

Achieving health equity in Aotearoa: strengthening responsiveness to Māori in health research

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ABSTRACT

Excellent health research is essential for good health outcomes, services and systems. Health research should also build towards equity and in doing so ensure that no one is left behind. As recipients of government funding, researchers are increasingly required to demonstrate an understanding of their delegated responsibilities to undertake research that has the potential to address Māori health needs and priorities. These requirements form the basis of responsiveness to Māori in health research, and several research institutions have implemented systems to support their organisational approach to this endeavour. However, many health researchers have a narrow view of responsiveness to Māori and how it might be relevant to their work. In this viewpoint paper we provide an overview of existing frameworks that can be used to develop thinking and positioning in relation to the Treaty of Waitangi and responsiveness to Māori. We also describe an equity-based approach to responsiveness to Māori and highlight four key areas that require careful consideration, namely: (1) relevance to Māori; (2) Māori as participants; (3) promoting the Māori voice, and; (4) human tissue. Finally, we argue for greater engagement with responsiveness to Māori activities as part of our commitment to achieving equitable health outcomes.

Health research has an extensive reach into health practice from evidence-based medicine and clinical trials through to systems monitoring and data reporting. As a result, health professionals are required to adhere to the policies, protocols and ethical parameters associated with research in Aotearoa New Zealand. Inherent within these processes are responsibilities for and responsiveness to Māori health development.

What is responsiveness to Māori?

Responsiveness to Māori reflects the Government's view that health research conducted in New Zealand should contribute to improving Māori health and eliminating health inequities.¹⁻³ Researchers must therefore consider how their processes can better reflect Māori health needs and priorities. Responsiveness to Māori recognises the Government's accountabilities under the Treaty of Waitangi, which flow on to research organisations

receiving government funding. The Crown expects these accountabilities to be made transparent and they are explicit in administration agreements between research funders and providers.

Health researchers are required to demonstrate an understanding of these delegated responsibilities, including whether the research:

- is a strategic priority for Māori;
- makes the most of opportunities to inform the elimination of ethnic inequities;
- incorporates traditional or contemporary Māori processes;
- supports Māori development, including workforce development;
- team has any explicit relationships with Māori, and;
- actively protects Māori rights, including cultural and intellectual property rights.

Health researchers must also consider a range of Māori expectations,⁴⁻⁷ including:

- that researchers respect and uphold the Treaty of Waitangi;
- that the research will impact positively on Māori and improve Māori health;
- that Māori rights and interests, including Māori ethical principles, are best protected through Māori involvement in research governance;
- that researchers will invest in research processes that facilitate greater communication and transparency; and,
- that accountability to Māori is demonstrated through sound reporting mechanisms and consultation-to-dissemination pathways.

Approaching responsiveness to Māori in health research

A number of 'Responsiveness to Māori' frameworks are available to health researchers such as those used by the Waitangi Tribunal and the Ministry of Health (Table 1). Both position the Treaty of Waitangi at the forefront of health research in New Zealand with the Waitangi Tribunal emphasising the Crown's role in upholding and protecting Māori rights and the delegation of these responsibilities to health researchers funded from government agencies. In addition, some iwi have developed their own frameworks and criteria for assessment of research to be conducted within their regions and/or with their people (eg, Ngati Porou Hauora and Ngai Tahu Research). Regardless of the source, frameworks are most effective for

Table 1: Summary of Treaty of Waitangi frameworks and responsiveness to Māori.

Framework	Principles	Application to responsiveness to Māori in research
Waitangi Tribunal Treaty Principles	Partnership	The Treaty requires each party to act with the utmost good faith towards the other. It includes the duty to consult with Māori and obtain the full, free and informed consent.
	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, including Māori rights to determine Māori processes and priorities.
	Active protection	The Crown's duty to protect Māori rights and interests. The duty is not passive but active and requires honourable conduct, full consultation and, where appropriate, decision-making by those whose interests are to be protected.
	Options	Māori have options stemming from both traditional/customary practices and modern 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 that 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.
Ministry of Health—He Korowai Oranga	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.

Sourced from:

<http://www.nph.org.nz/our-services/research-and-evaluation/>

<http://www.ngaitahuresearch.co.nz/about/>

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

responsiveness to Māori if they are incorporated in a comprehensive manner.

An equity-based approach to responsiveness to Māori

Responsiveness to Māori in research is not new^{8,9} and many institutions have implemented systems to support their organisational approach. Others promote equity as a starting point for responsiveness to Māori as this focus requires researchers to consider Māori health priorities based on inequities, develop appropriate relationships with Māori and commit to undertaking research that mitigates rather than extends health inequities. An equity-based approach encourages health researchers to consider responsiveness to Māori in relation to four main areas:

1. Relevance to Māori

Research that seeks to improve Māori health and reduce inequities is a Government priority.¹ Thus, researchers need to establish whether the topic is important for Māori health and/or whether inequities exist. Opportunities to enhance relevance to Māori include:

a. Consultation with Māori

Consultation with Māori is a fundamental obligation of Treaty responsiveness, and many researchers engage in this process. The Treaty Principles focus on quality relationships with Māori and acting with the utmost good faith. Researchers ought to consider and reflect on all of the different layers of research relationships they have with Māori, including as colleagues, students, advisors, partners, governors and participants. Consultation requires respectful information sharing and dialogue; it is not a one-way conversation or an opportunity for researchers to tell Māori what they want or need. Furthermore, consultation is very context-specific, thus some projects will require more in-depth consultation strategies than others.¹⁰

b. Dissemination

This goes hand-in-hand with consultation. It closes the consultation loop and as such it is an important standard of 'good faith'. Ideally, the project should be part of the development of a research relationship and the feeding back of results provides an opportunity to discuss further action. Dissemination to a broader Māori audience

should be considered as part of the consultation process, and worked towards as part of the research.

c. Enabling relationships with Māori individuals and communities

Good relationships can be mutually beneficial and enabling to both researchers and Māori. Ideally researchers should invest in and start this process during the conception of a research project and well in advance of research deadlines. Successful interactions happen when researchers engage in genuine, respectful and mutual relationships with Māori, and when common goals are enunciated, processes agreed and resources shared.

d. Māori health research workforce development

Addressing ethnic inequities in the health research workforce is a strategic priority across the sector.¹¹ Researchers should take opportunities to contribute to Māori health research workforce development by actively recruiting Māori students, researchers and support staff, and ensure that these individuals are supervised and mentored in a culturally safe environment.

e. Theoretical space

The advancement of Kaupapa Māori Theory (KMT) and Research (KMR)¹² has drawn many Māori researchers into this developing and contested theoretical space.¹³ The term KMR often signals Māori-led research that has a series of philosophical aims, including promoting Māori at the centre of the inquiry, developing research questions that Māori partners have signalled are important, appropriate sampling, utilising Māori processes where appropriate, resisting 'victim-blame' analyses, partnering with Māori with aligned objectives, Māori health research workforce development and contributing to the elimination of ethnic inequities.¹⁴ Other Māori researchers may use the terms KMR and KMT but focus primarily on Māori knowledge and traditional processes. It is important to note that KMR can encompass a broad range of epistemologies so researchers using KMR should reference their philosophical aims, objectives and theoretical positioning.

Non-Māori research teams should consider ways to support Māori research staff and students as they grow their theoretical iden-

tities and research capabilities. Not all Māori researchers agree to their work being classified as KMR. Non-Māori researchers may wish to familiarise themselves with KMT and KMR when partnering with KM researchers. The terms Kaupapa Māori-consistent or Kaupapa Māori-partnered research have been used for projects led by non-Māori but aligning with KM objectives.

2. Māori as participants

Health researchers should familiarise themselves with the concepts of Māori ethnicity, ancestry and descent and consider the relative strengths and limitations of each variable in relation to particular research questions. A range of tools are available for measurement of these constructs within the health sector.

a. Ethnicity

Ethnicity is a socio-demographic variable that is routinely collected across national 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 using ethnicity as a variable. Ethnicity is a social construct.¹⁵ 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 whom we affiliate and therefore how we might live our lives and experience society.¹⁶ Ethnicity is not fixed and people may change their ethnicity at different times of their lives.

b. Ethnicity data standards

Ethnicity should be collected using the standard ethnicity question that is used in the NZ Census and most official datasets.¹⁷ Failure to use the standard question introduces uncertainty into the research analysis and impacts on the comparability of data.¹⁶

c. Māori ancestry and descent

The Māori descent question in the New Zealand Census simply asks if one is descended from a New Zealand Māori, and for some research questions a family history or genealogy may be more relevant. This information should be gathered directly from the participant(s). Whakapapa (genealogy) information is considered by many to be tapu (sacred) and there may be restric-

tions on how this information is gathered, stored, used and governed.¹⁸ 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. In the 2013 Census, 0.8% of people who reported Māori ethnicity did not report Māori descent. In contrast, 16.1% of those who reported Māori descent did not identify Māori ethnicity.¹⁹

3. Promoting Māori voice

The Treaty guarantees that the Crown will act in such a way that Māori will not be disadvantaged, and if disadvantage is demonstrated, the Crown will take measures to correct the imbalance. The Māori population is 16% of the total New Zealand population, and few researchers think about the impact of a numerically minority voice on policy and programmes generated from research, especially the impact on further inequity and marginalisation. A random population sample will often contain fewer than 15% Māori, so the dominant 'voice' generated largely tells the 'story' of non-Māori: their strengths, risks, needs and preferred ways of being. The Māori 'story' could be very different. Researchers should be aware of this in the construction of their research. Promoting Māori voice is relevant to both qualitative and quantitative studies.

a. Qualitative research

If ethnic inequities exist in the research topic, it is important that priority be given to the group with the inequity—their 'voice' should be heard and their reality understood. A project that prioritises Māori 'voice' may require additional consideration, planning and perhaps staffing/supervision, but will add significantly to research impact and utility (eg,²⁰⁻²²).

b. Quantitative research

Equal explanatory power²³ means that research has either prioritised Māori participation in quantitative research or is constructed so that the Māori sample is equally powered to answer the research question in simple and/or complex analyses (eg,²⁴). It is not 'over-sampling' Māori, rather it is appropriate sampling and respect for the Māori 'voice'. Constructing a sample with

equal power to answer the research question for Māori as well as non-Māori will provide multiple opportunities for dissemination.

c. Data analysis

Researchers should be wary of common errors made when analysing Māori data. If Māori data are different, do not assume that the ‘difference’ lies within Māori (bodies, culture or behaviours). This tendency to ‘victim-blame’ peoples is called ‘deficit theorising’²⁵ and shows superficial knowledge of the determinants of health and health inequities.²⁶ Instead, consideration should be given to the structural or system-level factors likely to be involved (eg^{27,28}).

4. Human tissue

The term human tissue covers all physical samples, regardless of size (eg, blood samples, tissue biopsies and cells, molecules and genetic profiles) or source (eg, commercial cell lines, pathological specimens, research samples and those from tissue collections or biobanks). No matter the source, Māori, and indeed many New Zealanders, consider human tissue to be tapu, meaning it comes with a set of restrictions. These restrictions are usually managed by informed consent processes and the formal information made available to prospective participants, including:

- Agreed parameters surrounding the use of human tissue including possible future use;
- Agreement on storage, management and governance of samples. Many samples are now stored for future use that may extend beyond the career, or indeed life of the primary investigator or project. Samples may also be requested by international research partners. Thus, 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.^{4,29}

a. Genetic samples

In addition to the issues noted above, researchers who collect human tissue for the specific intention of, or potential for, genetic analysis must also consider the following:

- Genetic material not only provides information about the donor, but

also information about whānau of the donor. Because of this, there is growing interest in obtaining whānau consent in addition to individual consent. While not current practice, researchers planning to take samples for genetic analysis should consider ‘future proofing’ their samples by incorporating family into the consent process. Although there is no ‘best practice’ yet for gaining whānau permission, at the very least, researchers should note whether other ‘genetic relatives’ were consulted during the process of informed consent and whether their permissions were also gained.

- Some researchers consider the physical sample and the data generated from human tissue as different. Usually significant consideration is given to the ethical and secure storage, management and sometimes governance of the genetic material without similar attention given to the data it generates. Good research practice ought to include due consideration to the governance and secure storage of an individual’s tissue *and* generated data. Although this is not current practice we urge researchers to plan for this in future projects.
- Genetic samples are often sent overseas for sequencing or analysis by collaborators or commercial companies. Research teams need to consider how they will maintain their Treaty responsibilities once the samples are outside New Zealand’s jurisdiction. The likelihood of genetic material or data leaving New Zealand, now or in the future, should be reflected in the researcher’s governance plan and outlined as part of the informed consent process.

b. Data

Issues surrounding ownership and guardianship of research datasets have become more urgent with the growth of ‘big data’ and international collaborative research. Once integrated into large datasets, it is unclear how Māori data will be treated in terms of groupings, analyses and interpretations. Significant work on ‘data sovereignty’ by indigenous researchers here and overseas is underway,³⁰ so researchers should stay abreast of developments.

c. Working with genetically modified organisms

Many New Zealanders, including Māori, are concerned about the use of genetically modified organisms including in research.^{31,32} 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 and note relevant accreditation and regulation of laboratory facilities.

d. The special case of transgenic animals and xenotransplantation

The Royal Commission on Genetic Modification (2001) noted that a number of concerns were raised by Māori (and other New Zealanders) to xenotransplantation and transgenic animals. The Commission noted that there were research benefits to these

technologies but recommended strict regulation.³¹ Researchers should demonstrate an understanding of the range of views held by Māori and describe how the research will be conducted in accordance with appropriate standards and regulation.

Conclusion

All health researchers in New Zealand should be accountable to our delegated responsibilities under the Treaty of Waitangi and be able to enact issues of responsiveness to Māori. This paper proposes key elements to consider in this respect. In addition, researchers will need to consider what the standards of excellent practice will be in the future, especially as they train junior and emerging researchers and gather data and tissue samples. We encourage all researchers to engage in the work of 'future proofing' health research to ensure that responsiveness to Māori is achieved.

Competing interests:

Dr Paine is a previous Science Assessing Committee member for the Health Research Council of New Zealand, a co-opted member of the Māori Health Committee for the Health Research Council of New Zealand, and is currently involved in research projects that are funded by the Health Research Council of New Zealand and by the Ministry of Health.

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