

Guidelines for Researchers on Health Research Involving Māori

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VERSION 2



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Introduction

The Māori Health Committee of the Health Research Council of New Zealand (HRC) has produced these guidelines to assist researchers who intend undertaking biomedical, public health or clinical research involving Māori participants or research on issues relevant to Māori health. This includes projects focusing on Māori as a cohort and as part of the wider population being studied. This is a revision by the Māori Health Committee (MHC) of the guidelines released in 1998.

The guidelines will inform researchers about consultation and the processes involved in initiating consultation with Māori. The purpose of any consultation is to ensure that research contributes to Māori health development whenever possible. This consultation is also the foundation for co-operative and collaborative working relationships between researchers and Māori organisations and groups.

Version 2 of these Guidelines was created in 2010 to incorporate *Te Ara Tika. Guidelines for Māori Research Ethics: A framework for researchers and ethics committee members* as an appendix. *Te Ara Tika* outlines a framework for addressing Māori ethical issues within the context of decision-making by ethics committee members.

The Purpose of the Guidelines

The MHC has produced these guidelines to help develop:

- Research partnerships between health researchers and Māori communities or groups on issues important to Māori health.
- Research practices which ensure that biomedical, clinical and public health research effectively contributes to Māori health development whenever possible.

All health research conducted in New Zealand is of relevance to Māori. If researchers are intending to embark on any health research that involves Māori participants, then these guidelines may assist the research team in developing a research project in a culturally appropriate way and in a way that is responsive to Māori.

For more information on research of relevance to Māori health, researchers should refer to the HRC's *Nga Pou Rangahau Hauora Kia Whakapiki Ake Te Hauora Māori 2004-2008 – The Health Research Strategy to Improve Māori Health and Well-being 2004-2008* and the Ministry of Health's *He Korowai Oranga – Māori Health Strategy*. Researchers working within institutions also have access to assistance from established Māori advisory and ethics committees and these committees can be consulted as to the relevance of the research to Māori.

The guidelines are written specifically for applicants for HRC funding though they will generally assist with applications for funding from other sources. The guidelines provide an explanation of the MHC's requirements of research proposals which will involve Māori participants or a Māori health issue. These guidelines are also a reference and guide for referees and committee members who assess research proposals. Applicants for HRC funding should refer to these guidelines before completing HRC research proposal applications and the National Application Form for Ethical Approval. These guidelines should also be read in conjunction with the *HRC Guidelines on Ethics in Health Research* and the relevant application form guidelines.

The MHC's intent in these guidelines is to establish research practices which ensure that the research outcomes contribute as much as possible to improving Māori health and well-being, while the research process maintains or enhances mana Māori.

Why Involve Māori in Health Research?

Māori are the tangata whenua of New Zealand. As a Treaty partner and a priority population requiring appropriate health intervention, Māori involvement in health research is critical. Māori present disproportionately negatively in the majority of health and well-being statistics that have been gathered nationally.

The HRC's desire to increase Māori participation in health research arises from an intention for HRC-funded research to contribute as much as possible to the improvement of Māori health and well-being. This intention is reinforced by a combination of government policy, a desire to reduce Māori health disparities, and recognition of Māori as tangata whenua. Implementing these guidelines will often require additional work and effort – however, they should be seen as a way to enhance the quality of the research and the outcomes which are achieved.

The policy environment for health research

As the Crown's purchase agent for health research, the HRC's overall purpose is "*...to improve human health by promoting and funding research*" (Health Research Council Act 1990, section 4).

The ownership of HRC rests with the Minister of Health and the Government's *New Zealand Health Strategy*, released in December 2000, identifies priority areas and aims to ensure that health services are directed at those areas that will ensure the highest benefit for our population, focusing in particular on tackling inequalities in health. The need to improve Māori health is reflected throughout the principles, goals and objectives of the *New Zealand Health Strategy*. Two specific goals to improve Māori health provide for 'Reducing inequalities in health status' and 'Māori development in health'.

In relation to the first goal, the objective is to:

- Ensure accessible and appropriate services for Māori.

In relation to the second goal, the objectives are to:

- Build capacity for Māori participation in the health sector at all levels;
- Enable iwi/Māori communities to identify and provide for their own health needs;
- Recognise the importance of relationships between Māori and the Crown in health services, both mainstream and those provided by Māori;
- Collect high quality health and disability information to better inform Māori policy and research, and focus on health outcomes; and
- Foster and support Māori health workforce development.

The Ministry of Health's Strategic Research Agenda for He Korowai Oranga has three objectives:

- Continue to build an evidence base that contributes to the achievement of whanau ora, more effective service delivery for Māori and improved health and disability outcomes for whanau;
- Invest in high quality research and evaluation that contributes to the achievement of whanau ora, more effective service delivery for Māori and improved health and disability outcomes for whanau;

- Build Māori health research capacity that contributes to the achievement of whanau ora, more effective service delivery for Māori and improved health and disability outcomes for whanau.

The HRC is also accountable to the Minister of Research, Science and Technology. Pursuant to Operating Principles in the 2007/2008 Output Agreement with the Minister of Research, Science and Technology, the HRC is required to contribute to Māori advancement and development. Separate but complementary goals are used in Vote Research, Science and Technology to align research activities to the aspirations and needs of Māori. Māori development research is research carried out to consolidate and develop Māori knowledge and to deepen the Māori research skill base. This relates in particular to Article II of the Treaty of Waitangi. Māori advancement research is research that addresses the significant disadvantage of Māori relative to non-Māori in many areas and relates to Article III of the Treaty of Waitangi.

The HRC will invest in research projects that contribute to Māori development under the Māori Knowledge and Development output expense. The Council will also ensure that investments it makes contribute to Māori advancement under all other relevant output classes.

From those policy directions, there is recognition of a need for greater Māori involvement not only in Māori health research but in all areas of research which could result in health gain for Māori. As a consequence the HRC is seeking to support quality research that both involves Māori and has a resulting potential for increased health gain for Māori.

The Treaty of Waitangi

The Treaty of Waitangi is the founding document of New Zealand. The principles of partnership and sharing implicit in the Treaty should be respected by all researchers and, where applicable, should be incorporated into all health research proposals.¹

The HRC states its commitment to operate according to the principles of the Treaty of Waitangi in its Annual Report to Parliament. The HRC is committed to building both a sustainable Māori health research capacity and long term research partnerships between non-Māori researchers and Māori groups and communities. The underdeveloped nature of the current Māori health research workforce requires that partnerships between Māori communities and non-Māori researchers are made. Thus, collaborative research between Māori communities and non-Māori researchers is a key part of the accelerated development strategy for a Māori health research workforce. Such partnerships may provide training opportunities for emerging Māori researchers as well as providing information that contributes to Māori health development.

Baseline assumptions

This document was developed in the understanding that:

- Intending researchers are familiar with the principles of the Treaty of Waitangi, particularly that of partnership, and its implications for Māori health;
- Researchers are aware that informed consent can be required from both individuals and representative organisations (whanau, hapu or iwi - see the HRC [Guidelines on Ethics in Health Research](#));

¹ *Guidelines on Ethics for Health Research*, Health Research Council of New Zealand, 2002, p.1.

- The intended research is an ongoing collaboration between researchers and Māori communities or groups;
- The intended research is being undertaken to help address the significant differences in Māori and non-Māori health status;
- The researchers are committed to the goal of developing a high quality research project and the necessary processes required to ensure its effective implementation and completion.

Responsiveness to Māori

The HRC is required to demonstrate that its investment policies and assessment processes are responsive to the needs and diversity of Māori. Whilst this may be reflected in the alignment of individual research proposals to Māori Development and/or Māori Advancement, it is also an expectation that research provider institutions demonstrate the quality and extent of their partnership and relationship with Māori. Researchers should discuss with their host institution their policies and procedures with respect to consultation with Māori. The HRC may audit institutions to ensure appropriate processes are in place. To ensure that host institutions have met this requirement, the HRC requires a declaration on the Administrative Agreement, which forms part of each application, that consultation with Māori has taken place.

Considerations for researchers

In any research on a Māori health issue and/or involving Māori as participants, researchers need to start initial consultation and conversations with a variety of Māori and Māori groups before putting the research proposal together. Initial considerations should include the following:

- Does the research topic involve Māori as a population group?
- How will this proposed research project impact on Māori health?
- What are the benefits for Māori?
- How will Māori be involved? (e.g. as researchers, participants, advisors etc.)
- Which Māori could possibly be involved in this research project?
- If Māori researchers are involved in the research team, can a Māori researcher be the lead researcher?

Although this is not meant to be an exhaustive list of initial questions and considerations, it is designed to be a guide on what types of considerations researchers need to be cognisant of when devising a new research proposal.

It is extremely important, and strongly recommended, that researchers consult with Māori prior to a research proposal being devised. The benefits of including Māori in initial discussions about a new research proposal are huge.

The benefits to the researcher/research team include:

- Providing an opportunity for the researcher to articulate a research question to a particular audience;
- Providing the opportunity to develop clarity around the proposed project, its aims and its expected outcomes;
- Providing the opportunity for input and contributions by others to add to, build on and refine a proposed project;
- Building appropriate relationships in the initial stages of the research which will become invaluable later on for the success of the proposed project;
- Being able to discuss, develop and provide opportunities for building Māori workforce capacity from within the community.

The benefits for Māori include:

- Providing the opportunity for a voice in a project that may affect their own region, whānau, hāpū or iwi, or Māori generally;

- Providing the opportunity for meaningful engagement in the development of a research project which will be beneficial for Māori;
- Providing the opportunity to discuss and develop their own research ideas that are relevant research topics for their particular whānau, hāpū or iwi, or Māori generally;
- Providing the opportunity for community researchers to be involved in a research project of relevance to them and their community.

Kaupapa Māori research

There has been a growing movement by Māori to acknowledge Māori ways of knowing and conducting research. This philosophy has been encapsulated in the term 'kaupapa Māori research'. It is important for all researchers to have an awareness of kaupapa Māori research.

Kaupapa Māori research is just one part of the larger picture of indigenous research and the growing field of writing by indigenous academic writers that analyses indigenous ways of knowing and doing research. The emergence of indigenous research methodologies and theories, and kaupapa Māori research in particular, is a celebration and affirmation of indigenous ways and worldviews.

Kaupapa Māori research is philosophy, theory, methodology and practice of research for the benefit of Māori which is also produced by Māori. Critical to any research with Māori (as well as other indigenous peoples) are some fundamental questions:

- 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??

For non-Māori researchers who are conducting research that involves Māori health issues and/or involves Māori participants, kaupapa Māori research provides a guide for researchers considering their responsiveness to Māori.

Approaches to Māori health research

Researchers should also make themselves aware of the range of approaches to Māori health research, for example, kaupapa Māori research, Māori-centred research and research where Māori are involved as participants. The following chart provides the general characteristics of each type of research:³

² Smith, L. T., *Decolonizing methodologies: Research and Indigenous peoples*, New York: Zed Books, 1999, p.173.

³ To read more see Cunningham, C. 'The Foresight Project - Implementation. Māori Research and Development', *Healthcare Review Online*. 3(2) February 1999.

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 is 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 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.

Why Consult?

Consultation is a vital step in the development of a research project that involves Māori - either as participants or when the topic is of particular relevance to Māori health. The consultation process can lead to the development of research partnerships, the identification of the most useful research design methods, the resolution of contentious issues, and the maximisation of the potential health outcomes.

Research partnerships and co-operation

Consultation is also an excellent way of arriving at and sustaining a research partnership with Māori researchers and/or communities. To avoid suspicion and build trust meaningful consultation will need to take place.

Despite the urgent need for high quality Māori health research, it is common to encounter a perception among Māori that they are over-researched, and that much previous research has been, at best, of no benefit to Māori and at worst, actively disempowering. The researchers involved may not have intended their activities to be viewed with such misgivings. It is nevertheless important that these issues are considered and that efforts are made to address any potential conflicts or misunderstandings. Consultation assists in erasing this mistrust and building a more cooperative environment for current and future research activities.

Research topics and design

Defining a research topic

The research topic may be defined and enhanced as a result of consultation with Māori. A Māori community may convey a health issue to a researcher who could assist in the formulation of research questions which, if investigated, could result in useful information.

Alternatively a researcher may have their research topic reshaped to meet the health needs of a particular community. Such consultation at the outset helps ensure that both the researchers and the Māori community will benefit from the research project by matching research interest with local health needs. It is important that the researcher and the community have a clear understanding of the other party's expectation of the likely and possible outcomes of the research. The researcher must ensure that the benefits of participation in a particular research project are not oversold and that any risks or negative consequences are fully explained.

It is important to note that a researcher's perceptions of priorities for Māori health may differ substantially from those of particular Māori communities or groups, who may consider other issues more pressing than the researcher's chosen topic. Therefore a researcher planning a piece of research may encounter a less than enthusiastic response from the intended participants.

Such a response will require sincere consultation and negotiation to work through. With researcher-initiated research, it is strongly recommended that researchers consult with Māori as early as possible to ensure the acceptability of the intended research topic prior to the time-consuming process of developing the proposal. Again, these processes and activities are designed to enhance the research process and to ensure that potential benefits of the study are realised.

Research design

Consultation can also help identify the most suitable research methods and recruitment strategies. There may be significant differences of approach required within a Māori research sample due to iwi affiliation, ability with Te Reo Māori, age, geographic location and education. Some geographic areas with large Māori populations such as South Auckland may have been over-exposed to research or certain research tools by market researchers, making new research difficult.

The initial advice a researcher receives from within their host organisation may point to general methodological issues for the intended research topic. Subsequent local consultation and collaboration may provide valuable insights into what recruitment strategies and research methods will be best suited to the intended participants. It may also help to avoid problems arising from cultural and socio-economic differences, as well as previous over-exposure to some research techniques.

Resolving potentially difficult or contentious issues

A major benefit of consultation is to help resolve possible contentious or difficult issues in the research process before the research project starts. Initial and ongoing consultation can prevent problems from arising in the research process which may be unforeseen by researchers working alone. It can also provide mechanisms for overcoming any problems that may develop. Issues such as intellectual property rights, access to data, publication processes, accountability, authorship, storage of information and allocation of research funding can all be resolved in this manner.

Many researchers find it extremely difficult recruiting Māori as participants in research projects. Consultation provides an ideal mechanism for a study to be publicised through local networks. A study that has the overt endorsement of the local Māori community is less likely to have problems in recruiting participants.

Researchers should be aware that consultation may reveal that resolution of some research issues may not be possible. In such instances those involved could contact the HRC for further advice in resolving outstanding issues. However, the group's right to decline to proceed with research within their whānau, hāpū or iwi if the project is unacceptable to them, is paramount: see paragraph 4.5 of the *HRC Guidelines on Ethics in Health Research* (2002).

Maximising the benefits of research

Researcher development

The MHC regards development of research skills as one of the key benefits of effective research partnerships. Research projects on issues relevant to Māori health or that involve Māori participants provide excellent opportunities for researchers, students and communities to acquire new skills that are able to be applied in later research.

A mechanism of mutual mentoring can be established where the researchers provide research advice and other support to the community or group, which in turn assists with the development of the research project.

The process of consultation could lead to the development and implementation of novel research strategies that would be a learning experience for even the most senior researcher. Researchers not only acquire cross-cultural skills and experiences, but they can be exposed to

new research skills including recruitment methods, dissemination strategies and research tools.

In turn, experienced researchers are able to provide training and supervision to emerging Māori researchers seeking a practical component to their academic training. There is a shortage of Māori researchers, especially in the biomedical and clinical research fields, so opportunities to develop expertise here should be explored where possible.

The MHC is keen for researchers to use research projects as training opportunities to speed development of the Māori health workforce in all research fields. Such training opportunities could be supported by one of a range of career development awards for emerging Māori researchers.⁴

In this way the MHC is able to support an emerging researcher to get hands-on research training with an established researcher, while the research team benefits by having additional staff that are supported by the HRC. Alternatively, emerging researchers could be resourced as research staff on the primary grant.

As well as intending career researchers, local Māori can be provided with research skills which could have broader application than the current research project. Upskilling key members of the local community in research processes and accessing funding is an excellent way of assisting local Māori health development while providing a research workforce for the researcher's current project. HRC funds may also be available to support these activities, via an HRC Rangahau Hauora Award or the primary grant.

Dissemination of results

It is important that research results contribute to Māori development. This pragmatic approach requires that researchers consider how the results of the intended research will be disseminated and utilised, and outline their dissemination plan in the application. Consultation and ongoing dialogue should determine the appropriate dissemination strategies for the results of a particular project, making research-based information available in a suitable format and timely manner. Potential audiences for such information include Māori health organisations, health providers, Māori representative organisations, policy makers, other researchers and the community from which the information was sourced. By making research information accessible in this way, researchers maximise the project's potential benefits, and therefore its suitability for funding. They also minimise the risk of damage caused by the inappropriate circulation of confidential information.

Dissemination can be supported by either the primary research grant or an HRC Grant-in-Aid. Dissemination is particularly important when Māori have been participants in the research project. Māori have often found it difficult to gain access to, and therefore benefit from, health research findings. Dissemination of research information should be organised to include presentation of results, in an appropriate form, back to the community or group which supplied the information, before publication of the study. Some instances where Māori have been powerless to stop the inappropriate dissemination of information have generated unease within Māori communities. Researchers must take care to ensure that Māori participants understand and agree on which information is to be published in what formats and forums.

Permission to collect and analyse potentially sensitive information does not serve as a proxy to publish such information. Publication may be possible but the format needs to be

⁴ For more information on Career Development Award opportunities offered by the HRC see www.hrc.govt.nz

negotiated with the Māori community involved. If the research topic is relevant to Māori health, it is strongly recommended that the results are provided in a format which is suited to the particular needs of the relevant organisation.

Other opportunities

In situations where the likely utility of the results for Māori is less certain, it may be possible for the research process to contribute in other ways. Examples include providing some employment for local people on the research project or by providing health checks as separately funded additions to the project. Again, these issues should be worked through in conjunction with participant representatives and in recognition of the strong sense of ownership Māori feel towards information originating from their community.

When to Consult?

Is consultation required?

The purpose of any consultation is to ensure that research practices are appropriate and acceptable, and that outcomes contribute to Māori health development whenever possible. Consideration of whether or not consultation is required should be based around the purpose of the consultation process - to ensure that the research outcomes contribute as much as possible to improving Māori health and well-being, while the research process maintains or enhances mana Māori.

As a general rule, consultation should take place if Māori are to be involved as participants in a project or the project relates to a health issue of importance to Māori. You may need advice on whether the health issue is of importance.⁵ The extent of any consultation should always be appropriate to the scale of the intended project, its relevance and significance to Māori health and the potential for application of the research results.

Responsibility of host institutions

The HRC is committed to demonstrating that its investment policies and assessment processes are responsive to the needs and diversity of Māori. There is also an expectation that research provider institutions demonstrate the quality and extent of their partnership and relationship with Māori in the portfolio of research applications submitted to the HRC. Researchers should discuss with their host institution their policies and procedures with respect to consultation with Māori. To ensure that host institutions have met this requirement, the HRC requires a declaration on the Administrative Agreement, which forms part of each application, that appropriate consultation with Māori has taken place.

Key times to consult

Early in the research design

Consultation should begin as early as possible in the research process. Ideally this should be before the research topic is finalised to allow for potential changes to the research design. As a general rule, the later the consultation begins the more difficult and less successful it is likely to be.

Consultation should not be initiated once the research proposal has been completed, as this post-fact endorsement precludes effective Māori input into the research proposal, making true co-operative collaboration extremely difficult. Seeking this type of endorsement is highly likely to be unsuccessful, thereby resulting in much wasted effort in drawing up the proposal.

Throughout the project

Consultation should be ongoing throughout the project via whatever means are mutually agreed upon at the initial negotiations. Researchers should involve representatives of the community in as many facets of the research process as possible. In a medium to long term study (six months and more) regular contact should be kept with the community in order to

⁵ Universities, tertiary institutions and District Health Boards generally have Māori Research Review Committees who are able to decide whether a project is relevant to Māori.

update them on progress, and allow their representatives opportunities to contribute to the project's ongoing development.

While this process may be time consuming for all parties, it is essential to develop a co-operative working relationship between the researchers and the representatives of the research participants, so that the benefits outlined above are realised. Research budgets should also take these types of activities into account in light of costs which might be incurred.

Dissemination of results and beyond

The research partnership should ideally extend beyond the completion of the project and include the dissemination of the results. Such follow-up can provide opportunities for sharing ideas on the utilisation of research results and may lead to future research opportunities.

As a result of such ongoing dialogue, some researchers have established long term mutually beneficial research partnerships with Māori communities, which have extended well beyond the initial research project.

These partnerships have demonstrated that, notwithstanding occasional difficulties, ongoing consultation results in innovative, widely supported research projects providing high quality information to researchers and participants alike.

Who to Consult?

There are no set rules for consultation. The nature and extent of consultation is dependent upon:

- The intended research project's relevance to Māori health issues;
- The intended research project's degree of involvement of Māori participants;
- The research methodologies to be utilised;
- The size of the intended project;
- The intended research project's location;
- Any existing relationship with the Māori community involved.

What is essential is that advice on a suitable consultation process be sought as early as possible and that all consultation processes be described (who gave what advice and when) in the grant application. Where approval or involvement has been sought, such approval or involvement should always be described in the application and supported by a letter from the Māori organisation or group concerned.

Consultation advice

The first step

The first step in any consultation should always be to seek local advice from within your own research group, department or institution. Subsequent consultation may take researchers beyond their own organisation, but the nature of this consultation should always be based on the initial advice received.

Advice on a suitable consultation process could be provided by peers with experience in undertaking research with Māori, Māori staff within your research group or department, or your organisation's Māori advisers, management or kaumātua. Such people should be relatively accessible and well placed to advise you as to a consultation process for your intended research proposal. It should be remembered that this first step does not in itself constitute consultation, but will inevitably guide the consultation process and ensure that the correct initial steps are undertaken.

Māori departments or research centres may be able to act as advisory bodies at this stage of a project's development but will not usually be funded to provide this type of advice. However, Māori research units may be potential research collaborators. Departments of Māori Studies can be an excellent source of recruiting Māori staff and research trainees to a project. Local Māori members of ethics committees may also be able to provide some good advice.

Seeking external advice

Where limited local resources are available to advise on a suitable consultation process, an intending researcher should contact either the local office of Te Puni Kōkiri (Ministry of Māori Development) or the HRC. Te Puni Kōkiri is able to direct researchers to local contact people, relevant Māori organisations and key contacts for consultation. Their contact details will be in your local telephone directory and often locatable through conducting simple web-based searches.

The HRC Kaiwhakahaere Rangahau Hauora Māori (Manager, Māori Health Research) is also able to suggest possible consultation processes and contact people. This advice should be sought before a research proposal is completed, and well in advance of the closing date for a grant round.

Consultation process

There are a number of key organisations that should be consulted to assist in the design of research projects on issues which are relevant to Māori health or which may involve Māori participants.

These organisations should be contacted formally and, if practicable, in person as early as possible in the research design process. It is advisable to meet with representatives of the relevant group or community face-to-face to discuss the proposed research and any concerns expressed by the group. This may take time and several meetings may be required. This should be allowed for when planning a research project. Please note however that these organisations are not generally funded to provide this kind of advice. It may be necessary therefore to compensate the organisation in some way for their time and expertise.

Māori health organisations

There are a number of issue-related Māori health organisations or Māori sections within general health organisations which should be contacted when designing a research proposal in their area of interest. Such groups are also potential end-users of research-based information, as well as useful advisers, advocates, co-investigators and sources of research staff and participants. As such their involvement could be extremely useful in maximising the potential utility of an intended project and actually carrying out the study itself.

Consultation with such organisations can lead to a lasting working partnership which enables the researcher to have direct links into Māori networks and end-users without having to build such links themselves. The organisations benefit as they are able to be involved and guide research activities in their area of interest as well as direct access to research-based information.

The local contact details for such organisations should be available from your initial source of consultation advice or from the local offices of Te Puni Kokiri.

Māori health research units

In recent years a number of Māori health research units have been established and are able to provide good advice on appropriate consultation strategies and approaches. These include:

- Tomaioa (Auckland)
- Whariki (Auckland)
- Te Pūmanawa Hauora (Palmerston North and Wellington)
- Te Rōpu Rangahau Hauora ā Eru Pomare (Wellington)
- Mihi (Christchurch)
- Ngai Tahu Māori Health Research Unit (Dunedin)

Māori health care providers

The health reforms of the early 1990s facilitated a significant increase in the number and range of Māori health care providers. Unlike many of the organisations mentioned in the section above, these providers are locally based rather than national bodies.

Consultation with local providers usefully illustrates how local Māori can be involved in the research project while ensuring that the project realises its potential to provide useful spin-offs to the local community.

The combination of initial and on-going consultation ensures that the needs of local healthcare providers are incorporated as much as possible into the project, by determining the most effective dissemination strategies to get the research results to those who can use them.

Timely and sincere consultation can result in a lasting partnership that provides useful benefits to all parties for the duration of the intended project while enhancing the prospects of further studies.

Contact details for these organisations should be available from your initial source of consultation advice within your own organisation. Further information can be obtained from *Takoa, Te Aka Kumara o Aotearoa, A Directory of Māori Resources and People* and the Ministry of Health.

Local Māori representative organisations

When a project involves Māori within a given geographical area as participants, an intending researcher should always contact local Māori representative organisations, advise them of the nature of the intended study and invite their comments and/or involvement.

The extent of such consultation should be determined by the initial advice the researcher receives about the size of and timeframe for the project. Large scale projects with Māori as a distinct research sub-group within the study would require more intensive consultation, while small general population studies such as clinical trials involving patients may require more modest input.

Tangata whenua/mana whenua

The tangata whenua should always be the first local representative organisation contacted by a researcher, as tangata whenua have mana whenua over Māori activities in their area. Tangata whenua organisations may involve iwi or hāpū level structures.

In some regions and for studies of large geographic areas there may be more than one tangata whenua organisation and all will require some level of consultation if consultation is required. If you are in any doubt as to who the tangata whenua are, contact your local Te Puni Kōkiri office.

Taurahere, pan-tribal or matawaka organisations

Many Māori live outside their rohe, or tribal area, especially those in urban centres. However, there are pan-tribal organisations in many cities representing taurahere/matawaka within the region. Pan-tribal organisations range from large scale enterprises running their own education, health and social services to small incorporated societies.

The development of research projects planned for urban centres and involving Māori as participants should involve some degree of consultation with such groups, depending on the initial advice process and the results of the consultation with tangata whenua. The nearest Te Puni Kōkiri office is able to provide the contact details for the local pan-tribal organisations.

Special issues

Where the intended research process may challenge Māori cultural values, or involve highly sensitive issues or breaches of tikanga, more intensive consultation is an absolute requirement, no matter how large the research project. This type of consultation should provide greater clarity on issues of whether or not Māori should in fact be involved.

Exclusion of Māori participants from a general population study for cultural reasons should only occur if this was a clear recommendation arising from the consultation process. Where ethnicity is a likely confounder in the health issue, it may be useful to undertake a parallel research project for Māori or exclude Māori from the general study.

Any such exclusion would have to be well justified and should not restrict the potential Māori health gains for the project. Exclusion from a study funded by a Crown agency should not occur due to the researchers' perceived difficulties in working with Māori participants and their values.

Research that breaches tikanga or involves culturally sensitive issues

Some research involves processes that for some Māori are culturally sensitive or which breach their value system. In such circumstances consultation is essential. Involvement of Māori in such research may be possible, but the extent of this involvement can only be determined by consultation and negotiation.

The MHC is keen to ensure that research processes do not contribute to the erosion of Māori cultural values. It is also essential that researchers are not considered as desecrators of tapu or tikanga, and therefore regarded as the sources of any perceived resulting ill effects. The impacts of such research processes on Māori participant recruitment, sample collection or result generalisability are secondary issues affecting the validity of the research project.

The MHC will not support HRC funding for any Māori involvement in research that breaches tikanga, unless such involvement is specifically endorsed by the tangata whenua of the area in which the research occurs. Such endorsement should be in writing and should reflect the resolution of a meeting of a representative body of the tangata whenua, and not an individual's opinion. If this documentation is received, the committee will yield to the exercise of mana whenua and tino rangatiratanga by the tangata whenua of the region and support funding for such activities. From a researcher's point of view this would require that the researchers seek advice from a Māori colleague or advisers in order to determine if a project or process is likely to be contentious. If there are any contentious issues, Māori involvement is to be determined as soon as possible by the representative body of the tangata whenua. Their decision is to be documented within the application and incorporated in the research design. The researcher should also provide strong justification for using that particular contentious research process, as well as provide a strong rationale for the study.

Genetic studies involving Māori participants

As genetic research technology becomes more widespread, there is a concurrent increasing demand to undertake genetic research on Māori populations. Māori are regarded by some in

the research community as providing an ideal founder population, with well described lineages and a high incidence of genetically mediated diseases amenable to study.

Genetic research is an extremely contentious issue amongst many Māori. Attitudes range from acceptance to total rejection. Intending researchers should familiarise themselves with the issues as outlined at the 1995 HRC Consensus Development Conference report *Whose Genes Are They Anyway?* (Baird et al, 1995). Māori at this conference expressed "support for genetic research that enhances quality of life for Māori as defined by Māori ... [if that research occurs] within the paradigms of a Māori world view" (ibid, p 3). There are also a number of Māori and indigenous academic critiques of new technologies and genetic research that provide an overview of how genetic research impacts on Māori and indigenous peoples (IRI, 2000; Reynolds, 2004; Gardiner, 1997; Harry and Dukepoo, 1998; Harry, 2000; Mead, 2003). In 2001 a report was released after the Royal Commission on Genetic Modification concluded. Within the report an overview of Māori responses to genetic research, genetic modification and engineering was compiled.

Genetic studies require access to both whakapapa knowledge and blood or tissue samples. The development of such studies requires close co-operation between the research team and the whānau concerned as well as thorough consultation with the iwi to which the whānau belong.

This process can be lengthy and occasionally difficult, but if undertaken in good faith such consultation will ensure the commitment of all parties to the project and minimise the potential difficulties in such a study. Any researcher starting to plan a genetic research project involving Māori is strongly recommended to contact the HRC Kaiwhakahaere Rangahau Hauora Māori.

Genetic research projects involving Māori require the approval of the iwi or hāpū organisation representing the whanau involved. This approval could be obtained in a hui of the representative body following discussion of the project and be documented in writing. Such approval must be appended to the grant application.

It is extremely important to be aware that informed consent for research should, in many cases, be gained from more than just an individual. It is also important for researchers to be aware that even though they may have received consent to gather whakapapa knowledge and/or blood, hair, saliva, tissue or other human samples, from a whānau member, whānau or even hāpū, the resulting findings from conducting such research are not generalisable to the Māori population at large.

Ethics review of health research proposals involving Māori⁶

The principles of the Treaty of Waitangi must be incorporated in the proceedings and processes of ethics committees; particularly relevant are the principles of:

- i. Partnership – working together with iwi, hapu, whanau and Māori communities to ensure Māori individual and collective rights are respected and protected
- ii. Participation – involving Māori in the design, governance, management, implementation and analysis of research, especially research involving Māori
- iii. Protection – actively protecting Māori individual and collective rights, Māori data, Māori culture, cultural concepts, values, norms, practices and language in the research process.

⁶ This section has been sourced from paragraphs 1.4 and 1.5 of the *Operational Standard*.

All parties involved in research and the delivery of health and disability services should respect the principles implicit in the Treaty of Waitangi. Research, innovative practice and the provision of services must be undertaken in a culturally sensitive and appropriate manner in full discussion and partnership with research participants and/or health and disability services consumers. The results of any research must be appropriately disseminated in a full and frank manner. The rights of research participants and consumers of health and disability services with regard to personal data must be respected.

Te Reo Māori is an official language of New Zealand and is highly valued by many research respondents. Research respondents should be offered the choice of responding in either Māori or English (or, alternatively, if people volunteer to respond in Māori, they should not be excluded for wanting to do so). If researchers are not fluent speakers of Māori, appropriate alternative arrangements should be made to enable respondents to communicate in Māori. Māori cultural concepts should be respected and supported through ethical review. Such concepts include Māori perspectives of health and well-being such as te taha tinana (the physical element), te taha wairua (the spiritual element), te taha hinengaro (the emotional and psychological elements) and te taha whanau (the family and community elements). Other important concepts are hauora, kaupapa Māori, and tikanga Māori.

Research involving Māori or Māori health should be considered on a case by case basis to assess whether or not the research project requires explicit inclusion of Māori ethical perspectives in ethical approval documentation. Māori ethical perspectives not only operate to ensure high quality research on Māori or Māori health, but also to ensure Māori participants, tikanga, and cultural concepts are protected. In most cases a decision about inclusion of Māori ethical perspectives will not be known until the research project is presented for approval.

Māori ethical perspectives will be important when the situation in question would normally require observance of tikanga Māori, such as research that involves working with whanau of Māori who have recently died and/or the body of the deceased. Another example is when a research project seeks knowledge which may be considered tapu by the respondents and therefore not usually available to outsiders. Such knowledge can be held by living respondents or contained in personal documentation that has not yet been made public.

In cases where non-Māori researchers are proposing research about Māori or Māori health, ethics committees should consider these proposals in light of the Treaty of Waitangi principle of participation and the need to protect Māori participants.

It is often helpful for both Māori and non-Māori researchers to establish a Māori Advisory Group or a Tikanga Māori Advisory Group who will have overall responsibility for guiding the research in terms of appropriate Māori practice, tikanga and customs, ethics and outcomes. Suggested membership for the advisory group includes: Māori health experts, local community representatives and experts, kaumātua and kuia, and Māori researchers within the field. This group would provide invaluable contributions to the research project, to the researchers and to communities.

A Consultation Checklist

Preliminaries

- Clarify the reasons for consulting.
- Specify the objectives and outcomes
- Select the most appropriate methods and types of consultation to achieve the outcomes.
- Calculate the costs and ensure funds are available.
- Ensure adequate lead-time for all parties to the consultative process.
- Understand and communicate with community organisations.

Preparations

- Make contact with and invite participation of community groups to help prepare for the consultations.
- Discuss costs and negotiate if necessary.
- Agree on an agenda and the facilities needed to achieve the objectives, including documentation, presentation speakers, venue, time and date, equipment, workshop leaders, plenary session and recording of input.
- List tasks and timelines. Allocate responsibilities and ensure communication channels are open.
- Dispatch invitations and otherwise promote, allowing time for participants to prepare themselves and be briefed.
- Agree on feedback mechanisms and post-consultation strategies.

The face-to-face consultation

- Ensure all necessary material is readily available and distributed.
- Ensure evaluation methods are understood and, if evaluation sheets are used, that they are collected.
- Ensure all reports, workshop proceedings, tapes and records are collected for subsequent processing.
- Decide what follow-up is required.
- Announce agreed feedback mechanisms.

Post-consultation

- Evaluate the consultation.
- Provide feedback to all concerned according to the agreed mechanisms.
- Plan future improvements in light of experience and evaluations.
- Ensure that appropriate action is taken to follow up the feedback from consultations.
- Ensure feedback continues as subsequent actions are taken, including explanations about why some community aspirations cannot be met.
- Finalise consultation minutes and reports.

References and Further Reading

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- Putaioara Writing Group (2010), *Te Ara Tika. Guidelines for Maori Research Ethics: A framework for researchers and ethics committee members*, Auckland, Health Research Council of New Zealand (attached as Appendix 1).

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- Royal Commission on Genetic Modification, *Report of the Royal Commission on Genetic Modification: Report and recommendations 2001*, Wellington: PrintLink, 2001.

Websites

The following websites contain useful references on Māori research practice and other issues related to Māori research:

- <http://www.kaupapamaori.com/>
This website is dedicated to kaupapa Māori research. This is a site dedicated to a discussion of issues related to kaupapa Māori. This website has been established to assist in the development of whanau, hapu and iwi. There are three main sections on the website, including: theory, research and action, and provides a one-stop shop for a variety of resources, academic research & reports, references, film and a discussion forum for Māori researchers.
- <http://www.rangahau.co.nz/>
This Māori led website was set up in mid-2007 in particular for Māori researchers to access information about research. It includes sections on: research idea, research proposal, ethics, methodology, method, analysis and knowledge exchange. It also has some insightful film clips of Māori researchers talking of their experience of research. This website would be useful for both Māori and non-Māori researchers.

**Appendix 1. Te Ara Tika.
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 Nuremburg Code (1947)⁷, the Helsinki Declaration (1964)⁸, the Belmont Report (1979)⁹ and, more recently, the UNESCO Universal Declaration on Bioethics and Human Rights (2005)¹⁰ 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-vis¹¹ 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 development¹².

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

⁷ The Nuremburg Code (1947). The Nuremburg Code is made up of ten ethical principles that govern human experimentation <http://ohsr.od.nih.gov/guidelines/nuremberg.html>.

⁸ 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.

⁹ Belmont Report (1979). National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research,

¹⁰ UNESCO Universal Declaration on Bioethics and Human Rights (2005). United Nations Educational, Scientific and Cultural Organisation (UNESCO) (2005).

¹¹ *In relation to*

¹² National Health and Medical Research Council (2003). Values and Ethics: Guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research. Canberra: 24.

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 world¹³.

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)¹⁴ the Māori ethics committee member sits alongside other members of the committee to implement the principles of ethical review.

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.

¹³ 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.

¹⁴ Ministry of Health (2006). Operational Standard for Ethics Committees. Wellington, New Zealand, Ministry of Health.

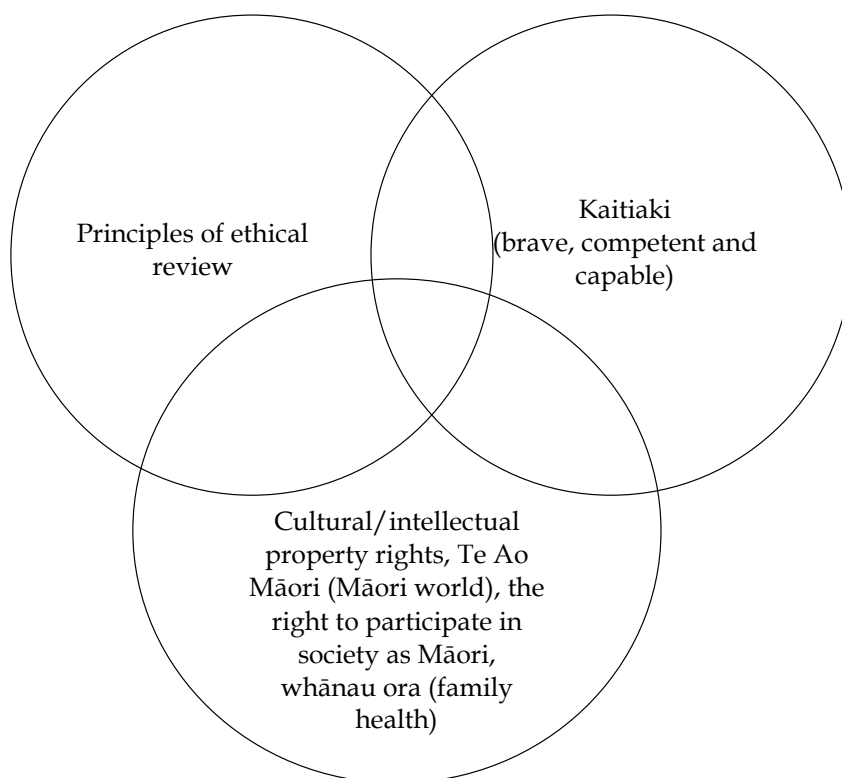


Figure 1: The roles and responsibilities of Māori ethics committee members

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.

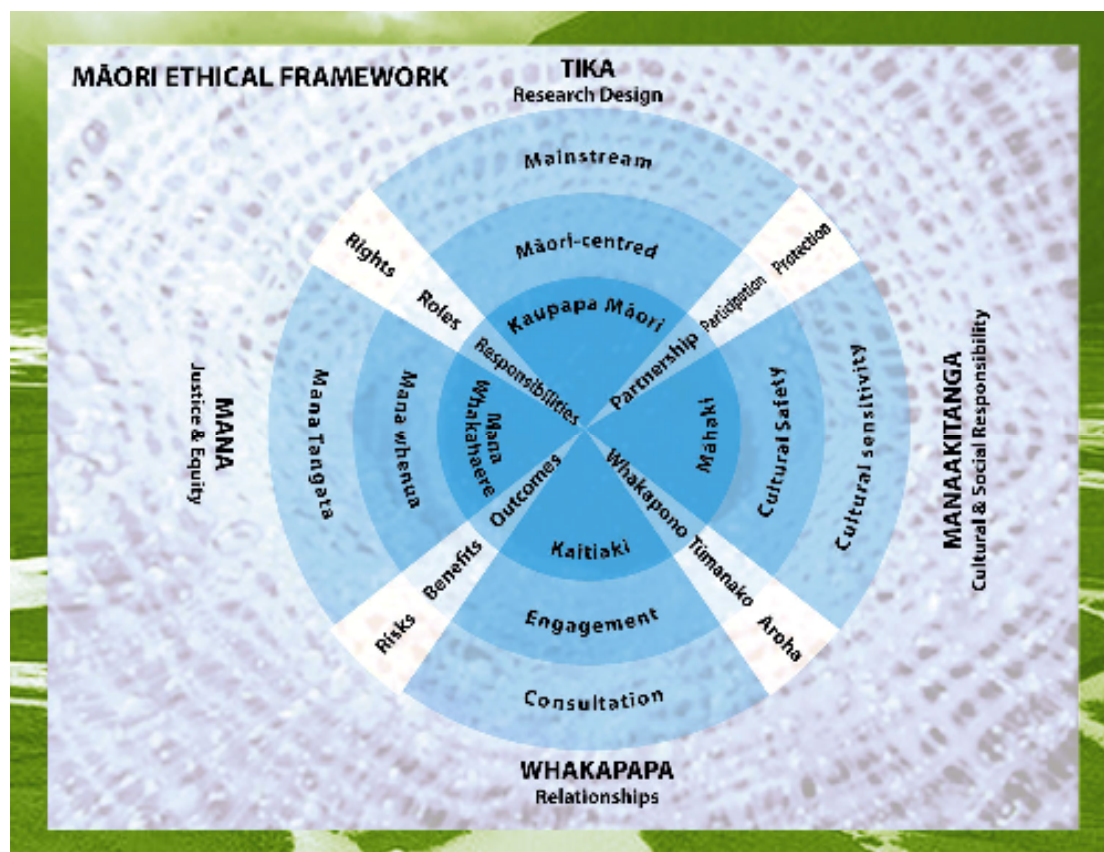


Figure 2: Māori ethical framework

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 Committees¹⁵.

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

¹⁵ Ministry of Health (2006). Operational Standard for Ethics Committees. Wellington, New Zealand, Ministry of Health.

themselves (partnership, participation and protection), a risk/benefit/outcome continuum, and the Māori values of whakapono (faith), tūmanako (aspirations) and aroha (awareness).

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?¹⁶

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.

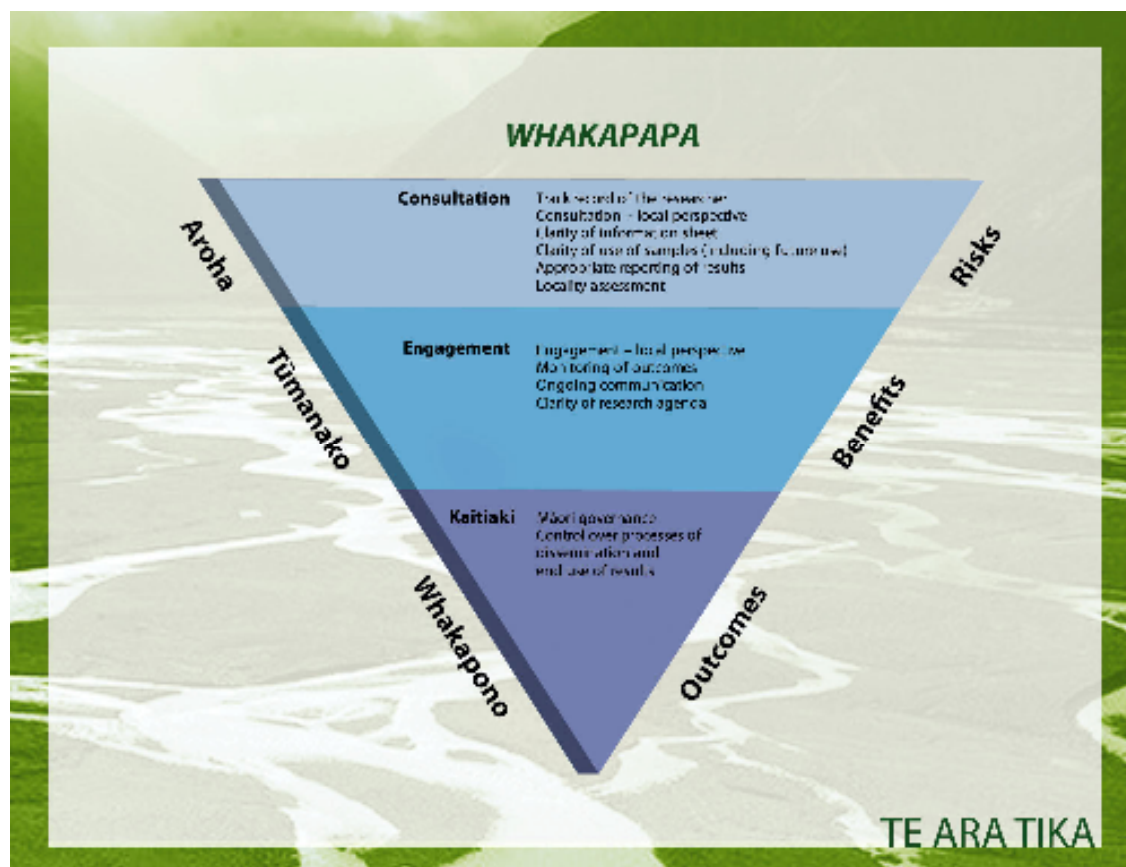


Figure 3: Whakapapa

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.

¹⁶ What is the genesis of this project?

Consultation^{17 18} 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 taken¹⁹, provide a mechanism for reporting back results to appropriate parties²⁰ and allow issues regarding the research scope and agenda^{21 22} to be discussed. These are considered minimum requirements and should be reflected in the locality assessment and section F of the ethics application.²³

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.

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 monitoring²⁴ the project through its life cycle. The dissemination of results from the project

¹⁷ Ministry of Health (2006). 2.2.37, p. 9.

¹⁸ Ministry of Health (2006). Appendix 8, Partnership 381-382, p. 79.

¹⁹ Ministry of Health (2006). 2.2.33, p. 9.

²⁰ Ministry of Health (2006). Appendix 8, Points to consider 386, p. 80.

²¹ Ministry of Health (2006). 2.0.23, p. 6.

²² Ministry of Health (2006). 2.7.82, p. 17.

²³ Ministry of Health (2009). National Application Form for Ethical Approval of a Research Project v1, Section F, 'Cultural and social responsibility'.

²⁴ Ministry of Health (2006). Appendix 8, 378, p. 78.

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?²⁵

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**²⁶ 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.

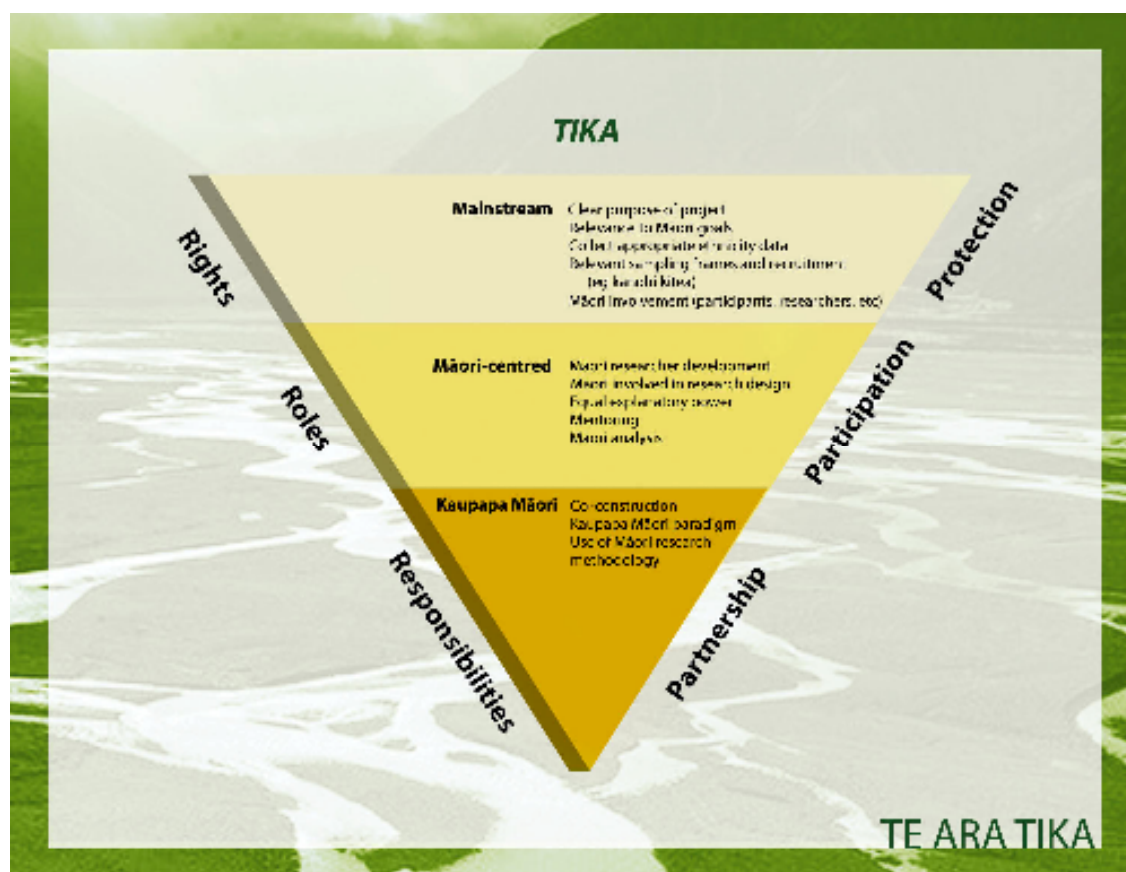


Figure 4: Tika

²⁵ How will the project proceed correctly?

²⁶ 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 C) 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^{27 28} and its relevance to Māori goals^{29 30}. If Māori are involved as participants³¹ 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 data³². 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^{33 34}, the role of mentors and Māori researcher development³⁵, use of sampling frameworks that allow equal explanatory power³⁶ and Māori involvement in analysis^{37 38}.

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?

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

²⁸ Ministry of Health (2006). 2.6.73, p. 15.

²⁹ Ministry of Health (2006). 2.7.82, p. 17.

³⁰ Ministry of Health (2006). Appendix 8, Participation 383, p.79.

³¹ Ministry of Health (2006). 2.6.74, pp. 15-6.

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

³³ Ministry of Health (2006). 2.5.66, p. 14.

³⁴ Ministry of Health (2006). 2.0.23, p. 6.

³⁵ Ministry of Health (2006). 2.6.73, p. 15.

³⁶ Ministry of Health (2006). 2.4.57, p. 13.

³⁷ Ministry of Health (2006). 2.4.57, p. 13.

³⁸ 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 project³⁹, supports kaupapa Māori theory⁴⁰ and uses Māori research methodologies as appropriate^{41 42}.

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?⁴³

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?⁴⁴

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**⁴⁵ and **respect for persons**⁴⁶.

Minimum Standard: Cultural Sensitivity

The minimum standard for manaakitanga acknowledges a persons inherent dignity⁴⁷ 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)^{48 49} and respect for concepts of **privacy and confidentiality**⁵⁰.

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.

³⁹ Ministry of Health (2006). 2.3.56, p. 12.

⁴⁰ Ministry of Health (2006). 2.4.61, p. 14.

⁴¹ Ministry of Health (2006). 2.0.32, p. 6.

⁴² Ministry of Health (2006). Appendix 8, Participation 383, p. 79.

⁴³ Smith, L. T., *Decolonizing methodologies: Research and Indigenous peoples*, New York: Zed Books, 1999, p.173.

⁴⁴ Who will ensure respect is maintained?

⁴⁵ Ministry of Health (2006). 2.7, p. 16.

⁴⁶ Ministry of Health (2006). 2.1, p. 6.

⁴⁷ Ministry of Health (2006). 2.7.77, p. 16.

⁴⁸ Ministry of Health (2006). 2.1.24-26, p. 6.

⁴⁹ Ministry of Health (2006). 2.7.77, p. 16.

⁵⁰ Ministry of Health (2006). 2.3, p. 11.

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.

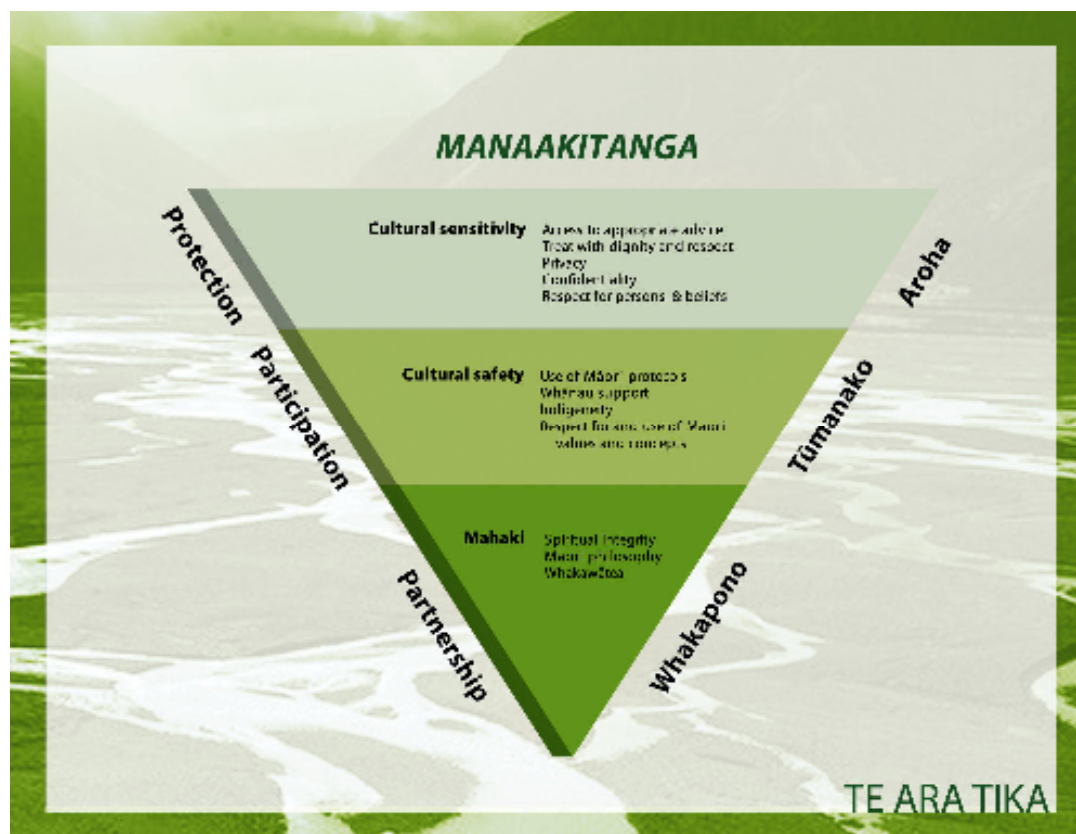


Figure 5: Manaakitanga

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**)^{51 52 53} of a research project and its **culturally safe** implementation⁵⁴. This is enhanced by considering the inclusion of Māori values and concepts^{55 56 57 58 59} indigenous values and concepts, and allowing for the use of whānau support^{60 61} and appropriate Māori protocols⁶².

⁵¹ Ministry of Health (2006). 2.7.82, p. 17.

⁵² Ministry of Health (2006). 2.6.73, p. 15.

⁵³ Ministry of Health (2006). Appendix 8, Protection 384, p. 79.

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

⁵⁵ Ministry of Health (2006). 1.5.14, p. 3.

⁵⁶ Ministry of Health (2006). 2.0.23, p. 6.

⁵⁷ Ministry of Health (2006). 2.5.66, p. 14.

⁵⁸ Ministry of Health (2006). 2.7.79-81, p. 16.

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 integrity⁶³, Māori philosophy⁶⁴, 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?⁶⁵

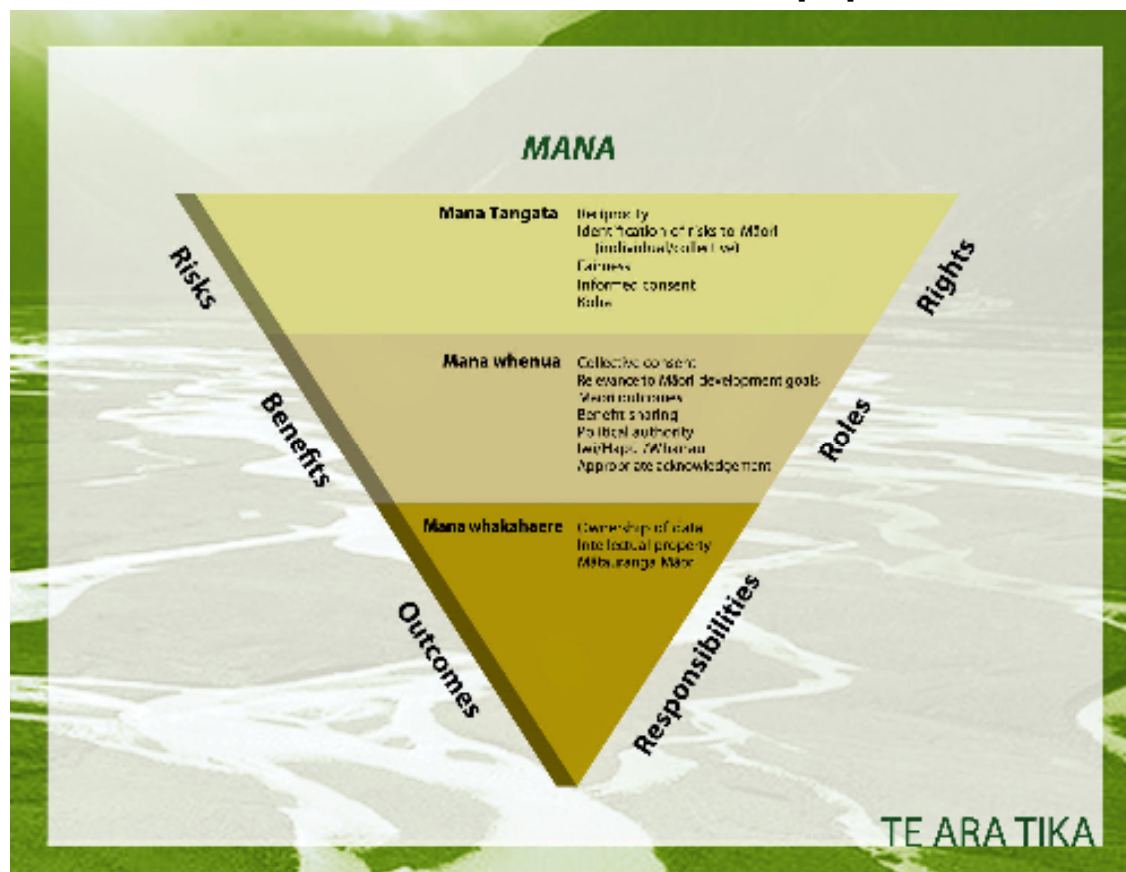


Figure 6: Mana

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

⁶⁰ Ministry of Health (2006). 2.0.23, p. 6.

⁶¹ Ministry of Health (2006). 2.7.77, p. 16.

⁶² Ministry of Health (2006). Appendix 8, Protection 384, p. 79.

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

⁶⁴ Ministry of Health (2006). Appendix 8, Protection 384, p. 79.

⁶⁵ 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 equity⁶⁶ and distributive **justice**⁶⁷. 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)^{68 69}, fairness in terms of their distribution⁷⁰ and the place of koha^{71 72}. Providing clear understanding of the requirements for informed consent⁷³, and recognising the place of oral consent in some Māori settings⁷⁴ 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)^{75 76 77}. Researchers should be establishing meaningful relationships with mana whenua at the research design/conceptual stage to ensure the research provides outcomes for Māori^{78 79 80} and provides opportunities to explore benefit sharing arrangements⁸¹.

⁶⁶ Ministry of Health (2006). 2.6.73, p. 15.

⁶⁷ Ministry of Health (2006). 2.6, p. 15.

⁶⁸ Ministry of Health (2006). 2.0.23, p. 6.

⁶⁹ Ministry of Health (2006). 2.5.64-72, pp. 14-5.

⁷⁰ Ministry of Health (2006). 2.6.73, p. 15.

⁷¹ Ministry of Health (2006). 2.2.43, p. 10.

⁷² Ministry of Health (2006). 2.7.85-6, p. 17.

⁷³ Ministry of Health (2006). 2.2, p. 7.

⁷⁴ Ministry of Health (2006). Appendix 8, Protection 384, p. 79.

⁷⁵ Ministry of Health (2006). 2.0.23, p. 6.

⁷⁶ Ministry of Health (2006). 2.3.55, p. 12.

⁷⁷ Ministry of Health (2006). Appendix 8, Protection 384, p. 79.

⁷⁸ Ministry of Health (2006). 2.6.73, p. 15.

⁷⁹ Ministry of Health (2006). 2.7.82, p. 17.

⁸⁰ Ministry of Health (2006). Appendix 8, Protection 384, p. 79.

⁸¹ Ministry of Health (2006). 2.6.73, p. 15.

Recognizing the mandated authority of hapū and iwi^{82 83 84} acknowledges the role they have in dealing with issues around consent. It may be appropriate to recognise ethical requirements for 'collective consent'^{85 86 87 88} 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 property⁸⁹, their knowledge systems (Mātauranga Māori)⁹⁰, ownership of research data^{91 92 93} 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?

Special ethical considerations

This section outlines areas of special ethical consideration.

Collection and use of human tissue

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

⁸³ Ministry of Health (2006). 2.3.55, p. 12.

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

⁸⁵ Ministry of Health (2006). 2.2.40-1, p. 10.

⁸⁶ Ministry of Health (2006). 2.3.56, p. 12.

⁸⁷ Ministry of Health (2006). 2.0.23, p. 6.

⁸⁸ Ministry of Health (2006). 2.7.78, p. 16.

⁸⁹ Ministry of Health (2006). Appendix 8, Protection 384, p. 79.

⁹⁰ Ministry of Health (2006). Appendix 8, Protection 384, p. 79.

⁹¹ Ministry of Health (2006). 2.0.23, p. 6.

⁹² Ministry of Health (2006). 2.3.55, p. 12.

⁹³ Ministry of Health (2006). Appendix 8, Protection 384, p. 79.

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 consent obtained in the informed consent process. 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 participate⁹⁴. 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.

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

⁹⁴ Hudson, M. (2009). Think Globally, Act Locally: 'Collective Consent' and the Ethics of Knowledge Production. *International Social Science Journal*. Accepted for publication.

outcomes⁹⁵. 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 Peoples⁹⁶, the Waitangi Tribunal (Wai 262)⁹⁷ and the Mataatua Declaration⁹⁸ (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.

⁹⁵ Hausman, D. (2008). Protecting groups from genetic research. *Bioethics*. Vol 22(3), pg 157-165.

⁹⁶ 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.

⁹⁷ More information on this claim can be found on the Waitangi Tribunal website at: <http://www.waitangi-tribunal.govt.nz/inquiries/genericinquiries2/florafauna/>.

⁹⁸ 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	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.

Appendix A: Timeline of developments in Māori research ethics

Date	Hui/Publication
1991	Ngahuaia 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, 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 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 is 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.

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
Kaupapa Māori research	Māori methodologies
Mana Māori	Māori authority or power
Matawaka	Authority over a particular area of land
Pakeha	New Zealander of European descent
Taurahere	Pan-tribal

Te reo Māori
Tino rangatiratanga
Wahine

Māori language
Māori sovereignty or control
Women