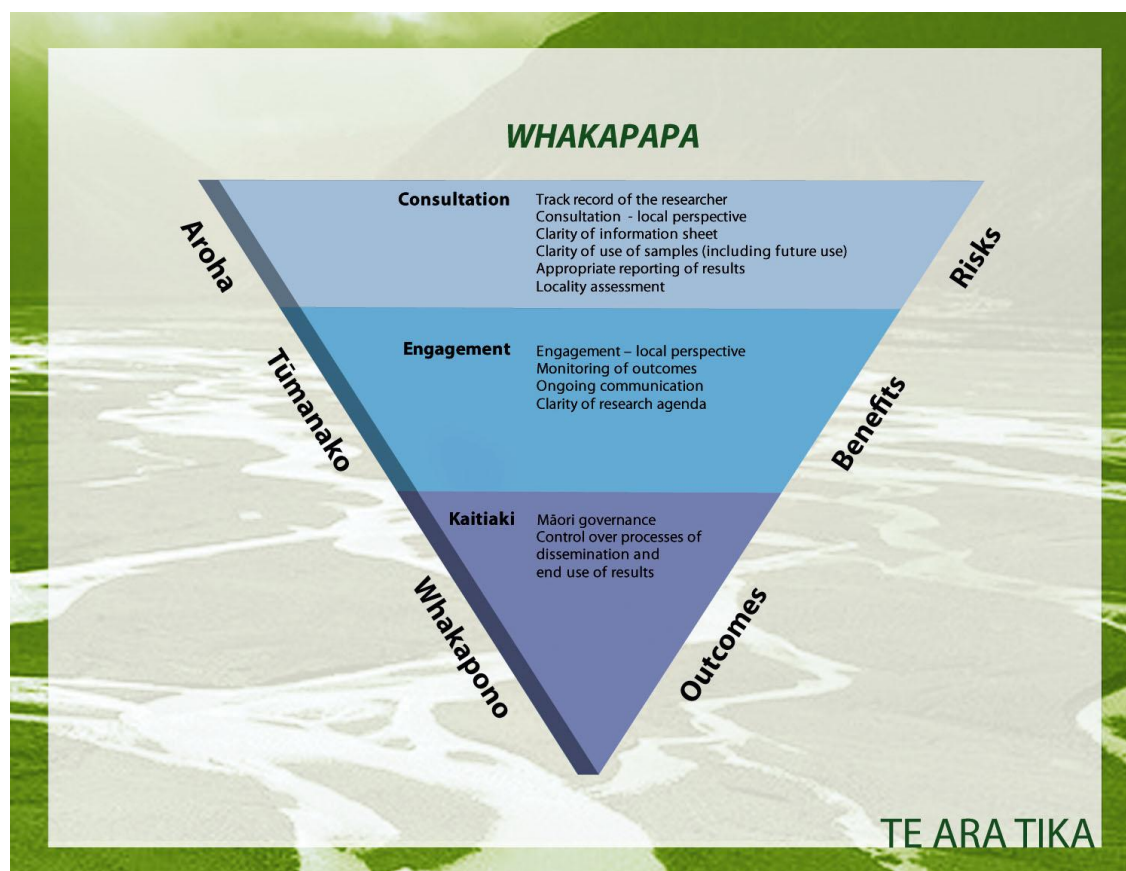


Figure 3: Whakapapa

Minimum standard: Consultation

An element of **aroha** (care) or aro ki te ha (awareness) 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' (*to be careful and aware of the potential dangers in the sea*). 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.

¹¹ What is the genesis of this project?

Consultation^{12 13} ensures that 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 taken¹⁴, provide a mechanism for reporting back results to appropriate parties¹⁵ and allow issues regarding the research scope and agenda¹⁶ to be discussed. These are considered minimum requirements and should be reflected in the locality assessment and section F of the ethics application.¹⁸

Questions asked should 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** (aspirations) and tangible **benefits** are derived. Where research is clearly Māori centred 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.

Questions 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** (hope) and the whakatauki (proverb) "*kia u ki te whakapono, kia aroha tetahi ki tetahi*" (Hold strong to your beliefs and care for one another). 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.

¹² Ministry of Health (2006). 2.2.37, p. 9.

¹³ Ministry of Health (2006). Appendix 8, Partnership 381-382, p. 79.

¹⁴ Ministry of Health (2006). 2.2.33, p. 9.

¹⁵ Ministry of Health (2006). Appendix 8, Points to consider 386, p. 80.

¹⁶ Ministry of Health (2006). 2.0.23, p. 6.

¹⁷ Ministry of Health (2006). 2.7.82, p. 17.

¹⁸ Ministry of Health (2009). National Application Form for Ethical Approval of a Research Project v1, Section F, 'Cultural and social responsibility'.

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 monitoring¹⁹ 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, hapū and whānau the prime recipients or contributors of results?
- what mechanisms are in place to optimise benefits to participants?
- is there an adequate monitoring mechanism?

Tika – Me pehea e tika ai tēnei kaupapa?²⁰

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**²¹ proposal. 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.

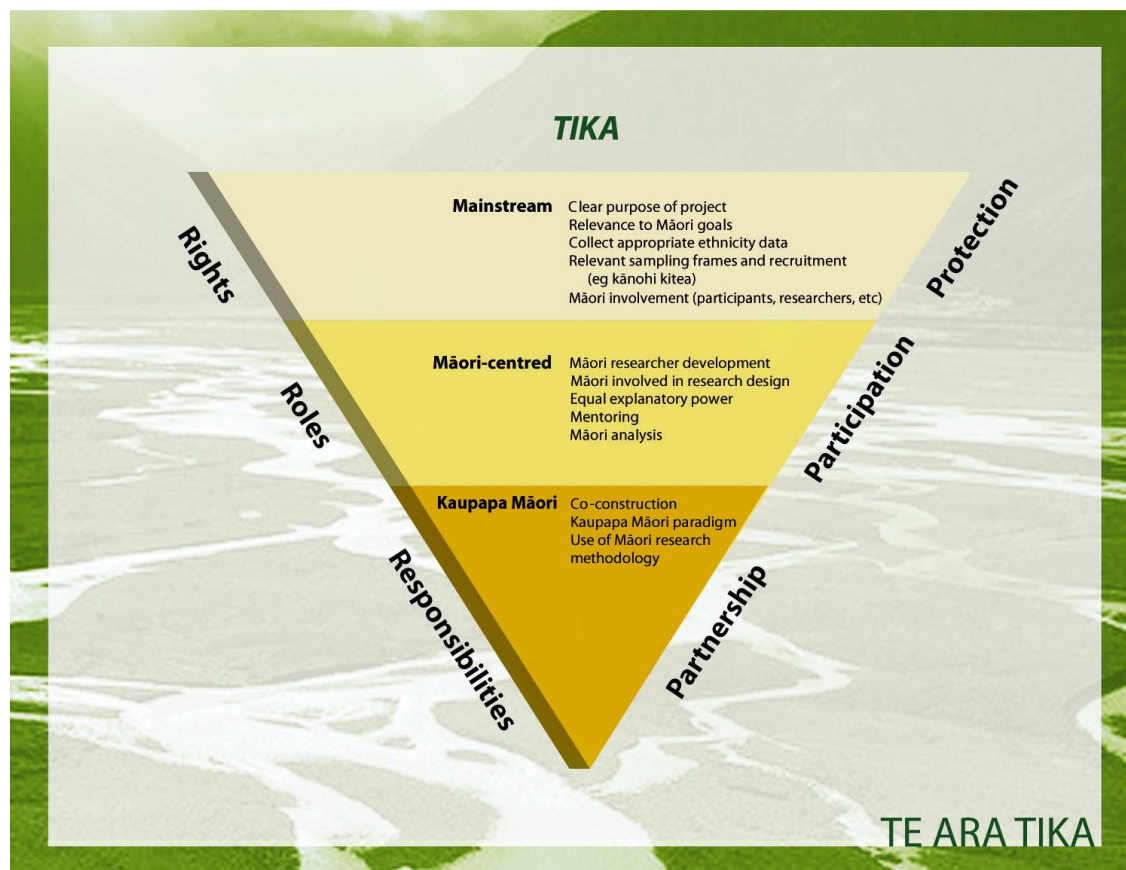


Figure 4: Tika

¹⁹ Ministry of Health (2006). Appendix 8, 378, p. 78.

²⁰ How will the project proceed correctly?

²¹ Ministry of Health (2006). 2.4, p. 13.

Respectful relations with Māori and mana whenua (regional authority) 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-centred, and Mainstream, (see Appendix D) are considered in relation to the Treaty of Waitangi principles of partnership, participation and protection.

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^{22 23} and its relevance to Māori goals^{24 25}. If Māori are involved as participants²⁶ then it is important to consider the recruitment methods, for example kanohi-ki-te-kanohi (face to face) and the sampling frameworks, and whether it is relevant and appropriate to collect ethnicity data²⁷. 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 asked should 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-centred

Research designs that give Māori a greater level of **participation** within the research process are encouraged. Māori-centred 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^{28 29}, the role of mentors and Māori researcher development³⁰, use of sampling frameworks that allow equal explanatory power³¹ and Māori involvement in analysis^{32 33}.

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?

²² Ministry of Health (2006). 2.4.57, p. 13.

²³ Ministry of Health (2006). 2.6.73, p. 15.

²⁴ Ministry of Health (2006). 2.7.82, p. 17.

²⁵ Ministry of Health (2006). Appendix 8, Participation 383, p.79.

²⁶ Ministry of Health (2006). 2.6.74, pp. 15-6.

²⁷ Ministry of Health (2006). 2.4.57, p. 13.

²⁸ Ministry of Health (2006). 2.5.66, p. 14.

²⁹ Ministry of Health (2006). 2.0.23, p. 6.

³⁰ Ministry of Health (2006). 2.6.73, p. 15.

³¹ Ministry of Health (2006). 2.4.57, p. 13.

³² Ministry of Health (2006). 2.4.57, p. 13.

³³ Ministry of Health (2006). 2.0.23, p. 6.

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 project³⁴, supports kaupapa Māori theory³⁵ and uses Māori research methodologies as appropriate^{36 37}.

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?³⁸

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

Manaakitanga – Mā wai e manaaki tēnei kaupapa?³⁹

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**⁴⁰ and **respect for persons**⁴¹.

Minimum Standard: Cultural Sensitivity

The minimum standard for manaakitanga acknowledges a persons inherent dignity⁴² and the responsibility that 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 (e.g. kaumātua (elder), advocate)^{43 44} and respect for concepts of **privacy and confidentiality**⁴⁵.

³⁴ Ministry of Health (2006). 2.3.56, p. 12.

³⁵ Ministry of Health (2006). 2.4.61, p. 14.

³⁶ Ministry of Health (2006). 2.0.32, p. 6.

³⁷ Ministry of Health (2006). Appendix 8, Participation 383, p. 79.

³⁸ Smith, L. T., *Decolonizing methodologies: Research and Indigenous peoples*, New York: Zed Books, 1999, p.173.

³⁹ Who will ensure respect is maintained?

⁴⁰ Ministry of Health (2006). 2.7, p. 16.

⁴¹ Ministry of Health (2006). 2.1, p. 6.

⁴² Ministry of Health (2006). 2.7.77, p. 16.

⁴³ Ministry of Health (2006). 2.1.24-26, p. 6.

⁴⁴ Ministry of Health (2006). 2.7.77, p. 16.

⁴⁵ Ministry of Health (2006). 2.3, p. 11.

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 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.

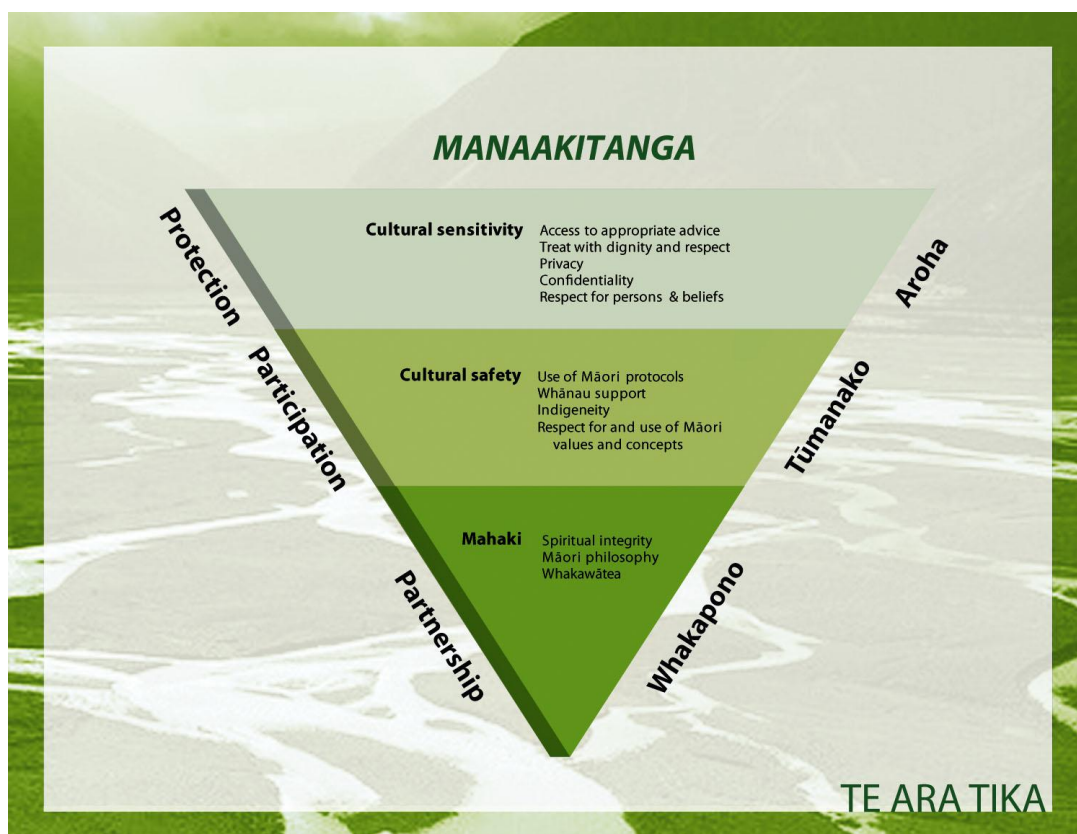


Figure 5: Manaakitanga

Questions asked should 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 and 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**)^{46 47 48} of a research project and its **culturally safe** implementation⁴⁹. This is enhanced by considering the inclusion of Māori values and concepts^{50 51 52 53 54} indigenous values and concepts, and allowing for the use of whānau support^{55 56} and appropriate Māori protocols⁵⁷.

⁴⁶ Ministry of Health (2006). 2.7.82, p. 17.

⁴⁷ Ministry of Health (2006). 2.6.73, p. 15.

⁴⁸ Ministry of Health (2006). Appendix 8, Protection 384, p. 79.

⁴⁹ Ministry of Health (2006). Appendix 8, Protection 384, p. 79.

⁵⁰ Ministry of Health (2006). 1.5.14, p. 3.

Questions of relevance include:

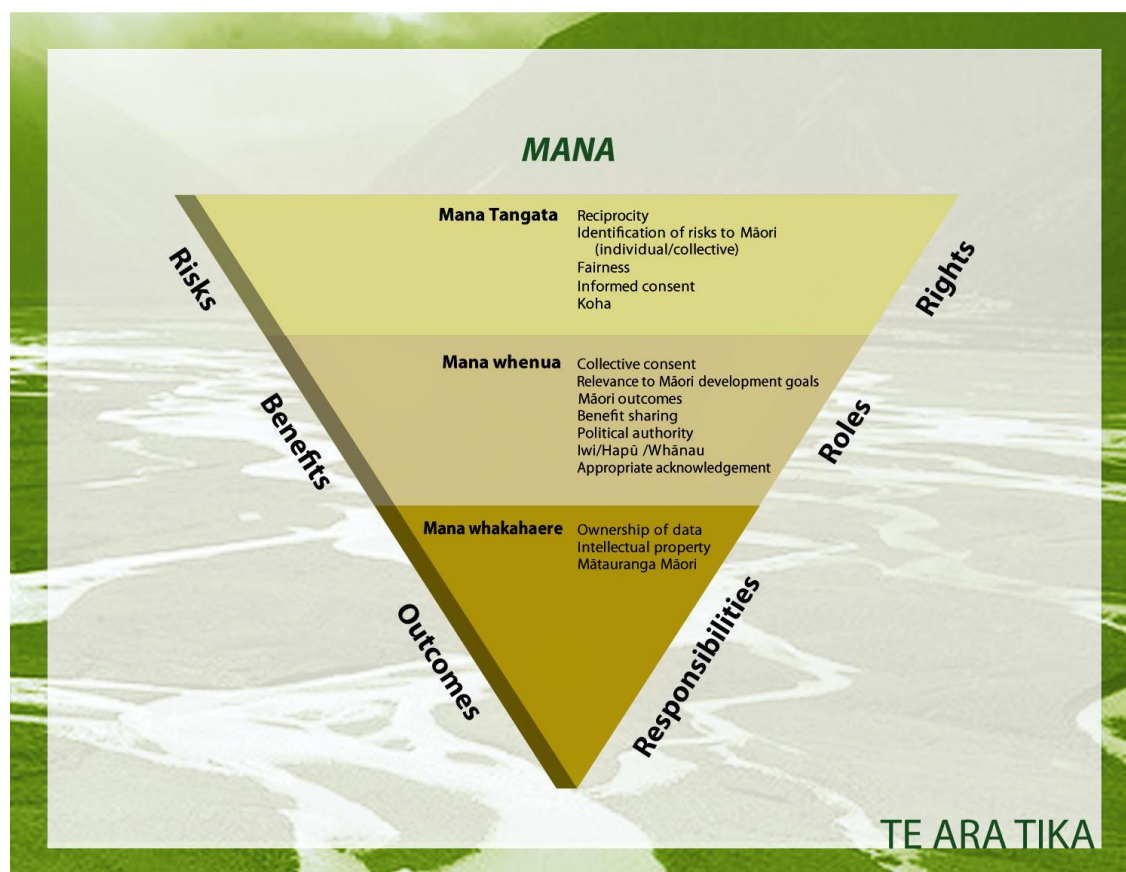
- are Māori values or concepts used within this research project?
- how will Māori protocols be observed as part of the research project?
- are whānau able to support participants within this project?

Best Practice: Māhaki

Manaakitanga is fully realized in the context of relationships. Here mana akiaki (empowerment) empowers **partnerships** whose quality is enhanced by the level of the parties' faith and trust in each other (**whakapono**). Extending beyond cultural safety, **māhaki** (respectful conduct) acknowledges the importance of recognizing spiritual integrity⁵⁸, Māori philosophy⁵⁹, and may include processes like whakawātea (realignment) 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?⁶⁰**Figure 6: Mana**

⁵¹ Ministry of Health (2006). 2.0.23, p. 6.

⁵² Ministry of Health (2006). 2.5.66, p. 14.

⁵³ Ministry of Health (2006). 2.7.79-81, p. 16.

⁵⁴ Ministry of Health (2006). Appendix 8, Protection 384, p. 79.

⁵⁵ Ministry of Health (2006). 2.0.23, p. 6.

⁵⁶ Ministry of Health (2006). 2.7.77, p. 16.

⁵⁷ Ministry of Health (2006). Appendix 8, Protection 384, p. 79.

⁵⁸ Ministry of Health (2006). 2.0.23, p. 6.

⁵⁹ Ministry of Health (2006). Appendix 8, Protection 384, p. 79.

⁶⁰ Who has control over the project?

Minimum standard: Mana tangata

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 equity⁶¹ and distributive **justice**⁶². 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.

Mana Tangata (autonomous individual), 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)^{63 64}, fairness in terms of their distribution⁶⁵ and the place of koha^{66 67}. Providing clear understanding of the requirements for informed consent⁶⁸, and recognising the place of oral consent in some Māori settings⁶⁹ is integral to demonstrating respect for the mana of Māori participants.

Questions asked should 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?
 - minimisation 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 hapū who are recognized as having regional authority and a primary **role** discerning **benefits** and making decisions around resource management and research being done in their rohe pōtae (tribal area)^{70 71 72}. Researchers should be establishing meaningful relationships with mana whenua at the research design/conceptual stage to ensure the research provides outcomes for Māori^{73 74 75} and provides opportunities to explore benefit sharing arrangements⁷⁶.

⁶¹ Ministry of Health (2006). 2.6.73, p. 15.

⁶² Ministry of Health (2006). 2.6, p. 15.

⁶³ Ministry of Health (2006). 2.0.23, p. 6.

⁶⁴ Ministry of Health (2006). 2.5.64-72, pp. 14-5.

⁶⁵ Ministry of Health (2006). 2.6.73, p. 15.

⁶⁶ Ministry of Health (2006). 2.2.43, p. 10.

⁶⁷ Ministry of Health (2006). 2.7.85-6, p. 17.

⁶⁸ Ministry of Health (2006). 2.2, p. 7.

⁶⁹ Ministry of Health (2006). Appendix 8, Protection 384, p. 79.

⁷⁰ Ministry of Health (2006). 2.0.23, p. 6.

⁷¹ Ministry of Health (2006). 2.3.55, p. 12.

⁷² Ministry of Health (2006). Appendix 8, Protection 384, p. 79.

⁷³ Ministry of Health (2006). 2.6.73, p. 15.

⁷⁴ Ministry of Health (2006). 2.7.82, p. 17.

⁷⁵ Ministry of Health (2006). Appendix 8, Protection 384, p. 79.

⁷⁶ Ministry of Health (2006). 2.6.73, p. 15.

Recognizing the mandated authority of hapū and iwi^{77 78 79} acknowledges the role they have in dealing with issues around consent. It may be appropriate to recognise ethical requirements for 'collective consent'^{80 81 82 83} 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 back to besides funders/institutions?
- 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 hapū, iwi or relevant Māori communities who assume the **responsibility** for the **outcomes** of the project. This presupposes engagement with Māori as mana whenua. Mana whakahaere represents Māori control within the research project and includes acknowledgement of iwi intellectual property⁸⁴, their knowledge systems (Mātauranga Māori)⁸⁵, ownership of research data^{86 87 88} 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, Mataawaka (Māori living within the area not related to local iwi), 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?

⁷⁷ Ministry of Health (2006). 2.0.23, p. 6.

⁷⁸ Ministry of Health (2006). 2.3.55, p. 12.

⁷⁹ Ministry of Health (2006). Appendix 8, Protection 384, p. 79.

⁸⁰ Ministry of Health (2006). 2.2.40-1, p. 10.

⁸¹ Ministry of Health (2006). 2.3.56, p. 12.

⁸² Ministry of Health (2006). 2.0.23, p. 6.

⁸³ Ministry of Health (2006). 2.7.78, p. 16.

⁸⁴ Ministry of Health (2006). Appendix 8, Protection 384, p. 79.

⁸⁵ Ministry of Health (2006). Appendix 8, Protection 384, p. 79.

⁸⁶ Ministry of Health (2006). 2.0.23, p. 6.

⁸⁷ Ministry of Health (2006). 2.3.55, p. 12.

⁸⁸ Ministry of Health (2006). Appendix 8, Protection 384, p. 79.

Special ethical considerations

This section outlines areas of special ethical consideration.

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.

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 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 participate⁸⁹. 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 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 of results

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.

⁸⁹ Hudson, M. (2009). Think Globally, Act Locally: 'Collective Consent' and the Ethics of Knowledge Production. *International Social Science Journal*. Accepted for publication.

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 outcomes⁹⁰. 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 (IP) rights through a range of mechanisms; the Treaty of Waitangi (article two: protection of taonga (resources), the United Nations Declaration on the Rights of Indigenous Peoples⁹¹, the Waitangi Tribunal (Wai 262)⁹² and the Mataatua Declaration⁹³ (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.

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 following table identifies some criteria for assessing the appropriateness of the representative body.

⁹⁰ Hausman, D. (2008). Protecting groups from genetic research. *Bioethics*. Vol 22(3), pg 157-165.

⁹¹ UN General Assembly, *United Nations Declaration on the Rights of Indigenous Peoples : resolution / adopted by the General Assembly*, 2 October 2007, http://www.un.org/documents/instruments/docs_en.asp?type=declarat.

⁹² More information on this claim can be found on the Waitangi Tribunal website at: <http://www.waitangi-tribunal.govt.nz/inquiries/genericinquiries2/florafauna/>.

⁹³ The Mataatua Declaration on Cultural and Intellectual Property Rights of Indigenous Peoples (1993). <http://www.ngatiawa.iwi.nz/cms/CMSFiles/File/Associations/mataatua%20declaration.pdf>.

Table 1: Assessing appropriateness of Māori consultation

| | Mana Whenua / Tangata Whenua | Institution-based group (DHB/University) | Other consultation group (e.g. Mataawaka) | Health professionals (e.g. Te Ora Māori Doctors) |
|---|------------------------------|--|---|--|
| 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 e.g. risk assessment tool, checklist | | | | |
| Relationships with other groups e.g. DHB representative | | | | |
| Current process for feedback, discussion, reporting | | | | |
| Capacity to engage in consultation, e.g. time, resources, expertise | | | | |
| Willingness to engage with ethics committee | | | | |

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 , for example health promoting events
- Researcher development for example qualifications and research experience
- Knowledge advancement, for example research outputs, hui (meetings/seminars) and wānanga (workshops/teaching sessions)
- Development of mātauranga Māori

Benefit to society

- Knowledge advancement for example research outputs, hui and 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 Ministry of Health’s Operational Standard for Ethics Committees (2006) and the majority of the concepts and issues identified within the Māori ethical framework are referenced within the Operational Standard for Ethics Committees. To gain a fuller appreciation of Māori ethical concepts, issues and concerns, additional training should be undertaken.

Glossary of Māori terms

Disclaimer: Many of the descriptions used in this glossary are specific interpretations for the purposes of this document and do not denote the fullness of meaning normally associated with the word or term.

| | |
|----------------------------------|---|
| Tikanga | Protocols and practises |
| Kawa | Primary values |
| Mana | Justice and equity, reflected through power and authority |
| Kaitiaki | Guardian/advocate |
| Whānau | Family, including extended, may not be blood ties |
| Te Ao Māori | Māori world |
| Whānau ora | Family health |
| Mātauranga | Traditional knowledge |
| Whakapapa | Relationships |
| Tika | Research design |
| Manaakitanga | Cultural and social responsibility |
| Whakapono | Faith |
| Tūmanako | Aspirations |
| Aroha | Care |
| Aro ki te ha | Awareness |
| Tapu | Restricted |
| Noa | Unrestricted |
| Kia Tūpato | To be careful |
| Kia āta-whakaaro | Precise analysis |
| Kia āta-korero | Robust discussion |
| Kia āta-whiriwhiri | Consciously determine |
| Kia āta-haere | Proceed with understanding |
| Kaupapa | Topic, purpose |
| Kia aroha ki a Tangaroa | To be careful and aware of the potential dangers in the sea |
| Mai i te whai ao ki te Ao Marama | Moving towards understanding |
| Whakatauki | Proverb |
| Mana Whenua | Regional authority, customary title over land |
| Kanohi ki te kanohi | Face to face |
| Kaumātua | Elder |
| Mana Akiaki | Empowerment |
| Māhaki | Respectful conduct |
| Whakawātea | Realignment |
| Mana Tangata | Autonomous individual |
| Rohe pōtae | Tribal area |
| Mana whakahaere | Shared power and control of outcomes and dissemination |
| Tangata whenua | People of the land |
| Mataawaka | Māori living within the area not related to local iwi |
| Taonga | Resources |
| Wānanga | Workshops, teaching sessions |
| Hui | Meetings, seminars |
| Hapū | Kinship group |
| Iwi | Tribe |

Appendix A: 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 Kōkiri publishes <i>Evaluation for Māori: Guidelines for Government agencies</i> (Te Puni Kōkiri, 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 |

| Date | Hui/Publication |
|------|---|
| 2003 | Hirini Moko Mead, <i>Tikanga Māori: Living by Māori values</i> |
| 2004 | Andrew Sporle & Jonathon Koea, <i>Māori Responsiveness in health and medical research</i> |
| 2004 | Mātauranga Tuku Iho Tikanga Rangahau, Ngā Pae o te Māramatanga hosts a Traditional Knowledge and Research Ethics Conference in Wellington |
| 2004 | Maui Hudson, <i>He Matatika Māori: Māori and Ethical Review of Health Research</i> |
| 2004 | Rachel Robson, <i>Māori framework for ethical review of health and disability research: Scoping report to the National Advisory Committee on Health and Disability Ethics</i> |
| 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. <i>The Ethics of Indigenous Peoples and Vulnerable Populations</i> |
| 2009 | Maui Hudson & Khyla Russell, <i>The Treaty of Waitangi and Research Ethics</i> |

Appendix B: 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 C: 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. |