

# A Framework for Māori Review of Research in District Health Boards

**A joint research project between Auckland and Waitematā District  
Health Board and Capital and Coast District Health Board**

**This research project was funded by a research grant from  
The Auckland District Health Board Charitable Trust,  
(A+ Trust)**

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May 2015

## Mihimihi

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E ngā mana, e ngā reo, tēnā koutou katoa

He mihi whānui tēnei ki a koutou e tautoko ana i te kaupapa nei;

Kia whai te ara tika mō te rangahau hauora.

He mihi miharo ki a koutou katoa e kaha ki te whai ake nei i te hauora mō tatou katoa, kia pūāwai te oranga o te iwi Māori.

Nō reira e rau rangatira mā,

Tēnā koutou, tēnā koutou, tēnā koutou katoa.

### **Suggested Citation:**

Simmonds S (2015) *A Framework for Māori Review of Research in District Health Boards*. Auckland and Waitematā District Health Boards and Capital and Coast District Health Board. Wellington, New Zealand

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## Introduction

Māori review of research is an ethical and legislative requirement for research conducted in District Health Boards (DHBs) in Aotearoa/New Zealand. Standardising the Māori review process across DHBs will likely increase efficiency of time, energy and resource and improve national consistency while still allowing for consideration of local context and collaboration with Māori in each DHB region. The current project sought to determine the processes currently in place in each of the twenty DHB regions and to develop a draft national framework for Māori review of research.

## Methods

Contact was made with each of the DHBs to determine the current process in place for Māori review of research, the key personnel involved, the steps for reviewing research applications, documentation utilised, challenges and limitations encountered, and aspirations for the review process. The information was obtained by email, phone interview or online questionnaire following a semi-standardised questionnaire template.

A review was undertaken to identify key literature regarding Māori research frameworks and research ethics. Following analysis of consultation results and the literature review, a draft framework was developed which underwent peer review before finalising.

## Discussion

The framework was largely guided by *Te Ara Tika, Guidelines for Māori Research Ethics* (Hudson et al 2010) and contains a description of different types of research and the levels of Māori involvement, detailed criteria for reviewing research applications, and for further consultation, and a template application form. Although the framework has immediate utilisation potential, it is recommended that it be piloted and then evaluated. Some issues raised during consultation were not covered by this framework, and these are discussed. However, the implementation of this framework can potentially make an important contribution towards ensuring the rights of Māori are upheld in a research setting.

Ngā mihi nui ki a koutou kua tautoko i tēnei kaupapa.

To the Māori general managers and representatives from each District Health Board for providing information and insight to the processes in each of their rohe.

To Helen Wihongi, for your empathetic supervision and guidance. Also to Tristram Ingham as co-supervisor of this report.

Thank you to Jonathan Koea for peer review of the final draft.

Valuable feedback and advice was gratefully received from Barry Smith and Maui Hudson. Thank you also to Katherine Reweti-Russell for helpful comments on the template application form.

The project was a joint project between Waitemātā Auckland DHB and Capital and Coast DHB. The project was funded by a research grant from Auckland District Health Board Charitable Trust (A+ Trust) <http://www.aplustrust.org.nz/> .

***Māori are tangata whenua of Aotearoa therefore all health research conducted in this country is of relevance to Māori.***

Māori have the right to good health, to participation in the health system at all levels, and to high quality health research that contributes positively to hauora Māori. These rights are derived not only from the World Health Organisation right of health for all<sup>1</sup>, but further acknowledged in the United Nations Declaration on the Rights of Indigenous Peoples (UN 2007), and in the Treaty of Waitangi (CERD 2007). As tangata whenua we have the right to self-determination, and our participation in all aspects of health research - from the development of study aims, data collection and choice of methods for data analysis, to the interpretation, framing and dissemination of results - can contribute to fulfilling this right.

The imperative for Māori participation in health research and research decisions also comes from the much-evidenced health disparities experienced by our people. The Ministry of Health has acknowledged Māori are a priority population for health interventions (MOH 2014), and the Health Research Council (HRC) has made a commitment to increasing Māori participation in health research, and for HRC-funded research to “contribute as much as possible to the improvement of Māori health and wellbeing, while the research process maintains or enhances mana Māori” (HRC 2010). Health research needs to be acceptable, accountable and relevant to Māori (Wyeth et al 2010).

Most health research in Aotearoa will require ethics approval through one of the four Health and Disability Ethics Committees (HDEC). Regardless of whether ethical approval is required of a research project or not<sup>2</sup>, all health research should attain approval from the appropriate locality. The process is known as a ‘Locality Authorisation’. A locality is an organisation in or through which there is to be substantial recruitment or in which the

<sup>1</sup> <http://www.who.int/mediacentre/factsheets/fs323/en/> accessed 5 May 2015

<sup>2</sup> See *HDEC Scope of Review Form V4*, which helps determine whether ethics review is required, also the Ministry of Health (2014) *Standard Operating Procedures for Health and Disability Ethics Committees v1.0*, p13 for a flowchart to determine whether a study requires ethical approval, and section 10 for a description of what constitutes a locality. Both documents available at [www.ethics.health.nz](http://www.ethics.health.nz)

study will be conducted, and in most cases, is the relevant District Health Board (DHB) (MOH 2014).<sup>3</sup>

The responsibility for engaging with Māori lies with both the DHB and with researchers themselves. District Health Boards are required to ensure that research carried out within their region protects Māori cultural interests, promotes Māori wellbeing and provides mechanisms for Māori participation (NEAC 2012a, 2012b, Ministry of Health, 2012), and in order to give effect to the Treaty of Waitangi, researchers must engage and formally consult with Māori (MOH 2012). Consultation with Māori is distinct from locality authorisation and therefore two different forms of approval are usually required. A 'high trust system' entails that the processes of ethics committee review, locality authorisation and Māori consultation may proceed in tandem, and to undertake the process with one is not dependant on having completed the other processes. However, approval from the Health and Disability Ethics Committees is conditional upon a favourable locality authorisation (MOH 2014).

The level to which Māori may be involved in, or potentially affected by, a research project will vary from project to project, depending on its scope, methodology and aims. Research that directly involves Māori is of considerable importance (Hudson et al 2010). As Māori, we are the best judges of how much a research project may impact upon our people, either positively or negatively. Therefore while all health research is deemed relevant, the *degree* to which a research project is relevant is a decision that can only be made by Māori (HRC 2010). Ideally, research proposals within DHBs should be developed in consultation with Māori, both mana whenua and taurahere, reviewed and approved by Māori before the research itself commences. However, many clinical trials are designed and initiated outside Aotearoa and may commence before the locality is approached for approval.

Providing the details of proposed research to District Health Boards for initial assessment by Māori can serve as a prerequisite for determining whether further engagement with Māori is required, and the nature, scope and depth of this engagement. Both are types of consultation; the initial assessment is considered Māori 'review' of research.

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<sup>3</sup> Note that locality authorisations were previously known as 'locality assessments', this recent change in the revised Standard Operating Procedures for Health and Disability Ethics Committees, August 2014. Several DHBs still use the older terminology.

Currently there is no standardised process for Māori review of research across the District Health Boards. Standardisation would have several potential advantages. These include increased efficiency of time, energy and resource, and improved national consistency while still allowing for consideration of local context and collaboration with mana whenua and other Māori in each DHB region. A standardised framework may be of further benefit for DHBs with limited capacity for Māori review, for those yet to establish a research review process, and for the evaluation and update of existing review processes that are already in place.

The Health Research Council (HRC) Strategic Plan for Māori Health Research 2010-2015 was developed by the Māori Health Committee (HRC 2008). It sets out the following six goals, to which this research project directly relates:

1. Transforming Māori health research knowledge and practice
2. Enhancing application of Māori methodologies to health research
3. Translating research into Māori health gains
4. Promoting Māori ethics processes and good practice
5. Extending the Māori health research workforce and promoting a culture of research
6. Strengthening the value of the HRC to respond to the needs of Māori for the benefit of New Zealand

In reviewing the current processes for review in DHBs, and by working towards a national framework, this project can potentially contribute to these goals, and to realising the mission of the HRC's Māori Health Committee - "*exercising rangatiratanga over the decisions that affect Māori Health Research*" (HRC 2008).

In Aotearoa the ethical review process has been challenged for not adequately considering Māori interests and ethical perspectives (Te Awekotuku 1991, Te Puni Kōkiri 1994, Durie 1998, Cram 2003, Hudson 2004, Moewaka Barnes et al 2009, Tupara 2011). In response to this, several frameworks have been developed and utilised in research each containing a similar set of core values that can serve to guide and inform research practices<sup>4</sup>. *Te Ara Tika* was developed in 2010 by the Pūtaiora Writing group (Hudson et al 2010), and published by the Health Research Council (HRC) along with an update of the HRC's *Guidelines for Research involving Māori* (2010). *Te Ara Tika* utilises tikanga Māori as a foundation for addressing ethical issues in health research, and is intended for use as

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<sup>4</sup> See Hudson and Ahuriri-Driscoll 2006, and also <http://www.rangahau.co.nz/ethics/166/> for a description of some frameworks. Accessed 1 May 2015



guidance for researchers, ethics committee members and those who engage in consultation or advice about Māori ethical issues. As such, it will be largely drawn on in the development of this framework.

## Whakapapa

## Background

The notion of standardisation of the Māori review process as part of the locality authorisation process emerged from the Waitemata and Auckland Chief Advisor Tikanga, research advisor Māori, the ADHB clinical director, the Māori research committee, the Awhina Research and Knowledge Centre and the ADHB Research Office.

Following this, two hui took place with representatives of up to twelve DHBs, the first in Auckland (24 October 2013) followed by a second in Wellington (23 June 2014). These hui were attended by those involved with, and interested in, Māori review of research. At both gatherings, the desire for a standardised national process for Māori review of research was affirmed. It was also decided to adopt *Te Ara Tika* as an overall framework for Māori review of research<sup>5</sup>.

Funding was sought and secured from the Auckland District Health Board Charitable Trust (otherwise known as the A+ Trust) in order to conduct the study<sup>6</sup>. The project defined two overall aims:

### ***Ngā Whāinga - Aims***

1. to gain an understanding of the current process for Māori review of research in each District Health Board
2. to draft a framework for Māori review of research, including guidelines for reviewing research proposals, application form template and sample response letter.

<sup>5</sup> See minutes of National Māori DHB Reviewers Hui, Marion Davis Library, Auckland DHB, 24 October 2013, and also DHB Reviewers Hui June 2014, Easthope Seminar Room, Wellington Regional Hospital.

<sup>6</sup> More information on the Trust can be found here: <http://www.aplustrust.org.nz/who-we-are>

Contact was made with each of the 20 District Health Boards to establish details of their review process, and a literature review on Māori health research ethics and consultation informs this research.

To contribute to this report, I have also drawn on my own experience as a Māori health researcher and a reviewer of research within a DHB, on conversations with those working in the area of Māori health ethics, and on two recent symposia on Māori Health and Indigenous ethics<sup>7</sup>.

Following peer review, the report will be finalised and distributed to all stakeholders.

## Ngā tapuae

## Methods

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Contact was made through the General Manager Māori of each of the 20 DHBs, initially to inform them of the study and to confirm the most appropriate contact person or persons for this topic, then to gather information on the review process. A semi-structured template was emailed to the contact person for each DHB. All relevant documentation such as application forms and policies were requested. Information was also obtained online for the DHBs that detailed their review process on their website, or the website of an associated institution.

Information sought included; steps for the review process, personnel involved, connection with mana whenua and taurahere<sup>8</sup>, whether tikanga training or Māori health training was offered by the DHB, common issues encountered by the reviewers, and any suggested improvements for the process.

Relevant documentation was reviewed. These included minutes of previous hui, presentations for these hui, and draft terms of reference for reviewing groups.

A literature review was undertaken on Māori research ethics and Māori consultation.

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<sup>7</sup> Māori Health Ethics Symposium, Wellington Regional Hospital, 12 March 2015 and Research, Resources and Indigenous Rights Symposium, Auckland District Health Board, 19 May 2015.

<sup>8</sup> Taurahere is a term for Māori living in an area who are not originally from this area. Other terms include matawaka or pan-tribal.

The key results for this study are:

- a) the description of current processes for Māori review of research in each DHB (provided in this section)
- b) a description of types of research and levels of involvement of Māori (provided as Table 1 in the Discussion section)
- c) the draft framework for Māori review of research (provided as Table 2 in the Discussion section)

While the description of processes within the DHBs is provided here, the latter two tables are embedded within the next section so that they accompany the discussion on the tables themselves.

## Current Processes for Māori Review of Research in District Health Boards

The process for Māori review of research differed across the different DHBs depending on the volume of applications received, whether or not the DHB was associated with another institution (such as a University), Māori reviewer capacity within the DHB, resource funding allocated to either establish or maintain the review process, and the structure of the internal processes within the DHB and between the DHB and the Māori relationship board.

Table 4 in appendix 2 provides an overview of the process for each of the DHBs for which there is information available at the time of this study. Copies of relevant documentation for each of these DHBs such as policies, application forms and information sheets for researchers can be found in Appendix 4, which is provided as a separate supplementary document to accompany this main report.

### *The Review Process*

The DHBs that were yet to establish a review process such as Midcentral, Tairāwhiti and Whanganui, or those that were currently reassessing or evaluating their existing process expressed a keen interest in this project to potentially support their development in this area. Taranaki and West Coast also have no formal process, rather applications are

assessed by the Chief advisor Māori and referred to the Iwi Relationship Board if necessary. Most guidance given is regarding consultation and engagement.

For some DHBs such as Northland, Counties Manukau and South Canterbury, the Māori review is contained within the Locality Authorisation process, whereas for others such as CCDHB, Bay of Plenty, Waikato, NMDHB and Auckland and Waitematā, the process for Māori review is separate. In Lakes DHB, a brief is prepared and sent to the iwi relationship board for consideration.

The process follows similar steps in most DHBs whereby research applications are received and acknowledged, they are then reviewed and feedback given to the research group as to whether their project is approved or endorsed, whether further evidence is required, or whether the researchers are required to meet with reviewers. Applications may be declined if the reviewers are not satisfied that criteria have been met. Some DHBs provided a flowchart to clarify this process<sup>9</sup>.

For most DHBs it appears that the Māori review process may happen simultaneously or independently of the ethics approval process, Hawkes Bay DHB acknowledges a direct responsibility to capture specific cultural requirements before the research application reaches the Ethics Committee approval stage, allowing an earlier cultural intervention and input into the design phase of the research project.

#### *The Reviewers or Reviewing Group*

In South Canterbury, Tairāwhiti, West Coast and also Wairarapa and Hutt, applications are reviewed by the General Manager Māori. However, South Canterbury reported that research applications are rare, and Wairarapa reported no record of Māori health research conducted in Wairarapa for the past eight years. Auckland and Waitematā has a designated position for a Māori reviewer, overseen by the Māori Research Committee. Waikato, Bay of Plenty, Counties Manukau, and Capital and Coast DHBs have separate Māori research review groups, and in Lakes DHB the research proposal is received by the Māori Health Development group who prepare a brief to be taken to the iwi relationship board. Southern DHB has an arrangement with Otago University for all research, and Māori consultation is facilitated through the Ngai Tahu Research Consultation Committee. Nelson Marlborough DHB contracts this service out to an independent consultancy company. If required, the Hawkes Bay DHB reviewing committee, Taumata Rangahau, may call in to the group specific expertise to assist any decisions that may arise.

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<sup>9</sup> See Appendix three, documentation for Auckland and Waitematā DHB, Wairarapa and Hutt Valley and Capital and Coast DHB, Nelson Marlborough DHB and Otago University for examples.

### *Connection with Mana whenua and Taurahere*

In most DHBs, reviewers maintain connection and communication with mana whenua and taurahere, providing mandate for the review process. In some instances, reviewers were members of the iwi relationship board (Northland), others were separate review groups overseen by the iwi relationship board (AWDHB, BOP, Waikato) or a subcommittee of the iwi relationship board as in the case with the CCDHB Research Advisory Group - Māori. In Nelson Marlborough, applications are submitted to the Iwi Health Board (IHB), and then reviewed by an external consultancy company before getting signoff by the IHB. The Taumata Rangahu reviewing group in Hawkes Bay DHB may use their community connections to seek feedback on a particular research project if this is needed, and also have representation at the Māori Relationship board where issues may be tabled and discussed if required.

Counties Manukau reviewing group currently comprises of three members including a community representative who is mana whenua.

### *Reviewing Criteria*

For the DHBs that supply an application form to researchers, the criteria for Māori review is largely contained within this form. Waikato DHB provides a series of questions as guidelines based on the Te Ara Tika framework (Hudson et al 2010) and incorporating the Treaty of Waitangi. Both Bay of Plenty and Counties Manukau application forms contain specific questions on recruitment, benefit of the study to Māori and dissemination. Counties Manukau also requests information on cultural issues identified, relevance of the research to Māori and expected health gains, and how the research might contribute to the health priorities of CMDHB, Māori development and the vision to reduce inequalities. Lakes DHB considers how the research might benefit Māori, and noted that they are a small DHB where most of the research groups will be already known to them. The CMDHB application form also requests specific details around collection and use of tissue samples, consent for genetic analysis, whānau involvement in the study and dissemination of study results to Māori communities. Capital and Coast DHB and the AWDHB forms request information on ethnicity data collection, recruitment of Māori, incorporating the cultural preferences of Māori into the study design, the appropriateness of participant information and consent forms, and the contribution of the study to Māori health. Nelson Marlborough DHB contains similar criteria, but also includes questions around dissemination, methodology used and appropriate communication with Māori. Bay of Plenty identifies four levels of consultation dependant on the number of Māori participants expected in the study (see the BOP description in

Table 4), and this determines the depth of consultation required. Both Waikato and Southern DHBs have a separate process or forms for research involving human tissue.

#### *District Health Board Policies*

Not all DHB research policies were available in the time period of this study. It would have been beneficial to review these as the commitment of the DHB to Māori health improvement may be indicated by the strength of the wording in the policy.<sup>10</sup>

The Northland policy locality authorisation includes a tickbox question: “have cultural issues specific to this locality or to people being recruited at this locality been addressed?” and South Canterbury specifies that research “does not increase disparity”. Both Tairāwhiti and CCDHB policies incorporate the Treaty of Waitangi. The CCDHB policy states the importance of ensuring the rights, needs and interests of Māori are met and that research contributes to the body of knowledge for Māori, the Tairāwhiti policy states that research should promote the wellbeing of Māori and ensure Māori participation. The NMDHB policy aligns with the HRC Guidelines and acknowledges the need for high quality information, and that research should contribute to Māori health and Māori health development. The Otago University and Southern DHB policy acknowledges the needs and aspirations of Ngāi Tahu for Māori Development.

#### *Cultural Training*

Some DHBs offer cultural training, and a desire for this form of training to be available for researchers was expressed during consultation. Tikanga workshops are offered by Waitemātā and Auckland DHBs, Northland, Waikato, Taranaki, Whanganui<sup>11</sup>, West Coast and South Canterbury, and CCDHB who offer a research-specific tikanga Māori education. A cultural competency course is also currently being piloted in CCDHB and Wairarapa. Treaty of Waitangi workshops are offered by Waitemātā and Auckland DHBs, Waikato, Taranaki, Lakes DHB and the West Coast. South Canterbury DHB funds staff to attend the Treaty Training at the local Polytechnic. Counties Manukau DHB has an online programme and offers a marae visit. Hawkes Bay DHB has a range of induction and orientation programmes for new staff, and Māori health services are also able to support individuals or groups with cultural training that may be required. The training at Lakes DHB includes the

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<sup>10</sup> All forms and documentation for DHBs including research policies are provided in Appendix 4, a separate supplement to this report.

<sup>11</sup> Whanganui has recently refreshed its cultural training programme, which is being piloted May-June 2015

health needs of Lakes DHB Māori, data issues, services available, enablers and tools delivered from the DHB. In addition, specific training on institutional racism and the Treaty are delivered when required.

A framework for Māori review of research can potentially have many advantages. During consultation, the concern was expressed that Māori communities are ‘over-researched for little benefit’, and previous research has indicated similar sentiments (Sporle and Koea 2004a). A need to distinguish between the different types of research and their application to, and involvement of, Māori was expressed during consultation, and in particular to distinguish clinical trials and streamline the review process for these which comprise the bulk of projects for review in some DHBs and can be quite time consuming<sup>12</sup>.

### Types of research

Different types of Māori research have been described by Cunningham (2000) and utilised in the development of Te Ara Tika (Hudson et al 2010) and in the Health Research Council’s Guidelines for Health Research involving Māori (2010). Table 1 below builds on these descriptions. Here, research that has been initiated by non-Māori, is further defined based on the level of expected involvement of Māori either as participants or part of the study team (levels 1 to 3).<sup>13</sup> Although Māori have been excluded by the research design in the first level, this type of study is still of interest to tangata whenua as it is conducted in Aotearoa, and also represents research that has been funded at the expense of a project that could have addressed Māori issues (Cunningham 2000). The challenge here, therefore is to identify opportunities within the project for Māori health development, such as health literacy improvement, resource sharing, or Māori researcher capacity development.

The second level of research includes the possible involvement of Māori as study participants (although minor), and/or junior research positions. A further consideration of the protection of Māori study participants comes into perspective here, and more so with the third level of research. Although the third level of research has been initiated by non-Māori, the expected Māori participation is considerable. It is likely to be an area of interest to Māori either where Māori may have high representation, or a health topic that has been prioritised by the DHB, mana whenua, or other Māori community groups. Depending on the design of the study it may be appropriate to use some Kaupapa Māori Research methods, and data should be analysed by ethnicity.

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<sup>12</sup> Appendix 1 provides a list of issues identified by DHBs during consultation

<sup>13</sup> See also the research review process for Bay of Plenty DHB in Appendix 5



Table 1 Types of research and levels of Māori involvement in a research project

	Non-Māori initiated research			Māori-centred research	Kaupapa Māori Research
Level of Māori involvement: • as participants • on research team	(1) No expected involvement	(2) Possible involvement	(3) Probable involvement	(4) Definite involvement	(5) Significant involvement, possibly exclusive
Type of consultation recommended	DHB Māori review	DHB Māori review	DHB Māori review and possible engagement with DHB Māori reviewers (face to face meeting)	Definite involvement as researchers, senior researchers and advisors Full and ongoing engagement and collaboration with appropriate Māori community group(s)	Significant involvement, possibly exclusively Māori researchers and advisors Full and ongoing engagement and collaboration with appropriate Māori community group(s), Māori are kaitiaki of project
Description of research	<ul style="list-style-type: none"> <li>Māori have not been included in the design of the project</li> <li>There are still possibilities to contribute to Māori development</li> </ul>	<ul style="list-style-type: none"> <li>The research topic is not designed to be analysed by ethnicity</li> <li>Not a topic of particular relevance for Māori.</li> <li>There are still possibilities to contribute to Māori development</li> </ul>	<ul style="list-style-type: none"> <li>the contribution of the research to Māori health and equity is detailed</li> <li>an area of health that Māori have high representation</li> <li>a topic of particular relevance for Māori (nationally or locally)</li> </ul>	<ul style="list-style-type: none"> <li>Clear aims for the contribution of the research to Māori Health and equity</li> <li>Māori knowledge produced, but non-Māori methods may be used</li> </ul>	<ul style="list-style-type: none"> <li>Clear aims for the contribution of the research to Māori health and equity</li> <li>Māori analysis is undertaken and Māori knowledge produced</li> </ul>
Control	Non-Māori	Non-Māori	Non-Māori	Non-Māori and/or Māori	Māori
Analysis	Non-Māori	Non-Māori	<ul style="list-style-type: none"> <li>Non-Māori and/or Māori</li> <li>Ethnicity analysis</li> <li>Equity analysis</li> </ul>	<ul style="list-style-type: none"> <li>Non-Māori and/or Māori</li> <li>Ethnicity analysis</li> </ul>	Kaupapa Māori
Tools	Non-Māori	Non-Māori	<ul style="list-style-type: none"> <li>Non-Māori</li> <li>Possibly some Kaupapa Māori Research methods</li> </ul>	<ul style="list-style-type: none"> <li>Non-Māori</li> <li>or Kaupapa Māori Research methods and Kaupapa Māori Epidemiology</li> </ul>	Kaupapa Māori Research methods and Kaupapa Māori Epidemiology

Māori-centred research (level 4) is that which has been initiated by Māori and has a high involvement of Māori as participants and as senior researchers and advisors. In Kaupapa Māori research (level 5) there is significant, and possibly exclusive, involvement of Māori, who have a governance role in the project. These two categories have clear aims on the contribution of the research to hauora Māori, and typically use Kaupapa Māori research methods and methodology.

While details of each type of research are provided (in Table 1), they are not necessarily distinct categories, rather there is a continuum of the types of research from no Māori participation at all to full and exclusive participation. One project has been described as taking a 'Kaupapa Māori consistent approach', whereby the Kaupapa Māori philosophies and methodologies were used in the study, however the principle investigator did not identify as Māori<sup>14</sup>.

An individual research project will sit somewhere along this spectrum. The further along the spectrum, the greater the expected contribution of the study to Māori health development. To fulfil the obligation of contributing to reduction of inequities, and to the forward advancement of Māori health, all researchers should continually seek to orientate their research projects further along this continuum.

#### *Clinical trials*

Ideally, best practice would entail that Māori are involved in research at every step of the process from inception to data collection, analysis and dissemination, and therefore Māori participation is sought at the earliest stage. However, most clinical trials have been developed and designed prior to presentation to the DHB for Māori review or locality authorisation.

The majority of clinical trials (particularly those initiated overseas) would fall into the first two levels of research types. These may be readily reviewed by providing (written) evidence to the DHB of criteria met. Some clinical trials may be focussed on an area of importance for Māori and may involve a large number of Māori as study participants (level 3). In this instance, closer engagement with DHB Māori reviewers may be required.

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<sup>14</sup> Anneka Anderson and Phillipa Malpas (June 2015) Working with diversity: Kaumatua and Māori and non-Māori researchers within the context of physician-assisted dying. Presentation at the AABHL conference, Otago University, Wellington (25-27 June 2015)

### *Types of consultation*

Review of research is a form of consultation, and may meet ethical requirements as such. It can be considered the minimum standard for consultation and a process to be undertaken to determine the nature and scope of any further engagement required. Review provides a screening process which can limit those projects passed on to Māori for further consultation, thus minimising the demands on Māori communities or organisations (Sporle and Koea 2004a).

Good practice would involve full and ongoing engagement and collaboration with appropriate Māori groups or communities, and best practice entails Māori researchers positioned as kaitiaki of a project, having full governance and decision-making power for all activities carried out as part of the study (Hudson et al 2010).

While the first two levels lend themselves to being readily reviewed by providing to the DHB written evidence of criteria met, Māori reviewers may wish to meet with the research team of a level 3 project to discuss recruitment, analysis, dissemination and consultation required and also to identify opportunities for benefit sharing.

## A framework for Māori Review of Research in District Health Boards

Te Ara Tika uses four core principles derived from tikanga Māori; whakapapa, tika, manaakitanga and mana (Hudson et al 2010). In this context, **whakapapa** refers to the quality and nature of relationships, how these are developed and how they are maintained. At minimum consultation is required with Māori communities, good practice entails substantial engagement with Māori and best practice empowers Māori to assume a kaitiaki role in a research project.

**Tika** relates to the validity of a research proposal, the knowledge, skills and track record of the research team, the incorporation of the Treaty principles into research design, and the research approach which determines the methods used - either non-Māori, Māori-centred or Kaupapa Māori.

The concept of **manaakitanga** centres on ensuring the mana of both parties involved in a relationship is upheld. At minimum an awareness of cultural issues is expected, good practice entails considering the inclusion of Māori values and concepts to ensure cultural safety and best practice ensures respectful conduct or māhaki and recognition in the project of spiritual integrity and Māori philosophy.

In the context of research, **mana** relates to equity and distributive justice. This acknowledges issues of power and authority in relation to rights, roles and responsibilities when considering the risks, benefits and outcomes of a project. *Mana tangata* refers to the rights of an individual, *mana whenua* recognises the *iwi* and *hapū* that have authority over a region and *mana whakahaere* entails the sharing of power and control in a project with *iwi*, *hapū* or relevant Māori communities.

These four *tikanga* have been used as a basis for this framework (see Table 2), and a statement that derives from each concept provides an aim for this aspect of research. They are as follows:

<b>Whakapapa</b>	Research involves the development and maintenance of respectful relationships and clear, appropriate communication
<b>Tika</b>	Researchers have the appropriate skills and experience to design research that contributes to equity and to Māori health development
<b>Manaakitanga</b>	Research is conducted with respect for all persons involved and respect for their culture
<b>Mana</b>	Research relationships are reciprocal and equitable and acknowledge the rights, roles and responsibilities of all involved

The criteria in the framework in Table 2 are arranged left to right, from minimum standard to good practice then best practice and beneath this are the types of research and level of involvement of Māori (as seen in Table 1). Again, this is a continuum and while research projects sit somewhere along this continuum, they should seek to work towards best practice. The type of consultation recommended at each level is provided in the table as guidance as this may differ with the preferences of each DHB.

The framework is written as a set of statements or criteria at each level. For the purpose of Māori review, research groups are required to provide evidence that these criteria have been met, allowing Māori reviewers to assess an application based on the documentation supplied. The framework can also be used by researchers to guide the development of their project, and in compiling evidence and preparing their application. A template application form has been drafted to reflect this framework, and is provided in Appendix 3 (also available as a separate document).

The minimum standard criteria are those that are ideally met by all research. It is likely that minimum standard criteria may be met and approved by providing written evidence

through the DHB locality authorisation process, without requiring face-to-face engagement, and that this will be the case for a large proportion of clinical studies. It is intended that this framework will streamline the process for clinical studies, saving time spent by reviewers while still ensuring all requirements are met. Closer engagement with the DHB reviewing team might be preferable for researchers undertaking projects expected to have a considerable number of Māori participants and/or are in an area of interest to Māori (see Table 2, 'Good Practice' column). Māori-centred or Kaupapa Māori research might undergo a separate process, as the review process (by providing written evidence) may be inadequate in these situations.

Table 2: Framework for Māori Review of Research in District Health Boards

Minimum standard All research should aim to meet these criteria		Good practice Additional criteria		Best Practice Additional criteria	
Type of research	Non-Māori Initiated	Non-Māori initiated	Non-Māori initiated	Māori-Centred	Kaupapa Māori
Level of Māori involvement	(1) no expected involvement	(2) possible involvement	(3) probable involvement	(4) definite involvement	(5) significant involvement, possibly exclusive
Type of consultation Recommended	DHB Māori review	DHB Māori review	Engagement with DHB reviewer(s)	Engagement with DHB reviewer(s) and Māori community	Engagement with DHB Māori reviewer(s), engagement with Māori community, Māori are kaitiaki of project
<b>WHAKAPAPA</b>  Research involves the development and maintenance of respectful relationships and clear, appropriate communication	<p>Māori participants are recruited in a respectful and appropriate manner</p> <p>The patient information and consent forms are clear, concise, provide lay explanations of medical jargon, possibly use diagrams to aid explanations, and detail issues of significance for Māori near the beginning of the form (such as provision for cultural requirements, offer of whānau involvement, tissue collection details)</p> <p>The patient information and consent forms have a Flesch reading score of 65 or above and are of a conservative length. The word count and number of pages is supplied.</p> <p>Steps are taken to ensure the patient information and consent forms are appropriate for Māori participants and whānau.</p> <p>Detail on the use of tissue samples is clearly described, including the nature and amount of samples, storage and transport, if they are to be sent overseas for analysis and method of disposal. Separate consent is requested for storage of samples for future unspecified use. Separate consent is requested for use of samples for genetic analysis.</p> <p>Study results and data are disseminated to all Māori groups consulted and to individual participants and their whānau, as consented, and also to the DHB.</p>	<p>Māori have considerable input to influencing the nature, shape and design of the research project</p> <p>Any previous and planned consultation with Māori is described including details of the nature, time scale and extent of this engagement</p> <p>A clear description is provided of Māori participation in the study design and analysis, and dissemination of results</p> <p>A process for ongoing communication with Māori involved in the project is jointly decided upon and implemented</p>	<p>Māori have governance over the research project</p> <p>Māori have control over processes of dissemination and the end use of study results</p>		

	<p>At the end of the study, a locality report is provided to the DHB detailing the numbers of Māori recruited and any specific issues or concerns recruiting or retaining Māori in the study. This can be submitted after local involvement in the study is complete.</p>		
<p><b>TIKA</b></p> <p>Researchers have the appropriate skills and experience to design research that contributes to equity and to Māori health development</p>	<p>Ethnicity data is collected, stored and handled using the standard ethnicity collection question (Census 2001) as recommended by the Ministry of Health <sup>1</sup></p> <p>The proportion of Māori participants in the study reflects the proportion of Māori in the community with the health condition of interest. The sources of information utilised to generate this data are provided.<sup>2</sup></p> <p>Researchers have undertaken appropriate tikanga Māori for research training or Treaty Training and/or have a proven track record for appropriate and successful Māori health research</p>	<p>The expected contribution of the study to improving hauora Māori and to the reduction of inequities is clearly articulated.</p> <p>The epidemiology of this health issue for Māori is described, including consideration of future demographic changes<sup>2</sup></p> <p>Analysis by ethnicity is undertaken</p> <p>Equal explanatory power is applied in study design<sup>3</sup></p> <p>Processes are in place to provide cultural support for the research, study participants and researchers</p>	<p>The study aims and design have been largely or solely determined by Māori</p> <p>A Kaupapa Māori paradigm forms the foundation of the study</p> <p>Kaupapa Māori research methodology and methods are applied throughout the research project</p> <p>Māori knowledge is generated by the study</p>
<p><b>MANAAKITANGA</b></p> <p>Research is conducted with respect for all persons involved and respect for their culture</p>	<p>Study participants are provided with the contact details of an appropriate Māori health service that can be accessed for cultural advice and support</p> <p>All measures to ensure privacy and confidentiality are detailed for participants and whānau</p>	<p>Māori values and concepts applied in the research project are clearly described.</p> <p>Whānau are welcome and encouraged to support study participants in the project</p> <p>Provision is made for participants and whānau to participate in the study using te reo Māori</p> <p>The appropriate Māori protocols are offered where they might be required, such as karakia for the disposal of tissue</p>	<p>Kaumātua guide and support the research team, particularly in terms of tikanga, observing protocol and wairuatanga.</p>

<p><b>MANA</b></p> <p>Research relationships are reciprocal and equitable and acknowledge the rights, roles and responsibilities of all involved</p>	<p>Participants and whānau are fully informed of all aspects of the study, including the risks and benefits, and are provided ample time to consider information, discuss the study and ask questions before consent to participate is requested</p> <p>Participants are given the opportunity to consult with whānau, hapū and iwi as required before consent is requested. It is particularly recommended that participants seek advice from their hapū or iwi regarding use of tissue and research involving genetic analysis.</p> <p>Koha and reimbursement of costs are provided where applicable, and in an appropriate manner.</p>	<p>Researchers engage meaningfully with mana whenua, taurahere or iwi researchers</p> <p>The study design and aims include goals and aspirations of mana whenua and taurahere</p> <p>Opportunities to contribute to health literacy of participants and whānau are identified and included in the project plan</p> <p>Opportunities to contribute to Māori research capacity development are identified and included in the project plan</p> <p>Provision is made for collective consent from iwi, hapū or Māori community groups</p> <p>The contributions from mana whenua and other Māori to the project are appropriately acknowledged</p> <p>A clear description is provided of who will benefit from this research and how this will be evidenced</p>	<p>Māori intellectual property is protected</p> <p>Consent is gained to access or use matauranga Māori where necessary. This contribution is appropriately acknowledged.</p> <p>The ownership of the data generated by the study is decided upon in consultation with Māori, and clearly stated.</p>
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Framework last updated May 2015

<sup>1</sup> <http://www.health.govt.nz/publication/ethnicity-data-protocols-health-and-disability-sector>

<sup>2</sup> useful sources of data for these calculations include stats NZ population data and projections ([www.stats.govt.nz](http://www.stats.govt.nz)), Health Needs Assessments for DHBs or Māori Health Profiles 2015 ([www.health.govt.nz](http://www.health.govt.nz)), Māori health plans and strategies for each DHB (available on DHB website)

<sup>3</sup> see Te Rōpū Rangahau Hauora a Eru Pōmare (2002) <https://www.fmhs.auckland.ac.nz/en/faculty/tkxm/office-of-tumuaki/responsiveness-to-maori/step-two/clinical-intervention.html>



## Gaps and Limitations of this Study

The design of the framework has attended to many of the issues identified during consultation, however some require further consideration<sup>15</sup>.

### *Roles and responsibilities of researchers*

Several DHBs offer some form of tikanga training or Māori health training for researchers. The qualities required of researchers working with Māori communities were expressed during consultation, these included not only the necessary cultural, reo, subject and research expertise, but also a commitment to things Māori, the trust of Māori communities and personal qualities suited to working with Māori. Kaupapa Māori involves active processes of whakawhanaungatanga, or relationship building and development (Wihongi 2002). Responsiveness to Māori requires continued involvement throughout the research, rather than just at the initial research application process.

The idea of some research groups acquiring a 'trusted researcher' status, conferred by the Māori reviewers and/or the iwi partnership board of a DHB has been discussed in previous hui. Some research groups have consistently produced high quality applications, and acknowledgement of this could be made through achievement of such a status. What needs to be considered is whether the status applies to the group or the individual (principal investigator) and how long the status lasts. A researcher 'grading' system has been described in a recent indigenous ethics symposium<sup>16</sup>.

### *Roles and responsibilities of reviewers*

The reviewing group or individual face several challenges. Time pressures was a concern, reviewers often have competing obligations and limited time. The desire for a research coordinator was expressed by one DHB in order to implement the research policy, and the need for funding to set up a Māori research department identified by another DHB. Similarly, the need for the capacity to respond to other relevant demands, such as the recent National Ethics Advisory Committee (NEAC) review<sup>17</sup>, was expressed during consultation. It is hoped that utilisation of the framework can reduce the time spent on processing some of the applications

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<sup>15</sup> A list of issues identified during consultation is provided in Table 3, Appendix one.

<sup>16</sup> Maile Taulii, Hawaii. Indigenous Research Ethics Symposium, Auckland 20 May 2015

<sup>17</sup> See the following link for further information about the review: <http://neac.health.govt.nz/cross-sectoral-ethics-arrangements-health-and-disability-research-consultation>

that have few expected Māori participants, while still ensuring these research groups meet the requirements of Māori consultation.

Reviewers require a range of expertise such as; experience in research, ethical committee training and a level of competency in te reo and tikanga Māori<sup>18</sup>. A desire was expressed for ongoing professional development and upskilling and the need to keep informed of latest advances in the area of Māori health and Māori health ethics. In addition, reviewers need to reflect the views of the Māori community as much as possible. The sentiment was expressed by at least one DHB that there needed to be closer, more regular engagement between the reviewing team and mana whenua to ensure that research contributed to the goals and aspirations for local Māori. Of the policies reviewed, only Southland DHB/Otago University had the goals of mana whenua embedded in their policy (Ngāi Tahu vision 2025).

Relationships are important, and responses from reviewers to researchers should be positive and encouraging. Similarly, the importance of clear internal processes between Chief Medical Officer, Iwi partnership board, and reviewers was identified.

Some discussion has also been had as to whether reviewers should be either 'approving' or 'endorsing' research projects. Approval indicates that there is the power to veto the research if approval is not given, whereas endorsement indicates support for the project. Most DHBs used 'approval' whereas CCDHB 'endorsed' projects that had been assessed.

The question has been raised as to whether it is appropriate for reviewers to assess Kaupapa Māori researchers who have a proven track record in this area<sup>19</sup>. It may be that engagement between these groups and reviewers provides an opportunity for capacity development of reviewers and the DHB, information exchange, or some other form of benefit-sharing.

#### *Roles and responsibilities of the District Health Board*

Some concern was expressed about the possibility of not capturing all research projects conducted in a DHB area. However researchers themselves have an ethical requirement to seek locality authorisations and to consult with Māori. Clarifying the scope for research to be reviewed is useful. The Health and Disability Ethics Committees has defined DHB research as; as

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<sup>18</sup> As specified in the draft terms of reference for National Māori DHB Reviewers Committee

<sup>19</sup> See Table 3, Appendix one: Issues identified regarding the Māori review of research process

research conducted on DHB premises, involving staff or patients, or through which substantial recruitment will be undertaken (MOH 2014). Similar descriptions are found in many DHB research policies<sup>20</sup>. For research that requires ethical approval, a Locality Authorisation is required before the research commences. For some DHBs the Māori Review process is contained within the Locality Authorisation, and this can serve to ensure that Māori review is undertaken.

Some questions were raised about the role of the DHB, as to how are the DHBs own goals are prioritised, whether the DHB should be commissioning research, and how to ensure an ethical contracting process for research. These are all considerations to be taken into account when establishing a DHB research policy.

During consultation and peer review, the view was expressed that the area of Māori review was under resourced in many DHBs and the process would benefit from direct resourcing or an FTE made available to reviewers. Many reviewers carry out this role voluntarily. Direct resourcing of Māori review would benefit both Māori and researcher and would help establish clear unambiguous pathways.

For researchers there is a considerable amount of paperwork to undertake for ethics applications and locality authorisations. During peer review the need to minimise duplication of information supplied in each of these processes was articulated, and the suggestion made that the proposed framework be merged with the current ethics application process.

#### *Next steps*

This is a draft framework and associated template application form, with suggested criteria for review that may be tailored to suit the specific circumstances of an individual DHB. Following peer review of the framework, it will be distributed to each DHB, and all other stakeholders consulted. It is recommended that the framework is piloted (in one or two DHBs) and then evaluated before finalising. The framework is intended as a living document, with regular updates to ensure its future application in the changing research environment. This would also help ensure that the framework aligns with other similar and emerging topics such as *Te Mata Ira* - Informing cultural guidelines for biobanking and genomic research<sup>21</sup>.

## Conclusion

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<sup>20</sup> See Appendix 4

<sup>21</sup> Maui Hudson, *Te Mata Ira* update March 2015

Research should be designed to contribute positively to equity and Māori health advancement, and should be conducted in a culturally appropriate manner, respecting and upholding the mana of all those involved. The framework developed here has used the four tikanga Māori principals from Te Ara Tika - whakapapa, tika, manaakitanga and mana to determine criteria for ensuring responsiveness to Māori throughout the entire study process; from the development of the aims and objectives, to the recruitment of participants and gathering of data, data analysis, interpretation and framing of results, and dissemination.

By providing evidence of meeting criteria within the framework for Māori review, researchers can ensure they are, at minimum, initiating the consultation process with tangata whenua. The implementation of this framework can potentially make an important contribution towards ensuring the rights of Māori are upheld in a research setting.

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## Appendix

### Appendix one: Issues identified regarding the Māori review of research process

Through the process of consulting with representatives of each DHB area, and in reviewing minutes of previous national hui, several issues were identified that indicated areas of consideration or improvement for the review process. These have been (loosely) grouped into themes and are listed in Table 3 below.

Table 3: List of issues identified regarding the Māori review of research process in DHBs

Theme	Issue
<b>Type of research</b>	<ul style="list-style-type: none"> <li>• What constitutes or defines which research projects that should be reviewed by DHB Māori reviewer(s)?</li> <li>• Is it important to know and count the number of Māori focussed research initiatives along the way?</li> <li>• What makes a research project Māori research?</li> <li>• A preliminary definition of Māori health research is: research which improves the health of Māori / or improves healthcare delivery to improve equity.</li> <li>• Hauora Māori research must be developed within a Māori cultural framework</li> <li>• Māori research should involve Māori as active participants at all stages of the development process</li> <li>• Māori research should be controlled by Māori.</li> <li>• Māori research should be measured against Māori-relevant standards. The methods, measures and procedures used must take full cognisance of Māori cultural preferences.</li> <li>• How does this research fit in with local DHB priorities?</li> <li>• How does this research address the health needs of Māori?</li> <li>• How can the research be performed in a way that is in-line with the “Treaty of Waitangi (Te Tiriti of Waitangi), cultural ethics and Kaupapa Māori?</li> </ul>
<b>The review process</b>	<ul style="list-style-type: none"> <li>• A considerable amount of time is spent on clinical trial studies which have very few Māori participants - is there another process to be used so that less time is spent reviewing clinical trials?</li> <li>• Health literacy needs to be acknowledged and addressed</li> <li>• Whānau support needs to be provided for and encouraged in the research projects</li> <li>• Often the clinical trials patient information sheets are really long and complex. These need to be simplified and ensured they are appropriate for Māori.</li> <li>• Māori communities are over-researched with little benefit in return</li> <li>• With a small population of Māori it can be difficult to recruit the required amount for a study</li> <li>• Clinical trials information sheet too long</li> <li>• Different types of research - which ones do we want to be involved in given capacity issues? (eg clinical trials with few Māori participants)</li> <li>• How does this research ‘fit’ in with local DHB priorities?</li> <li>• How does this research ‘address’ the health needs of Māori</li> <li>• Research should be focused on areas of importance and concern to Māori, and should arise out of self-identified needs and aspirations.</li> <li>• How can a Māori review assist the individual researcher to fulfil research objectives?</li> </ul>
<b>Roles and responsibilities of researchers</b>	<ul style="list-style-type: none"> <li>• An improvement on the process would be having the researchers complete a pre-research training around ethics and researching with Māori (perhaps included in their undergraduate training)</li> </ul>

Theme	Issue
	<ul style="list-style-type: none"> <li>• Can we consider a ‘trusted researcher’ status for research groups that have consistently met the requirements. If so, we need to consider if the status applies to the group or the individual (principal investigator) and how long the status lasts</li> <li>• How can the research be performed in a way that is in-line with the Treaty of Waitangi, Cultural Ethics and Kaupapa Māori?</li> <li>• Research which supports a Māori cultural framework must be conducted by people who have the necessary cultural, reo, subject and research expertise and a commitment to things Māori, the trust of Māori communities, cross-cultural competence, personal qualities suited to working with Māori</li> <li>• People involved in working with Māori should be accountable to the people they research</li> </ul>
<b>Roles and responsibilities of reviewers</b>	<ul style="list-style-type: none"> <li>• How do research reviewers keep informed and upskilled?</li> <li>• A research coordinator position is required (has been proposed) to implement the new research policy</li> <li>• We need the capacity in the reviewing team to respond to other demands such as the recent NEAC review</li> <li>• A decision needs to be made around which research do we want to be involved in given capacity issues</li> <li>• We need to consider how to be involved with Māori researchers undergoing kaupapa Māori research (do we need to review and approve these?)</li> <li>• How can a Māori review assist the individual researcher to fulfil research objectives?</li> <li>• We need to ensure we meet regularly with mana whenua groups and are kept informed of their priorities</li> <li>• Responses from reviewing committee to researchers should be positive and encouraging</li> <li>• Approval or endorsement of projects?</li> </ul>
<b>Roles and responsibilities of the DHB</b>	<ul style="list-style-type: none"> <li>• How do DHBs prioritise their own goals and aspirations regarding research?</li> <li>• Is it the DHB’s job to be commissioning research?</li> <li>• How do DHBs ensure an ethical contracting or commissioning process for research?</li> <li>• It is the responsibility of the DHB to contribute to health research as a leader, participant, follower, funder, provider and assistant</li> <li>• What are the internal communication processes (between Māori health directorate, iwi partnership board, chief medical officer etc)?</li> <li>• How do we (DHB/reviewing team) keep informed of research in the DHB region?</li> <li>• How do we (DHB) ensure mana whenua and other iwi in the DHB rohe are appropriately and regularly consulted?</li> <li>• It is important to get the research process right, and requires discussions between the Chief Medical Officer (CMO) and the Director of Māori health</li> <li>• We need more funding to set up a Māori research department (to process reviews)</li> <li>• We would like to implement a formal programme (for Māori review of research)</li> </ul>



## Appendix Two: Current processes for Māori review of research in District Health Boards

Table 4 Current process for Māori review of research in District Health Boards

DHB	Reviewer(s)	Iwi mandate	Description of review process
Northland	All locality authorisations are reviewed by 2 people within NDHB - the CMO and a representative from Te Poutokomanawa (Māori health directorate) meetings approx. every 2 weeks	Te Kaunihera Kaumatua (part of Te Poutokomanawa)	The process is contained within the research policy. Applications are coordinated by the assistant to CMO. All documents are requested (questionnaires, consents, HDEC approvals etc), and a locality authorisation form is completed. Decisions on the merits of each application are considered at the locality authorisation meetings. These involve the CMO, Te Poutokomanawa representative and the researcher(s). Locality authorisation form signed by CMO at the end of the meeting and a letter of support from Te Poutokomanawa. If appropriate, approval submitted electronically via HDEC site <ul style="list-style-type: none"> <li>Forms: Research policy and Locality Assessment form<sup>3</sup></li> <li>Tikanga training offered</li> </ul>
Waitematā and Auckland	One reviewer, no administrative support. Overseen by the Māori research committee, particularly for addressing tough issues.	Mana whenua and pan tribal are part of the Māori Research Committee	Promotion of the process is by word of mouth, through the research units, the intranet site and on the HDEC website. The application is received and reviewed, if criteria not met, more information is requested. Approval letter sent if criteria met, if not, then referred to Māori Research Committee. <ul style="list-style-type: none"> <li>Forms: Māori review form AWDHB and Māori local flowchart AWDHB<sup>3</sup></li> <li>Tikanga and Treaty training provided</li> </ul>
Counties Manukau	Currently three reviewers (monthly meeting)	Mana whenua community representative	Applications come through CMDHB research office, and are coordinated by the chair. Māori review process is part of the overall DHB locality approval process. <ul style="list-style-type: none"> <li>CMDHB Māori Research review committee application form</li> <li>Online tikanga training programme provided &amp; marae visit</li> </ul>
Bay of Plenty <sup>2</sup>	Māori Research Committee (monthly meeting)  Regional Māori Health Services		Four levels of Māori consultation: 1) No Māori participants expected, then no consultation 2) if possible Māori participants in study, then Regional Māori health services notified 3) if probable Māori participants then consultation with Regional Māori health services required 4) if there is definite involvement of Māori then full consultation is required with the Māori Research Committee at monthly hui. Specific questions on recruitment, benefit of study to Māori and dissemination <ul style="list-style-type: none"> <li>Forms: Māori Consultation Guidelines v5 25 November 2014<sup>3</sup></li> </ul>
Waikato	Currently three reviewers. Te Puna Oranga Māori Consultation Research Review Committee (MCRRC), inclusive of Kaumatua. Monthly review dates. No admin support	Communication with the Waikato DHB Kaunihera Kaumatua who are representatives of the iwi of the Waikato-Tainui Rohe	All Waikato DHB research projects (excluding clinical audits) must undergo a consultation process with Te Puna Oranga MCRRC. The application form provides a series of questions as guidelines, based on the Te Ara Tika framework and incorporating the Treaty. Issues covered include collection of ethnicity data, consultation with Māori, dissemination of study results, cultural competency of researcher(s), recruitment, inequalities and potential issues of cultural significance. There is also a separate process / questionnaire for use of human tissue. <ul style="list-style-type: none"> <li>Forms: Te Puna Oranga MCRRC application form<sup>3</sup>, Māori consultation at Waikato DHB, TPOMCRRC Human tissue and storage</li> <li>Te Ara Totika training is provided DHB wide quarterly, and online Treaty of Waitangi training</li> </ul>
Lakes	Research and Ethics committee	Currently two iwi groups: Te Rōpū Hauora o Te Arawa and Te Nohanga Kotahitanga o Tūwharetoa.	All research is forwarded to the Māori Health division, Te Huinga Takiora Māori (from the Research and Ethics Committee) and a brief prepared for Lakes DHB iwi governance boards to consider. An iwi representative sits on the Research and Ethics Committee. The Iwi governance group are asked to consider what the benefits of the research will be to Māori. Feedback is given to the Research and Ethics Committee.

DHB	Reviewer(s)	Iwi mandate	Description of review process
		However at the time of this report, <b>Te Kahui Oranga</b> Was being formed - joint strategic iwi governance group	<p>Researchers are recommended to work with the Māori health team - Te Huinga Takiora Māori</p> <ul style="list-style-type: none"> <li>• Māori health training available for all staff. Also an orientation on the health needs of Māori in Lakes DHB. Training includes data issues, services available, enablers and tools that are delivered by Lakes DHB. Te Pumamao training delivered twice yearly. And Institutional racism and Treaty training when required.</li> </ul>
Tairawhiti <sup>1</sup>	(no separate formal process)	<b>Te Waiora o Nukutaimemeha</b>	Tairawhiti clinical board refers any research involving Tairawhiti Māori to the GM Māori to be reviewed. Review considers whether the research has been before the ethics committee and whether it needs to be referred to the Iwi Runanga for review
Taranaki	No formal process. Research proposals are circulated to the Māori health team on receipt, for comment. There are no qualified reviewers as such. The circulation and sign-off process is coordinated by the PA for the Chief Advisor Māori Health (CAMH)	If this is required, the CAMH will refer to the TDHB Iwi Relationship Board <b>Te Whare Punanga Kōrero Trust</b>	<p>No formal process. The DHB research coordinator refers all proposals to the CAMH PA who coordinates circulation as required. Any comments or requirements are signed off by the CAMH then referred back to the DHB coordinator. Feedback generally relates to process and requirement to make kaimahi hauora available to Māori research participants that want or need support. Signoff form used.</p> <p>The Māori Health unit really isn't qualified to comment on the appropriateness of research topics other than to give advice on and support engagement with Māori and the points at which this should occur.</p> <ul style="list-style-type: none"> <li>• Tikanga training provided as required</li> </ul>
Whanganui <sup>1</sup>	No formal process	Through the Director Māori health to the iwi Māori relationship board: <b>Hauora a iwi</b>	<p>No formal process</p> <ul style="list-style-type: none"> <li>• Training: A refreshed cultural training programme is to be piloted May-Jun 2015</li> </ul>
Hawkes Bay	Māori Health Services Taumata Rangahau, and may call in outside expertise to provide advice on specific issues	Taumata Rangahau has a direct relationship and communication with the <b>Māori Relationship Board</b> . Community connections are also used when required to consult on particular projects	<p>The Taumata Rangahau group have a direct responsibility to capture specific cultural requirements before the research application reaches the Ethics Committee approval stage. This process allows an earlier cultural intervention, and therefore allows for early engagement with the researchers and other specialists. This phase of consultation "fits" in with the initial research application process. We therefore are privileged to discuss research objectives (if they require Maori input) at an earlier stage than may be required. Decisions therefore are made based on the queries that may arise before the Taumata Rangahau, and usually, a consensus is reached with the agreement of the researcher. Final signoff by Kaiwhakahaere of Māori Health Services.</p> <p>Induction and orientation programmes are provided for new DHB staff, and Māori Health Services are able to support individuals and groups according to their cultural training needs.</p>
Midcentral <sup>1</sup>	No formal process	<b>Mana whenua Hauora</b>	No formal process, currently establishing a policy
Wairarapa and Hutt Valley	GM Māori		Application is received and meeting date advised, application then send to Māori and Pacific Health to approve in principle (currently GM Māori), resource and financial implications and impacts on other services considered, one page summary sent to Opex members who meet to discuss applications monthly. Written decision sent to researcher. No record of Māori health research in the past 8 years in Wairarapa.
Capital and Coast	<b>Research advisory group</b> -	RAG-M is a subcommittee of	Proposals received by RAG-M office, sent to individual reviewers to review then peer reviewed at monthly RAG-M hui.

DHB	Reviewer(s)	Iwi mandate	Description of review process
	<b>Māori (RAG-M).</b> Currently consists of 5 Māori health research experts, a CCDHB representative and chaired by iwi representative. Also administrative support.	<b>the Māori Partnership Board,</b> the Māori relationship board to CCDHB, mandated by mana whenua; Te Atiawa, Ngāti Toa, Te Atiawa ki Whakarongotai. The group meets at least 6 times per year	Proposals are either endorsed, declined, or provisional endorsement granted subject to conditions which are required to be met before endorsement granted. Response letter sent. Researchers are asked at the completion of their study to provide RAG-M with a local report of Māori involved, and a copy of the final report of the study.  <ul style="list-style-type: none"> <li>Forms: RAG-M Coversheet, RAG-M information booklet and guidelines, RAG-M terms of reference<sup>3</sup></li> <li>Tikanga Māori - Research specific education (last Tuesday each month 2.30-3.30)</li> </ul>
<b>Nelson Marlborough</b>	Karake Consultancy, Dr Melissa Cragg. All interaction is via email, in the first instance there is a policy online which outlines the process. Expertise within the DHB is not sought as the policy clearly states the parameters for information needed	<b>The Iwi Health Board</b> is mandated by the 8 iwi in Te Tau Ihu o Te Waka. At the monthly meetings research requests are tabled once a recommendation is provided by Karake Consultancy.	Research proposal received, further information or action requested if necessary, report with recommendations sent to IHB (by Karake consultancy) for consideration at monthly hui. Additional information may be requested by IHB before endorsement granted. Information requested includes; involvement of Māori, collection of ethnicity data, how the research will contribute to Māori health gain, analysis by ethnicity, dissemination, communication for Māori, allowing for cultural difference without disadvantage.  <ul style="list-style-type: none"> <li>Cultural supervision policy for those in DHB who are Māori, or who are in roles where there's an expectation of proficiency in Te Ao Māori.</li> <li>some MOH funded cultural training programmes</li> <li>DHB runs Treaty training (2 days) several times per year (Nelson and Blenheim)</li> <li>IHB Research Policy 2014 supplied</li> </ul>
<b>Westcoast</b>	Reviewed by GM Māori	<b>Tatau Pounamu</b> (iwi relationship board)	Applications are discussed with the Iwi Relationship Board when required  <ul style="list-style-type: none"> <li>Training: Treaty of Waitangi workshops, Te Pikorua Bicultural training, Inequalities training package, Te Awatea cultural awareness training programme</li> </ul>
<b>Canterbury</b>		<b>Komiti Whakarite</b>	
<b>South Canterbury</b>	Initially reviewed by GM Māori. Followed by consultation with other personnel, kaumatua or local Māori as appropriate. There is no reviewing panel, so no regular meeting schedule. No admin support.	The GM Māori meets with the <b>Māori Health Advisory Committee</b> quarterly. This is a board subcommittee made up of representatives from both local runaka and maata waka.	All research applications submitted to Timaru Hospital are co-ordinated by the Quality Team. There is a standard process and documentation trail for research application approvals. Every Research application has to be approved through the same process. If the application gets declined at some stage of the process then it does not go on to the next stage for consideration ie; if an application is declined by the GM Secondary Services because it is not suitable for our facility then that application would not be considered by the GM Māori. Research proposals are quite rare <ul style="list-style-type: none"> <li>Forms: Clinical Research Policy South Canterbury DHB (contains application forms)<sup>3</sup></li> <li>The DHB kaumatua offers a cultural training programme for DHB staff. Staff are also offered funded Treaty Training at the local Polytechnic.</li> </ul>
<b>Southern<sup>2</sup></b>	Research Advisory Group	<b>Ngai Tahu Research Consultation Committee</b>	An agreement between SDHB and Otago University. Māori approval process can be used for both organisations Optional letter of approval to be obtained from Ngai Tahu for clinical research.

<sup>1</sup> DHB has not yet established a review process

<sup>2</sup> information obtained from DHB website only

<sup>3</sup> see Appendix Four for details of forms and documentation and for website links

## Appendix Three: Template Application Form for Māori Review of Research in District Health Boards

The template has been designed as a fillable form. The standard text can be 'protected' so that no alterations can be made by the applicants, leaving only the sections where a response is required to be filled.

Providing the form is submitted (to the reviewers) as a word document, the reviewer can type a response letter directly onto the beginning of the form (see 'office use only' shaded box at the beginning of the template application form). This removes the need for a separate document and all the evidence submitted with the form follows immediately. This also has the added advantage of increasing efficiency of the process and allows detailed feedback to be provided by the reviewer within the text of the original application (for example, by using track changes or insert comment).

[insert DHB letterhead or logo]

[office use only]

Tēnā koe

- Your application has been endorsed  
 Your application is not yet endorsed. Details of further requirements are provided below.

Ngā mihi nui,  
Signed:

## District Health Board Māori Review of Research

### Application Form

Date: [Click here to enter a date.](#)

Study title: <i>type or paste text here</i>	Documentation provided with this application:  <input type="checkbox"/> all patient information and consent forms <input type="checkbox"/> documentation for collecting patient information <input type="checkbox"/> study protocol <input type="checkbox"/> ethics application form <input type="checkbox"/> fee payment or receipt <input type="checkbox"/> other documentation, please describe: <i>type or paste text here</i>
Principal investigator: <i>type or paste text here</i>	
Contact person: <i>type or paste text here</i>	
Contact details: <i>type or paste text here</i>	
Phone: <i>type or paste text here</i>	email: <i>type or paste text here</i>

For guidance on completing this form and meeting the minimum requirements of Māori consultation, please refer to: *Simmonds S (2015) A Framework for Māori Review of Research in District Health Boards* [insert website link]. Other documentation that may help with this application process: [insert link/reference. For example, tikanga guidelines]

#### 1. Details of Research

1a) Please provide a brief outline of your research project:  
*type or paste text here*

1b) What type of research or trial design best describes your study? (tick any that apply)

- |  |  |
|--|--|
| <input type="checkbox"/> an observational study  | <input type="checkbox"/> a minimal risk observational study                  |
| <input type="checkbox"/> an interventional study | <input type="checkbox"/> audit or related activities                         |
| <input type="checkbox"/> student-led research    | <input type="checkbox"/> a multi-national study initiated outside NZ         |
| <input type="checkbox"/> a clinical trial        | <input type="checkbox"/> other, please detail <i>type or paste text here</i> |

For definitions, please refer to: *Standard Operating Procedures for Health and Disability Ethics Committees, version 1.0 2012*  
<http://ethics.health.govt.nz/operating-procedures>

1c) Which option best represents the current status of the study's ethical approval?

- received ethics                       applied for ethics

- not yet applied for ethics                       not applicable, please explain: *type or paste text here*

*Please include copies of all ethics documentation with this application form*

1d) What is the expected level of involvement for Māori in your research project? (either as participants, researchers or advisors)

- (1) no expected involvement                       (2) possible involvement  
 (3) probable involvement                       (4) definite involvement  
 (5) significant involvement (or exclusively Māori)

Please provide details: *type or paste text here*

*Note that if you have indicated levels 3-5, you may be requested to meet with the [Māori research review group of the DHB], and provide further detail of engagement with Māori. We will make contact with you if this is required.  
Please refer to Simmonds S (2015) A Framework for Māori Review of Research in District Health Boards, table 1 to help identify levels of Māori involvement in a research project.*

**2. WHAKAPAPA. Research should involve the development and maintenance of respectful relationships and clear, appropriate communication**

2a) Please detail how participants are recruited for this study, and strategies to ensure appropriate recruitment of Māori: *type or paste text here*

2b) Please provide the following details for each of your patient information and consent forms:

Consent form	Flesch reading score	Number of words	Number of pages
<i>type or paste text here</i>	<i>type or paste text here</i>	<i>type or paste text here</i>	<i>type or paste text here</i>

2c) What steps have you taken to ensure your patient information and consent forms are appropriate for Māori? *type or paste text here*

2d) Does this study involve the collection of tissue samples?

- No. Continue to question 2g.  
 Yes. Please provide all details of the nature and amount of samples, storage and transport, overseas transport and method of disposal:  
*type or paste text here*

2e) Please confirm that separate consent forms are supplied for storage of samples for future unspecified use

- Yes                       Not applicable (not part of this study)

2f) Please confirm that separate consent forms are supplied for use of samples for genetic analysis

- Yes                       Not applicable (not part of this study)

*Please include copies of all patient information and consent forms with this application*

2g) Please detail how study results will be disseminated to study participants and whānau *type or paste text here*

2h) Please confirm that the dissemination plan for the study includes a full report of study results to be sent to the Māori DHB reviewing team:

2i) Please confirm that the dissemination plan for the study includes a locality report to be provided to the Māori DHB reviewing team:

*The locality report will detail the numbers of Māori recruited and any specific issues or concerns recruiting or maintaining Māori in the study. This may be submitted following the completion of local involvement in the study.*

**3. TIKA. Researchers should have the appropriate skills and experience required to design research that contributes to equity and to Māori health development**

3a) Please confirm that ethnicity data is collected, stored and handled using the standard ethnicity question as recommended by the Ministry of Health

Yes  comment: *type or paste text here*

Please include copies of all documentation for collection of patient details with this application. Refer to ethnicity data protocols: <http://www.health.govt.nz/publication/ethnicity-data-protocols-health-and-disability-sector>

3b) Will the study undertake an analysis of results by ethnicity?

Yes, please describe: *type or paste text here*

No, please explain: *type or paste text here*

3c) The proportion of Māori participants in the study should reflect the proportion of Māori in the community with the health condition of interest. Please detail the following:

- Total number of study participants in this locality: *type or paste text here*
- Total number of Māori participants expected: *type or paste text here*
- Proportion of Māori participants expected: *type or paste text here*

3d) Please explain your calculations for 3c above, and provide the source of any data used:

*type or paste text here*

Useful sources of data for these calculations include stats NZ population data and projections ([www.stats.govt.nz](http://www.stats.govt.nz)), Health Needs Assessments for DHBs or Māori Health Profiles 2015 ([www.health.govt.nz](http://www.health.govt.nz)), Māori health plans and strategies for each DHB (available on DHB website)

3e) Researchers are strongly encouraged to attend the [tikanga training or Māori health training offered at DHB] training (or similar). Please provide the details of all researchers and their attendance at training:

Researcher name	Research role	Training attended	Attendance date
<i>type or paste text here</i>	<i>type or paste text here</i>	<i>type or paste text here</i>	<i>type or paste text here</i>

You can find details of [insert name of DHB tikanga training] at this link: [insert link to training details]

3f) Please provide the details of previous or current involvement by your research team in other research projects of particular importance to Māori: *type or paste text here*

**4. MANAAKITANGA. Research should be conducted with respect for all persons involved and respect for their culture**

Please confirm the following:

4a)  contact details for [Māori health services that support patients and whānau] are provided on your patient information and consent form

No, please explain: *type or paste text here*

4b)  provision has been made for the participant's whānau to be involved in the study

No, please explain: *type or paste text here*

4c)  provision has been made for participants to undertake the study in te reo Māori if desired

No, please explain: *type or paste text here*

4d)  provision has been made for appropriate tikanga Māori protocols to be carried out when required

No, please explain: *type or paste text here*



4e) Please describe how measures to ensure privacy and confidentiality are provided for participants and whānau:  
*type or paste text here*

b

4f) Does your research team have a support agreement with [Māori health services] or an equivalent provider?

No.  Yes. Please provide details: *type or paste text here*

*Please include copies of any support agreements with this application.*

**5. MANA. Research relationships should be reciprocal and equitable and acknowledge the rights, roles and responsibilities of all involved.**

5a) Describe the process for obtaining consent from participants (and whānau):  
*type or paste text here*

5b) Describe how this research project can contribute to improving health literacy for Māori participants and whānau:  
*type or paste text here*

Useful reference: <http://www.hqsc.govt.nz/publications-and-resources/publication/2046/>

5c) Describe how this research project can contribute to Māori research capacity development:  
*type or paste text here*

5d) Describe any contribution of koha (gift) to participants, or reimbursement of costs for study participation:  
*type or paste text here*

5e) Describe any other provisions you have made in your study to ensure the cultural preferences of Māori have been considered:  
*type or paste text here*

**Thank you for taking the time to complete this form. Please save as a word document and email with all other required documentation to: [insert contact details for DHB]. Kia ora.**

Office use only	Date	Comment
Date received:		
Date acknowledged:		
Proposal sent to review:		
Next committee date:		
Due date for feedback:		
Provisional endorsement:		
Response received:		
Final endorsement:		