

Approaching Māori Responsiveness and Vision Mātauranga

Purpose

This paper seeks to provide background information and resources to support FMHS staff and students develop thinking, positioning and relationships to best respond to Māori Responsiveness and Vision Mātauranga elements raised in research funding proposals and ethics applications.

Background Reading

We recommend that FMHS staff and students read the following documents to understand Māori responsiveness as outlined across the Research, Science and Technology (RS&T) sector:

Health Research Council of New Zealand:

Guidelines for Researchers on Health Research Involving Māori (2010, version 2, page 6)

[http://hrc.govt.nz/sites/default/files/Guidelines%20for%20HR%20on%20Maori-%20Jul10%20revised%20for%20Te%20Ara%20Tika%20v2%20FINAL\[1\].pdf](http://hrc.govt.nz/sites/default/files/Guidelines%20for%20HR%20on%20Maori-%20Jul10%20revised%20for%20Te%20Ara%20Tika%20v2%20FINAL[1].pdf)

Project Expression of Interest Application Guidelines (page 10)

<http://hrc.govt.nz/sites/default/files/GA217S%20Guidelines.pdf>

The Ministry of Business, Innovation and Employment:

<http://www.mbie.govt.nz/info-services/science-innovation/unlocking-maori-potential>

University of Auckland Human Ethics Committee:

<https://cdn.auckland.ac.nz/assets/central/documents/2011/Guiding%20Principles%20for%20Research%2024%20Feb%2010-%20Bookmark.pdf>

Health and Disability Ethics Committees:

<http://ethics.health.govt.nz/guidance-materials/guidance-researchers-expected-standard-responses-questions-line-forms-benefits>

Background – why Māori Responsiveness?

The Government has accountabilities under the Treaty of Waitangi and therefore those who receive government funding (for example from HRC under Vote RST) have delegated Treaty of Waitangi accountabilities. The Crown expects these to be made transparent in a variety of ways:

- They are explicit in the Institutional Administration Agreement between the Research Funder and the Research Institution.
- They are expected to be considered in both funding and ethics applications in terms of:
 - a. The topic of research being a strategic priority for Māori
 - b. The research team having explicit linkages or connections with Māori individuals or groups
 - c. That traditional or contemporary Māori processes are incorporated into the research processes
 - d. The ability of the project to support Māori development including Māori research workforce development
 - e. The protection of Māori rights including those to cultural and intellectual property
 - f. The research informs opportunities to reduce and eliminate ethnic inequities.

Frameworks of Treaty of Waitangi Accountabilities

Frameworks that describe Crown Treaty accountabilities should be used by researchers to understand delegated responsibilities; and as models to elaborate these responsibilities. These include:

- The Waitangi Tribunal Treaty Principles
- The Ministry of Health Māori Health Strategy – He Korowai Oranga
- Alternative or summary models

1) The Waitangi Tribunal is a permanent commission of inquiry that considers claims brought by Māori relating to Crown actions that breach guarantees made in the Treaty of Waitangi. The Tribunal has noted the complexity we New Zealanders (both Māori and non-Māori) have inherited due in the main to the imperfect translation of the Treaty from English into Māori, resulting in two somewhat different understandings of the Treaty of Waitangiⁱ. In an attempt to manage these discrepancies, the Crown developed Treaty principles.

The Waitangi Tribunal, the Crown's expert on the Treaty, has noted the following principles developed in relation to the claims before itⁱⁱ.

- **Partnership** – the Treaty signified a partnership which requires each party to act with the utmost good faith towards the other, a characteristic of partnership. It includes the duty to consult with Māori and obtain the full, free and informed consent of those involved.
- **Reciprocity** – the partnership is reciprocal for mutual advantage and benefit.
- **Autonomy** – the Crown guaranteed to protect Māori autonomy in recognition of the promises of kawanatanga and tino rangatiratanga and acknowledges Māori rights to determine Māori processes and priorities.

- **Active Protection** – the Crown’s duty to protect Māori rights and interests arises from promises made to secure Treaty acceptance by Māori. The duty is not passive but active and requires honourable conduct and full consultation and, where appropriate, decision-making by those whose interests are to be protected.
- **Options** – that Māori have options stemming from both traditional/customary practices and modern development possibilities.
- **Mutual Benefit** – the Treaty was signed for mutual benefit and Māori were to retain resources to ensure the colonisation of New Zealand was not detrimental.
- **Equity** – the obligations from the promises in the Treaty require the Crown to act fairly so that Māori were/are not disadvantaged. Where Māori have been disadvantaged, the Crown is required to take active measures to restore the balance.
- **Equal Treatment** – requires the Crown to act fairly between Māori groups.
- **Redress** – where the Crown has acted in breach of its obligations and Māori have suffered prejudice, the Crown has a clear duty to set matters right. In respect of historical grievances, this usually requires compromise on both sides and redress should not create a fresh injustice.

These principles: (1) have been developed by a Crown agency (the Waitangi Tribunal); (2) are comprehensive and focus on the Crown’s role in Māori rights; and (3) are delegated to researchers who are successful in obtaining government monies for their research.

2) The Ministry of Health, in its Māori Health Strategy, He Korowai Oranga noted the following Treaty principlesⁱⁱⁱ:

- **Partnership** – working with Māori individuals and communities to develop strategies for Māori health gain and access to appropriate services
- **Participation** – requires Māori involvement in all levels of the health and disability sector from delivery to planning and decision-making
- **Protection** – involves the Crown working to ensure Māori health equity and safeguarding Māori cultural concepts, values and practices.

Again these have been developed by a government agency and while they have the simplicity of just three items, they are less comprehensive than those promoted by the Waitangi Tribunal.

3) An equity based model has been promoted by the Office of the Tumuaki (FMHS) that sees equity as a starting point for Treaty responsiveness. From this focus, researchers can explore related Māori health inequities, the processes necessary to ensure adequate and appropriate relationships with Māori and a commitment that the research mitigates rather than extends health inequities. Inherent in this model are many of the Crown Treaty principles including the consideration of Māori as tangata whenua, valuing full Māori participation including as voice/data in the research through adequate representation, empowering analysis and careful consideration of intellectual, cultural and group property rights. Power relationships in the research team are a critical

component of this analysis, including a transparent assessment of Māori roles in governance, decision-making, design, implementation, analysis, representation and dissemination of the study results.

In summary, each of the above frameworks have the potential to be used effectively for Treaty responsiveness if incorporated in a comprehensive manner. However, some researchers still approach Māori responsiveness as a last-minute task, or in a naïve manner. The definitions used in these frameworks should guide researchers as to the meaning of these terms and therefore the importance of carefully considering these accountabilities.

Issues for Māori Responsiveness

1. Relevance to Māori

Please describe if the health topic being researched is important for Māori health and whether inequities exist. The Crown notes this as a priority in the recently refreshed New Zealand Health Strategy^{iv}. Important reference documents for researchers to review existing inequities include:

- Hauora IV:

<http://www.otago.ac.nz/wellington/departments/publichealth/research/erupomare/research/otago019494.html>

- Tatau Kahukura:

<https://www.health.govt.nz/publication/tatau-kahukura-maori-health-chart-book-2015-3rd-edition>

- Unequal Impact reports for cancer statistics:

<http://www.health.govt.nz/publication/unequal-impact-maori-and-non-maori-cancer-statistics-1996-2001>

<http://www.health.govt.nz/publication/unequal-impact-ii-maori-and-non-maori-cancer-statistics-deprivation-and-rural-urban-status-2002-2006>

- Te Ohonga Ake series for Māori child and adolescent health

http://dnmeds.otago.ac.nz/departments/womens/paediatrics/research/nz_cyes/maori.html

- The New Zealand Health Surveys for child and adult health status, health behaviours and health service utilisation

<http://www.health.govt.nz/nz-health-statistics/national-collections-and-surveys/surveys/current-recent-surveys/new-zealand-health-survey>

2. Consultation with Māori

The Waitangi Tribunal considers that consultation with Māori is a fundamental obligation of Treaty responsiveness and most researchers are now engaging in this process. The Treaty principles noted above focus on quality relationships with Māori and the need to act towards each other with the utmost good faith. Researchers need to consider all the different types of relationships they have with Māori in their research and reflect on how these factors are expressed. This should include Māori who are colleagues, advisors, partners and governors in addition to Māori as participants. Consultation requires respectful information sharing and dialogue. It is not a one way conversation, such as telling Māori what

you want to research. Furthermore consultation is very context dependant meaning some projects will require more in-depth consultation strategies than others. The minimum requirement for consultation is review by someone considered to have some authority in respect of Māori health research^v. In the FMHS, advice on consultation is provided through the Tumuaki who also supports researchers who have existing strategic research relationships with Māori.

3. Dissemination

This goes hand-in-hand with consultation. It closes the consultation loop and as such it is an important standard of 'good faith'. The minimum requirement would be to re-engage with Māori with whom the researcher consulted and provide feedback either verbally or with a copy of a written summary of the findings of the project.

4. Working with Genetically Modified Organisms

Many New Zealanders, including Māori, are concerned about the use of transgenic organisms including in research. The Hazardous Substances and New Organisms (HSNO) Act 1996 requires that the principles of the Treaty of Waitangi are considered in applications. Because of this obligation, it can be important to acknowledge this concern about the use of transgenic organisms in the research or ethics application but to note additionally how the laboratory facilities are accredited and regulated.

5. Māori Health Research Workforce Development

There are ethnic inequities in the health research workforce. Addressing this is a strategic priority for the University and most research funders. In the spirit of equity, research teams should identify and take opportunities to contribute to Māori health research workforce development by actively recruiting Māori staff and researchers and students at all levels.

6. Human Tissue

The term human tissue covers a physical sample no matter how large or small: from blood samples, tissue biopsies, cells, molecules and genetic profiles. It includes human tissue obtained from a variety of sources including commercial cell lines, pathological specimens, samples collected by research projects and those obtained from tissue collections. Almost all of this tissue is provided with informed consent but Ethics Committees have been asked to consider unconsented tissue in very exceptional circumstances. No matter the source, Māori (indeed many New Zealanders) consider human tissue to be tapu (sacred), meaning it comes with a set of restrictions. These restrictions are managed by considering a number of issues which should be reflected in the formal information made available to possible participants, including:

- Full and free informed consent
- Agreed parameters of use of samples
- Limitations on use of samples
- Agreed possibilities of any future use - while some researchers prefer to seek approval for 'unspecified future use', participants are being recommended to reject this permission as being too broad with too many unforeseen implications

- Agreement on storage and management of samples
- Agreement on governance of samples – as many samples are now stored for future use that may extend beyond the employment, career or indeed life of the primary investigator or project, or may be requested by research partners overseas, it is critical to consider who has governance over the future decision-making in respect of samples, and the data generated by them
- Processes for return or destruction of samples.
- Feedback to participants or their whānau on pertinent health information obtained from the samples
- Genetic information generated – see later – Genetic samples
- Consideration that samples that leave New Zealand for analysis by research collaborators or commercial companies, move outside of New Zealand jurisdiction and control. Some participants may be wary of this and may wish to opt out of any project that involves sending their sample overseas.

7. *Genetic samples*

Samples taken for the specific intention of genetic analysis, and those samples with the potential for genetic analysis, have all the issues of human tissue noted above but ought to include further consideration.

- Genetic material not only provides information about the donor, but also information about family and relatives of the donor. Because of this, there is growing consideration for whānau consent in addition to individual consent. While this may not be current practice, researchers planning to take samples for genetic analysis and future use, should consider ‘future proofing’ their samples by incorporating family into the consent process in addition to the individual. There is no ‘best practice’ yet for gaining whānau permission but there is no reason not to attempt to note if other ‘genetic relatives’ were consulted during the informed consenting process and if their permissions were also gained.
- Some researchers consider that the physical sample of genetic material is different from the genetic data generated. They offer to destroy or return remaining tissue samples in a genuine manner but fail to realise that the data generated is another iteration of that same material. Usually significant consideration is given to the ethical and secure storage, management and sometimes governance of the genetic material without similar consideration given to the data it generates. Future practice ought to consider including governance and secure storage of an individual’s data as part of the ethical management of an individual’s tissue samples from which the genetic data is derived. This reflects many of the delegated Treaty accountabilities including active protection and decision-making. Again this is not usual current practice but researchers ought to consider this in future projects.
- We are aware that genetic samples are often sent overseas for sequencing or analysis by research collaborators or commercial companies. Research teams need to consider how they will maintain their Treaty responsibilities to ensure the ethical and secure storage and use of Māori genetic samples and data once they are outside the jurisdiction of New

Zealand. This may require informing Māori participants as part of informed consent, if genetic material or data is likely to leave New Zealand.

8. Data

Following on from this regard of the relationship between human tissue and the genetic data it generates, some Māori researchers are asking about the ownership and guardianship of research datasets. This issue has become more urgent with the growth of 'big data' collections and international collaborative research. Once integrated into large datasets, it can become unclear how Māori data will be treated in terms of groupings, analyses and interpretations. There is significant work being done internationally by indigenous researchers on 'Data Sovereignty' so researchers in this space should stay abreast of developments.

9. The Special Case of Transgenic Animals and Xenotransplantation

The Royal Commission on Genetic Modification (2001) noted the concern by a number of Māori (and other New Zealanders) to xenotransplantation and transgenic animals, in respect to a number of issues ranging from deviation from traditional views of the sanctity of particular life forms to not being given appropriate time to fully consider issues. The Commission noted that there were research benefits to these technologies but recommended strict regulation^{vi}. It may be appropriate for FMHS researchers to note that they understand that some Māori may hold particularly strongly views against this technology, none-the-less the research is being conducted in accordance with the appropriate standards and regulation.

10. Māori as Participants

It is possible to have a research sample where it is not necessary to identify if participants are Māori. This is common with very small samples, especially in clinical research where a concept is being tested and ethnicity or ancestry is not a variable of analysis. However identifying Māori as participants is necessary when researchers need to identify and describe the demographics of their sample population and where ethnicity or ancestry is a variable of analysis in their research hypothesis. The research team must understand the differences between ethnicity and ancestry and their relative strengths and limitations in relation to particular research questions.

11. Ethnicity

Ethnicity is a socio-demographic variable collected across standard collections of health datasets to quite high levels of completeness. Because of this, ethnicity data in New Zealand are strong by international standards. However it is important to carefully consider what we are measuring when we use ethnicity data as a variable. Ethnicity is a social construct. It is not about how we look or act or what others think. It is not the same as ancestry or descent but rather it is about self-identifying the social group or groups with which we affiliate and therefore how we might live our lives and experience society. It is important to note that ethnicity is not fixed and people may change their ethnicity at different times of their lives – how our parents register our ethnicity as a child may differ when, as adults we express it ourselves.

<https://www.fmhs.auckland.ac.nz/en/faculty/tkxm/office-of-tumuaki/responsiveness-to-maori/te-ara-tika.html>

12. *Ethnicity Data Standards*

Ethnicity should be collected using the standard ethnicity question that is used in the NZ Census and most official datasets. While this question can seem cumbersome in small questionnaires, failure to use the standard question introduces uncertainty into the analysis of your research and impacts on the comparability of your data. The Ministry of Health has ethnicity data protocols for the health sector.

<http://www.stats.govt.nz/Census/2013-census/info-about-the-census/forms-guidenotes.aspx>

<http://www.health.govt.nz/system/files/documents/publications/ethnicitydataprotocols.pdf>

13. *Māori Ancestry and Descent*

If the research hypothesis relates to Māori ancestry or family history, this information needs to be directly sought. While there is a Māori descent question in the NZ Census, it simply asks if one is descended from a New Zealand Māori. Often a family history or genealogy is of more relevance when lineage and family connections are the variable of interest. Whakapapa (genealogy) information is considered by many to be tapu and there may well be restrictions on how this information is gathered, stored, used and governed.

Ethnicity data is an inappropriate proxy for descent as a small proportion of people who identify Māori ethnicity do not report Māori ancestry and a larger proportion of those who report Māori ancestry do not identify Māori ethnicity.

<http://www.stats.govt.nz/Census/2013-census/info-about-the-census/forms-guidenotes.aspx>

14. *Promoting Māori Voice*

The Treaty guaranteed that the Crown would act in such a way that Māori would not be disadvantaged and if disadvantage was demonstrated, the Crown would take measures to correct the imbalance. While most researchers are aware that the Māori population numbers some 16% of the total New Zealand population, few researchers think about the impact of a minority voice on policy and programmes generated from research, especially the impact on inequity and further marginalisation. A random population sample of New Zealanders will often contain less than 15% Māori so the dominant 'voice' generated largely tells the story of non-Māori New Zealanders: their strengths, risks, needs and preferred ways of being. If inequities exist, likely there could be a difference in the Māori story of strengths, risks, needs and preferred ways of being. Researchers need to be aware of this in the construction of their research especially where inequities exist.

15. *Promoting Māori Voice – in qualitative analyses*

If ethnic inequities exist in the topic being researched, it is important that priority be given to the group with the inequity in respect to the 'voice' being

sought to be heard and reality sought to be understood. The risk is that researchers seek Māori responsiveness advice quite late when their project is well-developed and they are unprepared to change. For example, it is known that Māori women have higher rates of gambling harm using pokie machines^{vii}. A proposal for further qualitative research to understand issues among New Zealand women in general, could possibly be irrelevant to Māori women and this project could thereby increase the inequity. Going ahead with the project after these issues have been pointed out knowingly breaches the Treaty of Waitangi. Admittedly a project that prioritises Māori 'voice' does require additional consideration, planning and perhaps staffing or supervision but ought to add significantly to research impact and utility.

16. Promoting Māori Voice – in quantitative research

A number of researchers within the FMHS have already listened to advice on this issue and have either prioritised Māori participation in quantitative research or constructed their study population so that the Māori sample is equally powered to answer the research question in simple and/or complex analyses^{viii}. This has often been supported by significant relationships with Māori communities and/or researchers. Furthermore it has usually led to extra benefits in terms of additional dissemination/publication opportunities and occasionally funding support. Constructing a sample with equal power to answer the research question for Māori as well as non-Māori does not reduce the research team's ability to inform the international literature about New Zealand but allows them to additionally inform the literature about what is happening with indigenous people in respect of this issue and equity.

17. Promoting Māori Voice - in analysis

Once research results have been obtained and analysis begins, researchers should be wary that common assumptions are not made when analysing Māori data. If Māori data are different, it is too easy to assume that the 'difference' lies within Māori (bodies, culture or behaviours) without taking a structural view or environmental scan. This could be as naïve as blaming the 3rd class passengers on the Titanic for their comparatively high death rate. This tendency to 'victim-blame' peoples who we see as different is called 'deficit theorising'^{ix} and should be avoided and instead consideration be given to a structural or systems analysis.

18. Empowering Relationships with Māori Individuals and Communities.

The term 'empowering' is used not in relation to Māori needing to be empowered but rather that good relationships could be mutually beneficial to researchers and Māori. It is a great time now to start seeking/developing relationships with Māori for next year's research applications. Many research teams have begun this and a number have well developed associations, perhaps even partnerships. It is hard to advise how to do this but the most successful have sought a genuine, respectful and mutual relationship where common goals are enunciated, processes are agreed and resources shared. The Waitangi Tribunal Treaty principles note that the key to partnership is to treat each other with the utmost respect. It is recommended that researchers and research teams invest in this activity.

19. Theory

The development of Kaupapa Māori Theory (KMT) and Research (KMR)^x especially in the last two decades has drawn many Māori researchers into this developing and contested theoretical space. Research teams that recruit Māori researchers and students need to be open to them participating in this development. It is the right of every researcher to define their own theoretical space and not all Māori researchers agree to their work being classified as KMR. For those Māori researchers who choose to be located in the KMR space, non-Māori researchers may wonder how partnerships can be negotiated and develop. Within Te Kupenga Hauora Māori, we now use the term KMR to apply to Māori-led research with a series of philosophical aims including: promoting Māori as the centre of the inquiry, appropriate sampling to ensure Māori voice, utilising Māori processes where appropriate, resisting victim blame analyses, partnering with Māori individuals and groups with aligned objectives, Māori health research workforce development and contributing to the elimination of ethnic inequities. We use the terms Kaupapa Māori-aligned Research or Kaupapa Māori-partnered Research for those projects which are usually not led by Māori but align with most of the above objectives. Other Māori researchers may use the terms KMR and KMT but focus primarily on Māori knowledge and processes. It is important to note that KMR is now a broad church so researchers using KMR should reference their philosophical aims, objectives and theoretical standpoint.

Summary

This paper seeks to inform researchers and students about key elements to consider in respect of Māori Responsiveness and Vision Mātauranga. With time we expect researchers to consider what future and excellent practice may become and work to 'future proof' health research, especially as they train junior and emerging researchers.

Please refer to the supplied documents/references and if necessary, seek further information from the Office of the Tumuaki.

ⁱ www.waitangitribunal.govt.nz

ⁱⁱ <http://www.waitangitribunal.govt.nz/treaty-of-waitangi/principles-of-the-treaty/>

ⁱⁱⁱ <http://www.health.govt.nz/our-work/populations/maori-health/he-korowai-oranga/strengthening-he-korowai-oranga/treaty-waitangi-principles>

^{iv} See the Refreshed Guiding Principles for the System *in*: Minister of Health (2016) New Zealand Health Strategy: Future Direction. Wellington: Ministry of Health
<https://www.health.govt.nz/system/files/documents/publications/new-zealand-health-strategy-futuredirection-2016-apr16.pdf>

^v Simmonds S. (2015) A Framework for Māori Review of Research in District Health Boards. Auckland & Waitemata District Health Boards and Capital and Coast District Health Board. Wellington New Zealand.

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- vi Royal Commission on Genetic Modification (2001)
<http://www.mfe.govt.nz/publications/hazards/report-royal-commission-genetic-modification>
[cited 13 Oct 2016]
- vii <http://www.wsanz.org.nz/journal/docs/WSJNZ231Dyall46-48.pdf>
- viii Simmonds, S; Robson, B; Cram, F and Purdie, G. Kaupapa Māori Epidemiology [online]. *Australasian Epidemiologist*, Vol. 15, No. 1, Apr 2008: 3-6.
<http://search.informit.com.au/documentSummary;dn=239017476323220;res=IELHEA> ISSN: 1327-8835. [cited 13 Oct 2016].
- ix Valencia, R. R. (1997). *The evolution of deficit thinking: Educational thought and practice*. London: Falmer Press.
- x Smith, L. T. (2012). *Decolonizing Methodologies: Research and Indigenous Peoples* (2nd Ed) London: Zed Books.