

GUIDELINES FOR RESEARCHERS ON HEALTH RESEARCH INVOLVING MAORI 1998

*Ka kahi te toi, ka whai te maramaratanga
If knowledge is gathered, enlightenment will follow*



Health Research Council
of New Zealand

Ta Kaunihera Rangahau Hauora o Aotearoa

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1 INTRODUCTION

THE MAORI 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 Maori participants or on issues relevant to Maori health.

These guidelines are intended to inform researchers about when consultation is necessary and the processes involved in initiating consultation with Maori. The purpose of any consultation is to ensure that research practices and outcomes contribute to Maori health development whenever possible. This consultation is also the foundation for co-operative and collaborative working relationships between researchers and Maori organisations and groups.

Maori health research practice and theory are developing rapidly. As a consequence, the Maori Health Committee will review these guidelines annually in October. The review will consider all comments received on the previous year's guidelines. The revised guidelines will then be made available through the HRC Secretariat, the HRC website and academic host institution research offices in December of each year.

GLOSSARY

Hapu - Group of whanau descended from the same ancestor
Hui - Large meeting
Iwi - Tribe, nation
Kaumatua - Male or female elder/s
Kaupapa Maori research - Maori methodologies
Mana Maori - Maori 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 Maori - Maori language
Tikanga - Customs, lore
Tino rangatiratanga - Maori sovereignty or control
Wahine - Women
Whakapapa - Genealogy
Whanau - Extended family, family group

2 THE PURPOSE OF THE GUIDELINES

THE MAORI Health Committee (MHC) has produced these guidelines at the request of the HRC to help develop -

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

If an intending researcher is not sure whether their topic of interest involves an issue relevant to Maori health, then they should refer to Pomare et al (1995) *Hauora: Maori Standards of Health III*, the HRC publication *Rangahau Hauora Maori - Maori Health Research Themes* and the Ministry of Health publication *Progress on Health Outcome Targets - The State of Public Health in New Zealand*.

These guidelines are expected to assist the development of Maori community-supported research in New Zealand, involving both Maori and non-Maori researchers.

The guidelines are written specifically for applicants for HRC funding. They explain in detail the MHC's requirements of research proposals which will involve Maori participants or a Maori health issue.

They will be referred to by referees and committee members who are assessing research proposals. Applicants for HRC funding should refer to these guidelines before completing Section 1 of the application form (GA-04) for both HRC Limited Budget and Project Grants.

The MHC's intent in publishing these guidelines is to establish research practices which ensure that the research outcomes contribute as much as possible to improving Maori health and well-being, while the research process maintains or enhances mana Maori. It is hoped that such practices will become normalised within the research community.

The activities outlined in these guidelines will add to the workload of all parties involved in developing a research proposal (including Maori). However, these additional tasks will significantly increase the potential for health gain from the intending research project. This in turn will make the research proposal more competitive within HRC funding rounds.

These guidelines should be read in con-

junction with the *HRC Guidelines on Ethics in Health Research* and the instructions for completion of the HRC grant application form (GA/04).

3 WHY INVOLVE MAORI IN HEALTH RESEARCH?

THE HRC's encouragement of increased Maori involvement in health research arises from an intention for HRC funded research to contribute as much as possible to the improvement of Maori health and well-being. This intention is reinforced by a combination of government policy and a stated recognition of the Treaty of Waitangi.

3.1 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).

More recently the 1996/97 *Policy Guidelines for the Health Research Council* (Shipley, 1996) reaffirmed the government's commitment to improving Maori health status through the purchase of health research and encouraged the HRC "to promote -

- Ø Greater Maori participation at all levels
- Ø Resource allocation which takes account of Maori health needs and perspectives
- Ø The development of culturally appropriate practices and procedures as integral requirements in the purchase and provision of health research." (ibid, section 3)

Explicit within the policy guidelines is a recognition of a need for greater Maori involvement not only in Maori health research but in all areas of research which could result in health gain for Maori. The Policy Guidelines also instruct the HRC, when making resource allocation decisions, to take into account

"the potential contribution to achieving the government's objectives, particularly to achieving health gain and to reducing disparities in health status between communities within the popula-

"these additional tasks will significantly increase the potential for health gain from the research project... making it more competitive within HRC funding rounds..."

tion” (ibid, section 4.4)

As a consequence the HRC is seeking to support quality research that both involves Maori and has a resulting potential for increased health gain for Maori.

3.2 THE TREATY OF WAITANGI

The HRC states its commitment to operate according to the Treaty of Waitangi in its Annual Report to Parliament. This commitment requires that due recognition be given to both Article Two and Article Three of the Treaty.

Article Two articulates the retention of Maori control (tino rangatiratanga) over Maori resources, including people. Article

Three provides a right to a fair share of society’s benefits. Maori health has been a consideration within the Treaty since its initial drafting in 1840 (see Durie 1994 pp. 83-84).

For health research, Article Two results in the recognition that iwi and hapu have an authority over their peoples’ involvement in research. Article Three generates an expectation for both an equivalent state of health between Maori and pakeha, and an equitable share of the benefits of any Crown expenditure.

The continuing disparities in standards of health between Maori and non-Maori produce a strong argument under Article Three for significant health research resources to be directed at resolving Maori health issues. High quality research is a key component in Maori health development, as it is essential that initiatives to resolve Maori health issues are based on a foundation of high quality information.

The HRC is committed to building both a sustainable Maori health research capacity and long term research partnerships between non-Maori researchers and Maori groups and communities. The shortage of a Maori health research workforce in all areas of health research requires the development of research partnerships between Maori communities and non-Maori researchers to meet the urgent need for research that benefits Maori health.

In addition, it is unlikely that the full range of technical and research skills in the biomedical and clinical research area will be located within a Maori research workforce within the foreseeable future, if at all.

Thus, collaborative research between Maori communities and non-Maori re-

searchers is a key part of the accelerated development strategy for a Maori health research workforce. Such partnerships provide training opportunities for emerging Maori researchers as well as providing information that contributes to Maori health development.

3.3 BASELINE ASSUMPTIONS

This document assumes that -

Ø Intending researchers understand the Treaty of Waitangi and its implications for Maori health.

Ø Researchers understand 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*).

Ø That the intended research is a collaboration between researchers and Maori communities or groups.

Ø The intended research is being undertaken to help address the significant differences in Maori and non-Maori health status.

Ø 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.

Article Two of the Treaty of Waitangi results in the recognition that iwi and hapu have an authority over their peoples’ involvement in research

4 DEFINITIONS

CONSULTATION is a key component in the development of research on a Maori health issue and/or involving Maori as participants. In the past there have been many instances of misunderstanding resulting from differences in opinions as to what constitutes consultation.

4.1 CONSULTATION

Consultation is a two way communication process for presenting and receiving information before final decisions are made, in order to influence those decisions. It is a dynamic and flexible process which is well summarised by Justice McGechan: “Consultation does not mean negotiation or agreement. It means -

Ø Setting out a proposal not fully decided upon.

Ø Adequately informing a party about relevant information upon which the proposal is based.

Ø Listening to what the others have to say

with an open mind (in that there is room to be persuaded against the proposal).

∅ Undertaking that task in a genuine and not cosmetic manner.

∅ Reaching a decision that may or may not alter the original proposal.” (Justice McGechan 1993).

4.2 NEGOTIATION

Negotiation may result from but is distinct from consultation. Negotiation involves a process of bargaining in order to reach a consensus decision.

5 WHY CONSULT?

CONSULTATION is a vital step in the development of a research project that involves Maori as participants or is on a topic of particular relevance to Maori health. The consultation process can lead to the development of research partnerships, focusing of research topics, identification of the most useful research design methods, the resolution of contentious issues and the maximisation of the various potential benefits of the intended research project.

5.1 RESEARCH PARTNERSHIPS AND CO-OPERATION

Consultation is also the only means of arriving at and sustaining a research partnership with Maori researchers and/or communities. One reason for this is the widespread suspicion and mistrust of both researchers and research among many Maori as a consequence of some previous research activities.

The researchers involved may not have intended their activities to have this effect. However, they helped to produce a wariness of participation in health research on the part of many Maori, and a reluctance to co-operate in further researcher-initiated projects.

Despite the urgent need for high quality Maori health research, it is common to encounter a perception among Maori that they are over-researched, and that much previous research has been, at best, of no benefit to Maori and at worst, actively disempowering.

Consultation assists in erasing this mistrust and building a more cooperative environment for current and future research ac-

tivities.

5.2 RESEARCH TOPICS AND DESIGN

5.2.1 DEFINING A RESEARCH TOPIC

The research topic may be defined or refined as a result of consultation with Maori. A Maori 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 local Maori health needs. Such consultation at the outset helps ensure that both the researchers and the Maori 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 parties' 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.

It is important to note that a researcher's perceptions of priorities for Maori health may differ substantially from those of particular Maori communities or groups, who may consider other issues more pressing than the researcher's chosen topic. Therefore a researcher planning a piece of researcher-initiated 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 Maori as early as possible to ensure the acceptability of the intended research topic prior to the time-consuming process of developing the proposal.

This does not preclude the involvement of Maori in fundamental biomedical research, but the state of Maori health requires that research priorities must lie with projects of a more 'applied' nature that support strategies for improving Maori health.

5.2.2 RESEARCH DESIGN

Consultation can also help identify the most suitable research methods and recruitment strategies. Research methods and tools that suit non-Maori participants are not always useful for Maori, requiring the development of different approaches to obtain answers

Consultation at the outset helps ensure that both the researchers and the Maori community will benefit from the research project by matching research interest with local health needs

to similar questions. There may also be significant differences of approach required within a Maori research sample due to iwi affiliation, ability with te reo Maori, age, geographic location and education.

Some geographic areas with large Maori 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 best be 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.

5.2.3 RESOLVING POTENTIALLY DIFFICULT OR CONTENTIOUS ISSUES

One of the main purposes 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 Maori 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 Maori community is unlikely to have many problems in recruiting participants.

Researchers should be aware that consultation may indicate 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 whanau, hapu or iwi if the project is unacceptable to them, is paramount (see Section

6.3 of the *HRC Guidelines on Ethics In Health Research*).

5.3 MAXIMISING THE BENEFITS OF RESEARCH

5.3.1 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 Maori health or that involve Maori 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 Maori researchers seeking a practical component to their academic training, if this is supported by the local community. There is a serious shortage of Maori researchers, especially in the biomedical and clinical research fields.

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

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 benefit by having additional staff without this adding to the size of their grant budget. Alternatively, emerging researchers could be supported as research staff on the primary grant.

As well as intending career researchers, local Maori 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 Maori

A study that has the overt endorsement of the local Maori community is unlikely to have many problems in recruiting participants

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.

5.3.2 RESULT DISSEMINATION

It is important that research results contribute to Maori 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 to those who could use it.

Potential audiences for such information include Maori health organisations, health providers, Maori representative organisations, policy makers, other researchers and the community from which the information was sourced, if applicable.

By making research information accessible in this way, researchers maximise the project's potential to contribute to health gain, and therefore its suitability for funding. They also minimise the risk of damage caused by the inappropriate circulation of some information.

Dissemination of results is able to be supported by either the primary research grant or an HRC Grant-in-Aid.

Dissemination is particularly important when Maori have been participants in the research project. Maori 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 a form that is understood, back to the community or group which supplied the information, before publication of the study.

Some instances where Maori people have been powerless to stop the inappropriate dissemination of information have generated unease within Maori communities. Researchers must take care to ensure that Maori participants understand and agree on which information is to be published and in what formats.

Permission to collect and analyse potentially sensitive information does not equate to permission to publish such information. Publication may be possible but the format needs to be negotiated with the Maori organisations involved.

If the research topic is relevant to Maori

health, it is strongly recommended that the results also be forwarded in a usable format to organisations which may be able to use the information.

5.3.3 OTHER POSSIBILITIES

In situations where the likely utility of the results for Maori 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 representatives of the Maori people to be involved in the study, recognising the strong sense of ownership Maori feel towards information originating in their community.

6 WHEN TO CONSULT?

6.1 IS CONSULTATION REQUIRED?

The purpose of any consultation is to ensure that research practices are appropriate and acceptable, and that outcomes contribute to Maori health development whenever possible. Consultation is required if a research project is on a topic relevant to a Maori health issue or Maori are to be involved as participants.

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 Maori health and well-being, while the research process maintains or enhances mana Maori.

As a general rule, consultation should take place if Maori are to be involved as participants in a project or the project relates to a health issue of importance to Maori.

Therefore the issue of consultation is unlikely to be relevant to most biological laboratory-based studies unless the results could be useful in addressing a Maori health issue. Clinical and public health research are more likely to require some degree of consultation.

The extent of any consultation should always be appropriate to the scale of the in-

Researchers must take care to ensure that Maori participants understand and agree on which information is to be published and in what formats

tended project, its relevance and significance to Maori health and the potential for application of the research results

An intending researcher should ask their host organisation's Maori advisers, management or kaumatua whether consultation is required.

6.2 KEY TIMES TO CONSULT

6.2.1 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 full participation in the entire process. As a general rule, the later the consultation begins the more difficult and less successful it is likely to be.

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Consultation should not be initiated once the research proposal has been completed, as this post-fact endorsement precludes effective Maori 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.

6.2.2 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 is possible. In a medium to long term study (six months and more) regular contact should be kept with the community in order to 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.

6.2.3 RESULT DISSEMINATION AND BEYOND

The research partnership is able to be extended beyond the completion of the project and the dissemination of the results. Such follow-up can provide opportunities for sharing ideas on the utilisation of research results and may lead to ongoing research opportunities.

As a result of such ongoing dialogue,

some researchers have established long term mutually beneficial research partnerships with Maori communities, which have extended well beyond the initial research project.

These partnerships have demonstrated that, while it is not without its occasional difficulties, ongoing consultation results in innovative, widely supported research projects providing high quality information to researchers and participants alike (see Beasley et al 1993 and Wairarapa Maori Executive 1992).

7 WHO TO CONSULT?

THERE IS NO set process of consultation that is applicable to all research projects. The nature and extent of consultation is dependent upon -

- ∅ The intended research project's relevance to Maori health issues
- ∅ The intended research project's degree of involvement of Maori participants
- ∅ The research methodologies to be utilised
- ∅ The size of the intended project
- ∅ The intended research project's location
- ∅ Any existing relationship with the Maori 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 Maori organisation or group concerned.

7.1 CONSULTATION ADVICE

7.1.1 THE FIRST STEP

The first step in any consultation should always be to seek local advice from the resource people 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 from peers with experience in undertaking research with Maori, Maori staff within your research

group or department, or your organisation's Maori advisers, management or kaumatua.

Such people should be relatively accessible and be well placed to advise you as to a consultation process for your intended research proposal. Please note that this first step does not in itself constitute consultation, but is extremely helpful to the intending researcher by clarifying the required consultation process.

Maori teaching departments or research centres may be able to act as advisory resources at this stage of a project's development but they are funded to undertake their own teaching and research and not to advise on the development of other researchers' projects.

However, Maori research units may be potential research collaborators. Departments of Maori Studies can be an excellent source of recruiting Maori staff and research trainees to a project. Local Maori members of ethics committees may also be able to provide some advice.

7.1.2 SEEKING EXTERNAL ADVICE

Where there are no local resources available to advise on a suitable consultation process, an intending researcher should contact either the local office of Te Puni Kokiri (Ministry of Maori Development) or the HRC. Te Puni Kokiri is able to direct researchers to local contact people, relevant Maori organisations and key contacts for consultation. Their contact details will be in your local telephone directory.

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

7.2 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 Maori health or which may involve Maori participants.

Such 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 al-

lowed for when planning the development of a research project.

7.2.1 MAORI HEALTH ORGANISATIONS

There are a number of issue-related Maori health organisations or Maori sections within general health organisations which should be contacted when designing a research proposal in their area of interest. They include -

ORGANISATION	AREA OF INTEREST
Maori Women's Welfare League	Wahine and whanau wellbeing
Te Hotu Manawa Maori	Cardiovascular health
Te Puawai Tapu	Fertility and sexual health
Asthma Foundation	Asthma and respiratory illness
Te Roopu Mate Huka	Diabetes
Te Ao Marama	Dental health

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 Maori 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.

7.2.2 MAORI HEALTH CARE PROVIDERS

A positive outcome of the health reforms has been the establishment of an increased number and range of Maori health care providers. Unlike the organisations mentioned in the section above, these providers are locally-based rather than national bodies.

Consultation with local providers also indicates useful processes for involving lo-

Consultation with these organisations can lead to a lasting working partnership which provides direct links into Maori networks and end-users without researchers having to build such links themselves

cal Maori 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 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 and beyond while enhancing the prospects of further studies.

Contact details for such organisations should be available from your initial source of consultation advice within your own organisation.

7.2.3 LOCAL MAORI REPRESENTATIVE ORGANISATIONS

When a project involves Maori within a given geographical area as participants, an intending researcher should always contact local Maori 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 Maori 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 at most consulting the local host institution's Maori advisors.

7.2.3.1 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 Maori activities in their area. Tangata whenua organisations may involve iwi or hapu 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 Kokiri office.

7.2.3.2 TAURAHERE, PAN-TRIBAL OR MATAWAKA ORGANISATIONS

Many Maori live outside their iwi rohe, or tribal area, especially 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 Maori 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 Kokiri office is able to provide the contact details for the local pan-tribal organisations.

7.2.4 SPECIAL ISSUES

Where the intended research process may challenge Maori cultural values, involve highly sensitive issues or breaches of tikanga, more intensive consultation is an absolute requirement, no matter how large the research project. As a result of this consultation it may be decided to exclude Maori participants from the study.

Exclusion of Maori participants for cultural reasons from a general population study 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 Maori or exclude Maori from the general study.

Any such exclusion would have to be well justified and should not restrict the potential Maori 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 Maori participants and their values, as it could be argued that such exclusion is contrary to Article 3 of the Treaty of Waitangi (see 3.2 above).

7.2.4.1 RESEARCH THAT BREACHES TIKANGA OR INVOLVES CULTURALLY SENSITIVE ISSUES

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

The tangata whenua should always be the first local representative organisation contacted by a researcher, as tangata whenua have mana whenua over Maori activities in their area.

The MHC is keen to ensure that research processes do not contribute to the further erosion of Maori 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 Maori 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 Maori 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 ask their Maori colleagues or advisers if a project or process is likely to be contentious. If there are any contentious issues, Maori 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.

7.2.4.2 GENETIC STUDIES INVOLVING MAORI PARTICIPANTS

As genetic research technology becomes more widespread, there is a concurrent increasing demand to undertake genetic research on Maori populations. Maori 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 among Maori. Attitudes range from acceptance to total rejection in principle. Intending researchers should familiarise themselves with the issues as outlined at the 1996 HRC Consensus Development Conference report *Whose Genes Are They Anyway?* (Baird et al, 1995).

Maori at this conference expressed "support for genetic research that enhances quality of life for Maori as defined by Maori ... [if that research occurs] within the paradigms of a Maori world view" (ibid, p 3). 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 whanau concerned as well as thorough consultation with the iwi to which the whanau 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 Maori is strongly recommended to contact the HRC Kaiwhakahaere Rangahau Hauora Maori.

Genetic research projects involving Maori require the approval of the iwi or hapu 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.

The MHC will not support HRC funding for any Maori involvement in research that breaches tikanga, unless such involvement is specifically endorsed by the tangata whenua of the area in which the research occurs

8 A CONSULTATION CHECKLIST

8.1 PRELIMINARIES

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

8.2 PREPARATIONS

- Ø Make contact with and invite participation of community groups to help prepare for the consultations.
- Ø Discuss costs and negotiate if necessary.
- Ø 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.
- Ø List tasks and timelines. Allocate responsibilities and ensure communication channels are open.
- Ø Dispatch invitations and otherwise promote, allowing time for participants to

- prepare themselves and be briefed.
- Ø Agree on feedback mechanisms and post-consultation strategies.

8.3 THE FACE-TO-FACE CONSULTATION

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

8.4 POST-CONSULTATION

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

9 REFERENCES AND FURTHER READING

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