

# **Guidelines for Researchers on Health Research Involving Māori**

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# Table of Contents

Introduction.....	1
The Purpose of the Guidelines.....	2
Why Involve Māori in Health Research?.....	3
The policy environment for health research.....	3
The Treaty of Waitangi.....	4
Baseline assumptions.....	4
Responsiveness to Māori.....	6
Considerations for researchers.....	6
Kaupapa Māori research.....	7
Approaches to Māori health research.....	7
Why Consult?.....	9
Research partnerships and co-operation.....	9
Research topics and design.....	9
Defining a research topic.....	9
Research design.....	10
Resolving potentially difficult or contentious issues.....	10
Maximising the benefits of research.....	10
Researcher development.....	10
Dissemination of results.....	11
Other opportunities.....	12
When to Consult?.....	13
Is consultation required?.....	13
Responsibility of host institutions.....	13
Key times to consult.....	13
Early in the research design.....	13
Throughout the project.....	13
Dissemination of results and beyond.....	14
Who to Consult?.....	15
Consultation advice.....	15
The first step.....	15
Seeking external advice.....	15
Consultation process.....	16
Māori health organisations.....	16
Māori health research units.....	16
Māori health care providers.....	17
Local Māori representative organisations.....	17
Special issues.....	18
Ethics review of health research proposals involving Māori.....	19
A Consultation Checklist.....	21
Preliminaries.....	21
Preparations.....	21
The face-to-face consultation.....	21
Post-consultation.....	21
References and Further Reading.....	22
Government policy.....	22
General Māori health.....	22
Kaupapa Māori research.....	22
Issues in research with Māori.....	22
Websites.....	23
Glossary.....	24



## 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.

## 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.<sup>1</sup>

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](#));

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<sup>1</sup> *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?<sup>2</sup>

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:<sup>3</sup>

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

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

<b>Characteristics</b>	<b>Research Involving Māori</b>	<b>Māori-Centred Research</b>	<b>Kaupapa Māori Research</b>
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.<sup>4</sup>

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

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<sup>4</sup> For more information on Career Development Award opportunities offered by the HRC see [www.hrc.govt.nz](http://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.<sup>5</sup> 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

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<sup>5</sup> 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 Māori<sup>6</sup>**

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.

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<sup>6</sup> 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

### Government policy

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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.

## Glossary

**Hapu** - Group of whanau descended from the same ancestor

**Hui** - Large meeting

**Iwi** - Tribe, nation

**Kaumatua** - Male or female elder/s

**Kaupapa Māori research** - Māori methodologies

**Mana Māori** - Māori authority or power

**Mana whenua** - Authority over a particular area of land

**Matawaka** - Of many canoes

**Pakeha** - New Zealander of European descent

**Tangata whenua** - Indigenous people of an area or country

**Tapu** - Sacred or spiritually restricted

**Taurahere** - Pan-tribal

**Te reo Māori** - Māori language

**Tikanga** - Customs, lore

**Tino rangatiratanga** - Māori sovereignty or control

**Wahine** - Women

**Whakapapa** - Genealogy

**Whanau** - Extended family, family group