

Key informant views on biobanking and genomic research with Māori

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ABSTRACT

The aim of the Te Mata Ira project was to explore Māori views on biobanking and genomic research, and to identify ways to address Māori concerns over the collection and use of human tissue. Key informant interviews and workshops were conducted with Māori to identify Māori views in relation to biobanking and genomic research; and, informed by these views, interviews and workshops were conducted with Māori and non-Māori key informants (Indigenous Advisory Panel (IAP) members and science communities) to explore key issues in relation to Māori participation in biobanking and genomic research. Māori key informants identified the following as key deliberations: (1) the tension for Māori between previous well-publicised negative experiences with genomic research and the potential value for whānau and communities as technologies develop, (2) protection of Māori rights and interest, (3) focus on Māori health priorities, (4) control of samples and data, (5) expectations of consultation and consent and (6) a desire for greater feedback and communication. Māori and non-Māori key informants highlighted the need to enhance levels of Māori participation in the governance of genomic research and biobanking initiatives, and acknowledged that only by increasing the level of transparency and accountability in relation to these activities will Māori communities feel that their whakapapa, rights and interests are being appropriately protected.

Māori have been contributing to the debates about research ethics¹⁻³ and genetics⁴⁻⁸ for a number of years. Several studies exploring Māori views on genetic research⁹⁻¹³ and biobanking^{14,15} have described Māori perspectives on these types of research and the key issues that arise, including cultural issues,^{16,17} governance issues,^{18,19} consent processes,²⁰ social equi-poise,^{21,22} distribution of risks and benefits,^{2,23} tissue storage,^{16,24} analysis^{10,23} and interpretation of results.^{10,20,23}

*Te Ara Tika—Guidelines on Māori Research Ethics: A framework for researchers and ethics committee members*² established a framework for understanding the diverse views that inform Māori ethical deliberations and noted the heightened ethical sensitivities that exist for Māori in relation to the use of tissue and genetic information. However, the document did not provide substantive comment or practical advice for genetic researchers or biobanks

in relation to Māori cultural, ethical and legal parameters for these activities. Māori continue to consent for their tissue to be used in biomedical research projects,^{4,10,11,13} so it is important that their expectations of ethical research behaviour are reflected in developing guidelines. The Te Mata Ira research project explored the issues that Māori encounter when they choose to be involved in genomic research and biobanking with the aim of providing more substantive culturally appropriate guidance to researchers and communities alike.

Background

Genomic research represents a new frontier for health research and provides a platform for personalised medicines (pharmacogenomics). The scale of biological samples required to adequately power genomic studies has led to significant growth, nationally and internationally, of both biobanks and genomic databases.²⁵⁻²⁹

Though genomic research has yet to fulfil the promise of personalised medicine, ethical discussions within Māori communities^{4,9,11,30} and among ethicists in the international domain^{31–34} are evolving to meet emerging challenges and technologies. Subsequently, there has been a proliferation of international genetic databases^{25,35} and national^{34,36} and international guidance documents^{37–39} suggesting various ways for governing them. Yet commercialisation practices and the return of individual results varies.^{14,28} Nevertheless, it is vital to include Indigenous ethical principles in genomic research, particularly given the existing storage of Indigenous genetic material and because it is possible that genomics could play a role in future contests over Indigenous people's claims of identity and rights.^{40–42}

Ethical controversies surrounding genetic studies, like the human genome diversity project,²³ the 'warrior gene'^{43,44} and the Arizona State University settlement with the Havasupai, a Native American tribe,⁴⁵ have prompted Indigenous critiques. These have included research by Indigenous Peoples Council on biocolonialism about the Havasupai^{15,46–48} and work undertaken by the National Congress of American Indians (NCAI) studying views of genetic health research in Indian Country.^{15,49–51} Researchers are also recognising the need for change, and a recent *Nature Reviews Genetics* paper by Gottweis, Chen⁵² called for biobanks to address issues of trust, benefit sharing, data security, privacy and practicing reciprocity.

The use of biobanks and sharing of research data across projects are also being discussed in New Zealand as a cost-saving measure, particularly in relation to a number of high-cost medicines associated with cancer treatment. In the past two years the Health Research Council of New Zealand (HRC) Ethics Committee was approached for guidance on both secondary and unspecified future use of data and human tissue as well as appropriate use of information databases, prompting the HRC to consider developing a data-sharing policy. Recent research by New Zealand's Virtual Institute of Statistical Genetics has also shown that sample sizes of 1,000,000–10,000,000 are needed to obtain sufficient evidence for

association, meaning extensive data sharing, including that relating to Māori genetic material, is required for genome-wide association studies.²⁶ In many instances the data being shared will be based on biological samples (genetic/genomic information) and pressure is increasing for anonymous datasets be placed in the public domain as a prerequisite for publication. Similarly, the linking of computerised medical records with genetic/genomic information and population-level genome sequencing is also on the horizon.

The speed of technological advance is outpacing the development of ethical oversight and it is apparent that in New Zealand much of the guidance on genetic research and data sharing is not specific enough to deal with emerging ethical issues associated with the types of genomic research now possible. The recent establishment of the Auckland Regional Tissue Bank (Auckland), Rare Diseases Tissue Bank (Dunedin), Melanoma Tissue Bank (Dunedin) and the Centre for Brain Research Biobank (Auckland) illustrate a shift towards developing more formal tissue storage facilities and the provision of more transparent consent processes for the ongoing use of tissue in research including genetic and genomic studies.

Methods

Three sets of participants contributed views to gain understanding about the genomic research and biobanking contexts, how Indigenous populations have fared in these contexts and strategies to regulate these contexts. Semi-structured interviews were held with seven Te Mata Ira International Advisory Panel (IAP) members until saturation was achieved. The panel members, who belong to Indigenous communities in Australia, Hawaii, Canada, US and New Zealand, represent a diverse range of research expertise in Indigenous health, health policy, medical genomics and bioinformatics. Given their diverse locations, IAP members were interviewed by telephone or skype. Five stakeholder workshops were conducted at Auckland, Christchurch and Dunedin (n=5). Two were science focussed workshops aimed at genetic researchers and biobank personnel (n=27, both Māori and non-Māori), and three

were Māori focussed workshops to gain views from Māori who have a role in health research, ethics or genetics (n=31).

The three key questions asked in the interviews and workshops were;

1. Why should Māori/Indigenous communities participate in biobanking and/or genomic research?
2. What are the key issues for Māori/Indigenous participation in biobanking and genomic research?
3. How might we address these issues?

The interviews and workshops were digitally audio-recorded, transcribed and summarised. Summaries were checked with IAP members to enhance validity. A guided thematic analysis—the process of coding empirical material to the research questions and emerging themes^{53,54}—was conducted across several key domains, including but not limited to potential benefits of participation, barriers to participation and expectations of behaviour. Answers to the first and second questions are detailed below. Because key informants answered question three while discussing issues prompted by question two, these findings are presented together.

Findings

Why should Māori participate in biobanking and genomic research?

The question of whether it is useful or appropriate for Indigenous/Māori communities to engage with new technologies continues to be the subject of discussion and debate. The views advanced by the three groups of participants reflect a wide range of opinions on the value of participation in genomic research and biobanking initiatives. The key opportunities outlined by participants provided by engaging in genomic research and biobanking are the potential;

1. to derive health outcomes
2. to increase understanding and trust in the science and scientists
3. to improve processes of research
4. to protect broader interests of the Māori community
5. to realise other opportunities

Potential health outcomes were described largely in relation to lessening the incidence and prevalence of disease, along with recognising that genomic medicine may be another type of health care that Māori communities can benefit from. Māori key informants considered the value of participation in two distinct ways, namely, individual value and community value. At an individual level, key informants spoke about the potential to enhance health outcomes for the individual seeking treatment and expressed a keen sense of altruism in wanting to be part of something that they believed may help others outside of their immediate family. Māori participation in genomic research was also described by some as a potential tool for reducing inequalities but only if it is applied at both the individual and the community levels in an appropriate manner, along with a clear understanding of the limitations of genomic research. The optimism about potential health gains was balanced by a recognition that genetic contributions towards health outcomes are only part of the answer and will be situated within a broader context of social determinants.

What is the ethical balance between doing genetic research and what we know about the impacts of inequalities and poverty? (Māori key informant, workshop)

The perceived link between enhanced treatment for disease and participation in genomic research was particularly pronounced in the discussion within the science workshops. Key informants in the science workshops explained that the current limited evidence on genetic variation between Māori tissue and other populations provides a unique opportunity and motivation for scientists to work with these communities in biomarker discovery. Māori participation is also seen as necessary to provide representative population wide data, something necessary to ensure that Māori communities directly benefit from genomic medicine in the future. Along with other limitations, Māori would only benefit if there were sufficient numbers of Māori participants and statistical power for Māori specific analyses to be conducted. Key informants in the science workshops also suggested increasing Māori samples

in biobanks would provide greater opportunities for Māori specific health priorities to be researched. They noted that Māori participation in genomic research and biobanking projects would require a greater level of trust in the people and processes responsible for the storage and use of tissue samples, as well as a greater level of transparency and culturally appropriate engagement from scientists.

Participation as a potential opportunity and facilitator of other community development and capacity building initiatives was also discussed. The benefits described included those arising through greater control such as ownership of intellectual as well as biological property, and were described in a way that strategically positions Indigenous communities as decision-makers including supporting aspirations for sovereignty.

Key informants also felt that it is important to consider the factors that motivate whānau to get involved in genetic research and how this impacts on their ability to ask critical questions about the nature of the project. Families with genetic concerns participate in the interest of their family's health as their primary focus is coping with the condition not how their genetic data might be used in the future.

If I've got it then I want my kids to be protected [from the disease] so it was a real whakapapa thing. It wasn't a raced based, community based, [or] Iwi based thing at all. They did it [genetic testing] because they thought, "If I have something genetically wrong and my kid inherits it...then I want my kid to know that and for that to drive practice" (Māori key informant, workshop).

Generally, the key informants that participated in the science workshops were more positive about the value of Māori participation in biobanking and genomic research in terms of improving the science and ensuring outcomes from research benefit Māori. The Indigenous Advisory Panel and the key informants at the Māori workshops were more reticent about the value of participation but recognised it has direct benefit for specific individuals and families, and that other collective interests could be addressed if Māori were more involved in governance and decision making to ensure the wider health benefits are realised.

What are the key issues related to Māori participation in biobanking and genomic research?

Protection of Māori rights and interests

Key informants described a legacy of mistrust created by examples of unethical engagement with Indigenous peoples in biomedical research, and this motivates Māori to evaluate genomic research projects with a greater degree of scrutiny. Māori research principles promoting community participation, culturally appropriate protocols and Māori involvement in research and governance provide the foundation for sound partnerships and quality research. Key informants spoke about the need to protect Māori interests through Māori control promoting concepts of power-sharing over benefit-sharing.

We'll get this right if we know that the control sits with Māori. Not individual Māori because actually that's a personal decision that they're making based on a personal perspective...But this stuff has to occur on a much bigger scale and it has to be able to shift this down [to the level of Māori community] otherwise it's of no value (Māori workshop).

Focus on Māori and Indigenous health priorities

Key informants questioned whether genomic research is what is needed to change negative health outcomes for Māori. Key informants recognised the usefulness of genetic information for some conditions; however, they were less convinced of its utility for key Māori health priorities—like diabetes or cardiovascular disease—where multiple genes and environmental factors contribute to its expression. If health status is considered within a determinants of health framework then there are other places you would put resources to address environmental and systemic factors impacting on individuals and populations. Key informants in the Māori workshops generally thought that prioritising funding for genomic research would divert resources away from public health research, which they believe had more immediate benefits for Māori communities.

They've got this information that they might have this gene contributing to whatever disease but then what do they do

with that information? How can they use that to improve health? (Key informant interview).

We are at the intervention stage in public health. So when you're putting resources into this unknown area when we've got all this mahi that we should be doing [it is mismatched] (Key informant, Māori workshop).

Robustness of genetic research methods

A number of the key informants had high levels of research expertise and were able to critique the framing and methods used in specific genomic research projects. Some of the concerns expressed include;

- a) the construction of racial or ethnic groupings for genetic comparisons,
- b) the attribution of familial characteristics to larger groupings,
- c) the analysis and interpretation of results and
- d) an interest in the scientific novelty rather than clinical application.

Inappropriate interpretation of results, as occurred with the 'Warrior Gene' hypothesis where polymorphisms in the monoamine oxidase A gene, were linked to aggressive behaviour in Māori, stigmatised the Māori community and reinforced negative stereotypes of researchers.^{20,55} One of the key challenges for genomic researchers when communicating results of genetic studies in specific ethnic populations is to ensure people understand that the use of the group to help identify a functional gene or phenotype does not mean that the phenotype is an ethnic marker, that is, a Māori gene. As a key informant in one of the Māori workshops explained, they had reframed their views of race and genetics on the basis of learning basic knowledge on genetics and admixture.

Genetics is not race based; it's familial. Māori are an admixed population...How do you know that that's our Māori genes? How come it's not our Scottish genes? (Māori key informant, workshop).

Because if you look at the Human Genome Project, for instance, we're from the family of Maui apparently...It's pretty much all Polynesian, brown people...but it just seems so racialised...They never find bad genes in the white population. It's always in the Māori group (Māori key informant, workshop).

Key informants also described how genetic analyses rarely recognised the broader social context and distracted attention from social determinants of health, including the impact of colonisation and poverty.

The truth is we didn't have diabetes before we had a western diet, so how can that be genetically right? Pakeha get diabetes and they get gout so we use prevalence and incidence rates to again racialise an illness which really is an illness of poverty...In genetics they never discuss poverty (Māori key informant, workshop).

Control over samples and data

Key informants described the importance of Māori involvement in decisions over access, storage and use of tissue and data. They could see the potential for Māori participation in genomic research shifting from being a subject of research and a provider of tissue towards greater participation in the research design and governance. Control over tissue and data ensures that it is used for research that directly benefits the community and in a manner that recognises its cultural significance. They spoke about the need for Māori to have more influence over the use of data and the direction of research.

Stewardship requires access to research and data to support developments within our communities. Engagement with research is a key activity related to accessing quality data in support of our aspirations for sovereignty (Key informant interview).

Some groups are exercising sovereignty by being involved in decisions on genetic research and biobanking (Key informant interview).

Increasing Māori participation in regulatory roles and strengthening Māori governance was potential mechanisms to improve the level of monitoring for researchers and biobanks in possession of Māori tissue. Possession of tissue was viewed as carrying strong implications in terms of stewardship and care. Key informants stated that it is important to be involved in the development of policies for these groups.

I think it comes back to accountability because whoever owns the keys to the freezer typically determines what happens to the samples, and if the person who had the keys to the freezer is not keeping [researchers] accountable to what was agreed on in the

first place then really they can do whatever they want (Māori key informant, workshop).

With the biobank...you almost need...like a Māori with veto powers on a committee that evaluates [the research] and says, "Look if you don't use the tissue for the purpose you signed up for in the beginning then nothing gets published because you...had the ability to be able to say I don't want this published". But I mean an Iwi group won't have the same [power] (Māori key informant, workshop).

Benefit sharing

Benefit sharing is an important element of the research relationship. Key informants recognised that benefits would not always be direct health improvements but thought there was scope to explore other possibilities through education, capacity building and intellectual property. Ownership of material and data was discussed as an issue related to potential development of commercial products. Key informants stated that both researchers and participants can realise benefits from a project and a balance needs to be found to ensure communities receive an equitable share of the benefits produced through genomic research.

So we need to think about it in the broader context, and then there's the ethics and the quality of the research, partnerships... and negotiation of benefits (International Advisory Panel).

Expectations of consultation and engagement

A desire to protect Māori/Indigenous rights and interests through the entire process of research informs their expectations of consultation. Key informants discussed the place of community engagement in the development of projects and the need for researchers to talk to the right individuals within communities. Appropriate consultation will provide an opportunity to negotiate issues of research design, sampling strategies, language, cultural support, research governance, review processes and publication protocols. Overall the use of appropriate research design was seen as a significant factor in the protection of Māori and Indigenous interests. Key informants spoke about Māori values informing the parameters around which tissue can be used. Health research has a number of best practice models which

emphasise the importance of early discussions with Iwi/Māori, which is especially relevant for this context given the complex nature of the studies and the ethical issues associated with it.

This is where having a conversation with Iwi becomes really important... We have groups that...don't necessarily know what it is they are saying yes to (Māori key informant, workshop).

Expectations of consent

Key informants suggested that community consent was required to gain support for the genomic project taking place. Māori communities needed access to someone who could 'translate' genomic research jargon into practical terms for consideration. The translator would have the ability to explain what the research is likely to provide to the community, what will not be provided and any risks associated with participation. Access to independent resources and guidelines would create a more transparent and safer process for communities.

You need somebody on your own team, Iwi need someone for themselves that actually can broker with the geneticists...you actually need someone who can talk the geneticist's language that actually understands what methods should be used (Māori key informant, workshop).

If you want to explore that uniqueness of a certain collective then you actually have to have that collectives consent, that way you can go forward...The academic freedom is seen as the sort of guiding principle by the researcher, like I don't need to be told by some community how to do my science (Non-Māori key informant, interview).

Key informants felt that individual consent provides a mechanism to both allow participation while also restricting certain activities that participants might not be comfortable with like sending tissue overseas and consent for future use. It is important to consider the timing of consent and allowing individuals time to discuss risks and benefits with family and friends. The recruitment process is a key part of the gaining informed consent. Māori involved in the direct recruitment of participants often felt their connection to those communities may have influenced peoples' decision to participate more than the information

provided. This can create a tension for the Māori recruiter who becomes responsible for the tissue, in the eyes of the community, even if they have no decision-making power within the project team.

Once again, who was the person who was getting the consent? It was actually Māori to Māori. You're sitting there, you're talking about it [genetic research project], we're selling it and they're buying in (Māori key informant, science workshop).

To me the biggest lesson I've learnt is that we shouldn't say anything. We should put them in front of our people and if our people don't like them they say no and then that's how it is (Māori key informant, science workshop).

Ongoing communication and feedback

Key informants explained how a lack of knowledge is seen as a key factor in creating barriers for both researchers and Māori participants. Key informants in the science workshops perceived that Māori reluctance to participate in genomic research is due to not knowing how genomic research works and that this can also lead to suspicion and misunderstanding. They also spoke about having a lack of knowledge on how to engage with Māori to ensure that effective consultation and negotiation is part of the process of research and biobanking. In contrast, key informants in the Māori workshops expressed frustration with the lack of feedback and information about the progress and outcomes of research projects and stated that this reinforced negative sentiments about researcher commitment to their communities.

Increasing the level of genetic literacy was identified as important in the context of having communities make more informed decisions about participation in genomic research. Education initiatives to increase awareness were seen as vital for both Māori and science communities. Increasing levels of cultural literacy within science communities should lead to a greater acknowledgement and respect for Māori views within the research project, enabling researchers to develop research questions that align with community health priorities, and implementation of research processes that support opportunities for Māori development.

[Guidance for scientists is important] to increase the comfort level of Indigenous people who are participants in biobanking and genomic research (Māori key informant interview, workshop).

Discussion

There are a small number of established biobanks in New Zealand that manage tissue for research purposes including genomic research but a much larger number of 'informal biobanks', research-based tissue collections, which have samples that have been consented for future use. As there is no register for biobanks or research-based tissue collections there is no way of knowing how many samples are in storage or how many of them have been provided by Māori participants. Few projects have specifically collected samples from Māori populations for genomic research, in part due to the challenge of ensuring Māori support. Notable exceptions include the Gout and Related Conditions Project in Ngāti Porou, the Rakaipaaka Health and Ancestry Study and Te Wai o Rona based in the Waikato. While Māori views on genetic research and biotechnologies indicate an increasing willingness to engage if there is a health benefit for the family or community,^{11,18,66} it was evident in the workshops that communities are also becoming more critical about the nature of participation and expectations of researchers.

Māori communities are often uneasy about participating in genomic research, based on past experiences where projects have operated outside the ethical boundaries agreed with communities. Projects led by Arizona State University and Institute of Environmental Science and Research did not end well for Indigenous communities and highlight the potential risks associated with engagement in genomic research. Researchers at Arizona State University (ASU) gathered blood samples from Havasupai Tribe in Arizona to search for a link to diabetes, but used the samples to look for other diseases and genetic markers. Researchers at the Institute of Environmental Science and Research Ltd initiated a Health and Ancestry study with the Ngāti Rakaipaaka tribe in New Zealand. The

primary researcher was the protagonist of the 'Warrior Gene' and while this incident was not directly associated with the study, it led to its demise. Indigenous and Māori researchers, and communities themselves are becoming increasingly vigilant in their expectations of research partners.

The value of participation

Māori views on the potential benefits of biobanking, genetics and genomic research are largely related to helping others. Māori cultural concepts, in particular the concept of *manaakitanga* (caring, kindness), is said to increase the likelihood of Māori agreeing to participate in genetic research.¹⁴ Believing that participation will help a family member or someone else in the community who is unwell is a key motivator for Māori participation in health-related biotechnologies.¹¹ Māori views on the value of partnership between Māori communities and genetic researchers are shown to be positive if the research is seen to be of benefit, particularly in areas such as predictive cancer testing.¹⁷

While there are concerns raised over the reductionist nature of genetics, the value of genetic testing for Māori may lie in finding solutions to immediate and severe health states¹⁸ and through predictive genetic tests that identify risks of developing disease.¹⁷ However, Māori recognise that health inequalities may not be adequately explained by genetics, and one potential consequence of genetic research is that it could contribute to diminishing support for equity-based policies that recognise the role of social justice in relation to inequalities.⁵⁵

The challenge of effective participation

The challenges for Māori communities in participating effectively in genomic research and biobanking projects reflect the broader political dynamic relating to Indigenous-State relationships and equitable access to resources, including research. It traverses the interface between *mātauranga* Māori and science, and touches on the difference between the 'value' associated with biological tissue, a *taonga* (treasure) in a cultural context and a biological resource in the science community. It is informed by a diverse range of Māori discourses, experiences and worldviews, and as there are numerous opportunities for misinterpretation and misunderstanding, an authentic

engagement should be underpinned by clear processes and values.⁵⁷

It is apparent that one of the effects of colonisation is a general marginalisation of Māori communities within the realms of education, limiting Māori capacity and capability to engage in research. This is especially true for the increasingly technical research projects conducted in scientific disciplines. The Māori key informants indicated that there was a general lack of understanding about genomic research and biobanking in their communities and also identified that there were limited opportunities for involvement in the research process. Becoming 'informed' is a significant challenge for both communities engaging with researchers and individuals considering participation in projects. The information imbalance reflects the power imbalance that exists between researchers and communities, a situation that can only be effectively mediated through the development of ethical relationships and use of culturally appropriate biobanking and research processes.^{58,59}

The increasingly complex and technical nature of genomic research creates challenges for effective communication between communities and researchers. A high degree of literacy and understanding is required to understand the contexts of the health condition, genetics and research for Māori communities to engage meaningfully in consultation and consent processes. One example of education initiatives that inform Indigenous communities is the National Congress of American Indians Genetics Resource Centre.

The alignment of Māori health priorities with scientific research agendas is two-fold. At a superficial level, it is about defining the scope, aligning the research inquiry with an area of Māori health need and identifying the potential benefits and risks. At a deeper level, it is about understanding the contribution of the research project to equitable health outcomes, which means a greater focus on the pathway to implementation, specifically for Māori communities. Existing inequalities in access to and provision of services within the health system mean that the development of new medicines or treatments does not automatically equate to a health gain. While the implementation pathway may not

be the direct responsibility of the researcher, involving Māori communities in determining the purpose of the research provides a key advocate for its implementation through tribal and other health services. Māori key informants in workshops indicated that it would be important to have the ability to steer research processes for Māori interests.

Māori involvement in the governance of research programmes provides opportunities for Māori interests to be promoted and protected. In the context of biobanks, decisions about the use of Māori tissue samples should be made by Māori members or committees who can assess the value of the proposed project and level of Māori support either through individual or collective Iwi consent. This oversight is likely to increase the level of confidence of potential donors that their tissue will be used in a culturally appropriate manner,⁶⁰ especially in relation to the inherent uncertainty associated with its 'future use' in a changing scientific and funding environment.

The key informants suggested that the overarching goals of any ethical framework should both provide a level of ethical oversight to protect the interests of participants and their communities, and educate the communities so that they can better determine how they might like to engage, or not, with genomic research and biobanking projects. The important issues that emerged from the key informants include;

- Research Purpose: Clarity, alignment with community priorities and keeping to scope of research question
- Outcomes: Community benefits, capacity building
- Benefits and Risks: Identification, realisation/mitigation, coercion
- Researchers talking about the issues to the right people at the right levels. Levels of engagement include individuals, communities and experts
- Opportunity to engage: Policies, capacity, involvement in design and questions, ongoing communication, research governance
- Control/ownership: Samples, data, intellectual property
- Governance of sample storage and use: Status—mana and wairua, access and storage, use and future use

- Governance of data: Use of data, data sharing
- Informing consent: Access to technical advice and support, increase in functional literacy, interactivity, access to information
- Language: Translation of science concepts, cultural contextualising
- Consent: Duration of use of tissue, specificity, timing, process, parameter
- Results: Use, interpretation, contextualisation, presentation
- Application to health service delivery: Action

The themes that emerged from this project echo issues identified in other Indigenous communities. Taualii⁶¹ proposed a GREAT Research model reiterating the importance of Governance, Re-consent, Education, Accountability, Transparency, Research priorities for Native Hawaiian communities. Improved consultation, consent and transparency of research intent, conduct and use of specimens and results among Alaska Native people was noted by Hiratsuka and others.⁶¹ Anderson and others⁶² mapped a series of issues complicating Aboriginal and Torres Strait Islander participation in genetic research, including issues with the research process, the research findings and the research samples. These studies highlight a common Indigenous interest in improving the processes of biobanking, genetic research and the practices of researchers.

Enhancing Māori participation in biobanking and genomic research

Various ethical guidelines now reference specific Indigenous principles and identify issues that should be resolved. Taniguchi and others⁶⁴ conducted a comparative analysis of Indigenous research guidelines for genomic research and found that no one document provided comprehensive guidance for all the issues. The continuing development of Indigenous research guidelines will be beneficial to both communities and researchers. Increasing the level of involvement in the governance of Indigenous biospecimens and genomic data is also on the agenda for Indigenous communities. This not only involves participation on governance structures for existing biobanks but also encourages the establishment of more enduring and co-ordinated

entities, including Indigenous biorespositories (ie Alaska Area Specimen Bank; International Collaborating Centre for Indigenous Peoples and Genomic Research, South Australian Medical and Health Research Institute) and biospecimen networks.

Governance structures provide a mechanism for protecting Māori interests and can both strengthen issues of mandate and consent as well as allay concerns about individual participants' consent being properly informed. This will include addressing historic project-based collections of biological samples that have been consented for future use, where the decision-making power defaults to the principal researcher and their institution. There is little transparency in relation to the governance of these research collections, which might be considered 'informal biobanks' and rarely any Māori participation in decisions about how the samples get used. The general uncertainty about future use provisions highlight the trust and accountability in the relationships established between research teams and communities and the importance of understanding the role of Māori communities in the protective functions of governance and consent. Discussions with the key informants in the science workshops illustrated that some biomedical researchers are becoming more aware of the importance of cultural protocols and the need to work with communities to ensure that research processes prevent the misuse of tissue.

Processes of consent that recognise collective decision-making^{5,43} and dynamic consent,^{65,66} including providing options for differential consent (to various components of a project or elements of future use) and supporting expectations to re-consent for future use, are more likely to be mandated by Māori and Indigenous communities.⁶¹ Strengthening governance and consent processes is also related to capacity building within Māori communities. The technical nature of genomic research, which requires high levels of literacy in relation to research, genetics and the health condition, are a barrier to public understanding. Access to good public education resources and targeted support for Māori communities will assist them to become informed and enhance their contributions

to the project. The 'education' of communities involves more than just upskilling people in the sciences. Māori communities hold knowledge that can contribute to understanding what is safe, necessary and possible in their communities.⁶⁷ Indeed, the advancement of health and wellbeing is reliant on the intelligent use of different types of knowledge so genomic science, public health, indigenous knowledge and other disciplines can provide useful contributions to this aim.

Conclusion

Māori views on biobanking and genomic research are evolving, as the points of engagement between these communities and researchers increase with the merging of the clinical and research contexts. A wide range of views are present in Māori communities from actively opposed to non-supporting, from ambivalent to conditionally supportive. There is a recognition that Māori individuals and whānau will engage with genomic research and biobanking if it is in their interests and that this should be supported within a framework that protects the broader interests of Māori communities at hapū, Iwi and national levels.

A range of concerns were expressed by key informants covering issues at individual, project and system levels. The protection of Māori rights and interests is of primary concern, as is the targeting of this type of research towards Māori health priorities. There was dissatisfaction with current engagement and a preference for a greater level of consultation and more dynamic and inclusive processes of consent. Ongoing control over samples and data was identified as a key consideration, including the robustness and interpretation of genomic research methods. Informed engagement is dependent on the level of knowledge about biobanking and genomic research highlighting the need for public education initiatives as well as ongoing communication and feedback about specific projects.

Effective engagement will not only require a more active process of consultation in the development of projects but a continuing relationship with hapū, Iwi and other Māori entities. The 'model of trust' which underpin

current approaches to biobanking will need to change to 'model of participation' to allow individuals, through dynamic consent, or communities, through participatory governance, to exercise their rights and interests in relation to biological tissue and data.

Establishing a robust social and cultural mandate for biobanking and genomic research is the key to enhancing Māori participation, a challenge for both Māori and New Zealand's medical science communities.

Competing interests:

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REFERENCES:

1. Cram F. Rangahau Māori: Tōna tika, tōna pono. In: Tolich M, editor. Research ethics in Aotearoa. Auckland, New Zealand: Longman; 2001. p. 35–52.
2. Hudson M, Milne M, Reynolds P, Russell K, Smith B. Te Ara Tika - Guidelines for Māori research ethics: A framework for researchers and ethics committee members. Auckland, New Zealand: Health Research Council of New Zealand; 2010.
3. Powick K. Ngā take matatika mo te mahi rangahau Māori. Māori research ethics: A literature review. University of Waikato, Hamilton: School of Education, 2002.
4. Hudson M, Ahuri-ri-Driscoll ALM, Lea MG, Lea RA. Whakapapa – A foundation for genetic research? *Bioethical Inquiry*. 2007; 4(1):43–9. 5.
5. Hutchings J. A transformative Māori approach to bioethics: Exploring Māori notions of collective consent as a form of resistance to health related new technologies. Palmerston North, New Zealand: Te Mata o te Tau, the Academy for Māori Research and Scholarship, 2009.
6. Port RV. Māori culture and genetic technology. *MAI Review*. 2009; 3(3):1–11.
7. Reynolds P. Ngā puni whakapiri: Indigenous struggle and genetic engineering. Burnaby, British Columbia: Simon Fraser University; 2004.
8. Te Momo F. Biotechnology: The language of multiple views in Māori communities. *Biotechnology Journal*. 2007; 2(9):1179–83.
9. Cram F, Pihama L, Philip-Barbara G. Māori and genetic engineering. Auckland, New Zealand: International Research Institute for Māori and Indigenous Education; 2000.
10. Port RV. He whakamatautau pi taua mo te mate pukupuku: Ngā tikanga a Te Ao Māori - DNA testing for cancer susceptibility:

- The needs of Māori [Doctoral thesis]. New Zealand: University of Auckland; 2007.
11. Roberts MR, Fairweather JR. South Island Māori perceptions of biotechnology. Lincoln, New Zealand: Agribusiness and Economics Research Unit, Lincoln University, 2004 Contract No.: Research Report No. 268.
 12. Taupo KPT. Close encounters of the genetic testing kind: Negotiating the interfaces between Mātauranga Māori and other knowledge systems [Master's thesis]. University of Canterbury: Christchurch, New Zealand; 2006.
 13. Wyeth EH. Hauhakatia tō wahia i mua i te takurua: Māori and genetic health research: A case study. Dunedin, New Zealand: University of Otago; 2007.
 14. Tipene-Matua B, Henaghan M. Establishing a Māori ethical framework for genetic research with Māori. *Genes, Society and the Future*. 2007; 1(4).
 15. Scott A, Phillips H, Moore A, Du Plessis R. Ethics in practice: Conversations about biobanks. *Critical Public Health*. 2005; 15(4):359–68. PubMed PMID: 19937395.
 16. Cheung MJ, Gibbons HM, Dracunow M, Faull RL. Tikanga in the laboratory: Engaging safe practice. *MAI Review*. 2007; 1(1):1–7.
 17. Port RV, Arnold J, Kerr D, Glavish N, Winship I. Cultural enhancement of a clinical service to meet the needs of indigenous people; genetic service development in response to issues for New Zealand Māori. *Clinical Genetics*. 2008 Feb; 73(2):132–8. PubMed PMID: 18177468.
 18. Tipene-Matua B. Having honest conversations about the impact of new technologies on Indigenous people's knowledge and values. Mātauranga Taketake: Traditional Knowledge Conference: Indigenous Indicators of Wellbeing: Perspectives Practices Solutions; Christchurch, New Zealand: Constructive Conversations/Kōrero Whakaaetanga Research Project, Christchurch Polytechnic Institute of Technology; 2006.
 19. Wilcox PL, Charity JA, Roberts MR, Tauwhare SEK, Tipene-Matua B, Kereama-Royal I, et al. A values-based framework for cross-cultural dialogue between scientist and Māori. *Journal of the Royal Society of New Zealand*. 2008; 38(3):215–27.
 20. Hudson M. Changing genes: Science and being Māori. *MAI Review*. 2009; 2:62–4.
 21. Marks AD, Steinberg KK. The ethics of access to online genetic databases. *American Journal of Pharmacogenomics*. 2002; 2(3):207–12.
 22. Smith B. Barriers to achieving 'social equipoise' in health research involving Indigenous participants. *International Association of Bioethics 10th World Congress of Bioethics*; July 28–31; Singapore. 2010.
 23. Mead AT. The Polynesian excellence gene and patent bottom-trawling. In: Mead AT, Ratuva S, editors. *Pacific genes and life patents: Pacific indigenous experiences and analysis of the commodification and ownership of life*. Wellington, New Zealand: Call of the Earth Llamado de la Tierra and the United Nations University Institute of Advanced Studies; 2007. p. 34–59.
 24. Hudson ML, Allan CA, Bedford KR, Buckleton JS, Stuart K. The impact of Māori cultural values on forensic science practice in New Zealand. *Journal of Forensic Sciences*. 2008; 53(2):380–3.
 25. Auray-Blais C, Patenaude J. A biobank management model applicable to biomedical research. *Medical Ethics*. 2006 2006/04/06; 7(1):1–9. English.
 26. Ball RD. Experimental designs for robust detection of effects in genome-wide case-control studies. *Genetics*. 2011; 189(4):1497–514.
 27. Black L, Avard D, Zawati MH, Knoppers BM, Hébert J, Sauvageau G. Funding considerations for the disclosure of genetic incidental findings in biobank research. *Clinical Genetics*. 2013; 84(5):397–406.
 28. Du Plessis RA. Biobanking in Aotearoa: A case study of the New Zealand Rare Disease Biobank operated by the NZ Institute for Rare Disease Research Ltd Christchurch, New Zealand: University of Canterbury, 2007 Contract No.: Report No. 11.
 29. Graham C, Dawkins H, Baynam G, Lockmuller H, Bushby K, Monaco L, et al. Current trends in biobanking for rare diseases: A review. *Journal of Biorepository Science for Applied Medicine*. 2014; 2:49–61.
 30. Te Rūnanga o Ngāi Tahu. Interested person submission [IP41] to the Royal Commission on genetic modification 2001. Available from: <http://www.royalsociety.org.nz/Site/news/>

- science_topics/biol/gene/submis/ngai_tahu.aspx.
31. Juengst ET. FACE facts: Why human genetics will always provoke bioethics. *Journal of Law, Medicine and Ethics*. 2004; 32(2):267–75.
 32. Sharp RR, Foster MW. Grappling with groups: Protecting collective interests in biomedical research. *Journal of Medicine and Philosophy*. 2007; 32(4):321–37.
 33. Winickoff DE. From benefit sharing to power sharing: Partnership governance in population genomics research. Berkeley, CA: Center for the Study of Law and Society Jurisprudence and Social Policy Program, 2008.
 34. Winship I, Marbrook J. Ethical considerations relating to research in human genetics. Auckland, New Zealand: Health Research Council of New Zealand, 2000.
 35. European Group on Ethics in Science and New Technologies to the European Commission. Ethically speaking. Luxembourg: European Commission, 2010 July. Report No.: Contract No.: Issue No. 14.
 36. National Advisory Committee on Health and Disability. Molecular genetic testing in New Zealand. Wellington, New Zealand: Author, 2003.
 37. Ronchi E, Harper D, Taylor A, Haslberger AG. Genetic testing: Policy issues for the new millennium. *Public Health Genomics*. 2000; 3(4):161–3.
 38. Organisation for Economic Co-operation and Development. OECD guidelines for quality assurance in molecular genetic testing Paris, France: Author; 2007. Available from: <http://www.oecd.org/sti/biotech/38839788.pdf>.
 39. Organisation of Economic Co-operation and Development. OECD guidelines on human biobanks and genetic research databases 2009. Available from: <http://www.oecd.org/sti/biotech/44054609.pdf>.
 40. James RD, Yu J, Henrikson NB, Bowen DJ, Fullerton SM. Strategies and stakeholders: Minority recruitment in cancer genetics research. *Public Health Genomics*. 2008; 11(4):241–9.
 41. MacIntosh C. Indigenous self-determination and research on human genetic material: A consideration of the relevance of debates on patents and informed consent, and the political demands on researchers. *Health Law Journal*. 2005; 13(213):213–51.
 42. TallBear K. Genomic articulations of indigeneity. *Social Studies of Science*. 2013; 43(4):509–33.
 43. Hudson M. Think globally, act locally: Collective consent and the ethics of knowledge production. *International Social Science Journal*. 2009; 60(195):125–33.
 44. Wensley D, King M. Scientific responsibility for the dissemination and interpretation of genetic research: Lessons from the “warrior gene” controversy. *Journal of Medical Ethics*. 2008; 34(6):507–9.
 45. Mello MM, Wolf LE. The Havasupai Indian Tribe case - Lessons for research involving stored biologic samples. *New England Journal of Medicine*. 2010; 363(3):204–7.
 46. Harry D, Howard S, Shelton BL. Indigenous people, genes and genetics: What indigenous people should know about biocolonialism: A primer and resource guide Wadsworth, NV: Indigenous Peoples Council on Biocolonialism; 2000. Available from: <http://www.ipcb.org/publications/primers/index.html>.
 47. Harry D, Kanehe LM. The BS in access and benefit sharing (ABS): Critical questions for indigenous peoples. In: Burrows B, editor. *The catch: Perspectives in benefit sharing*. Edmond, DC: Edmonds Institute; 2005. p. 102–22.
 48. Harry D, Kanehe LM. The right of indigenous peoples to permanent sovereignty over the genetic resources and associated indigenous knowledge. *Journal of Indigenous Policy [Internet]*. 2006; 6:[28–43 pp.]. Available from: <http://www.austlii.edu.au/au/journals/JIndigP/2006/21.pdf>.
 49. Burhansstipanov L, Bemis L. A new collection of stories explaining “genes” and “genetics research” specifically for American Indian and Alaskan Native communities: National Congress of American Indians Policy Research Centre; 2011. Available from: <http://genetics.ncai.org/about-genetics.cfm>.
 50. Burke W, James R. An overview of health research involving genetics: National Congress of American Indians Policy Research Centre; 2011. Available from: <http://genetics.ncai.org/about-genetics.cfm>.
 51. Sahota PC. Research regulation in American Indian/Alaskan Native communities: Policy and practice considerations. National Congress of

- American Indians Policy Research Center, 2007.
52. Gottweis H, Chen H, Starkbaum J. Biobanks and the phantom public. *Human Genetics*. Sep 2011 2013-09-26; 130(3):433–40. PubMed PMID: 889580781; 15511031. English.
 53. Huberman MA, Miles MB. *Qualitative data analysis*. 2nd ed. Thousand Oaks, CA: Sage; 1994.
 54. Coffey A, Atkinson P. *Making sense of qualitative data: Complementary research strategies*. Thousand Oaks, CA: Sage; 1996.
 55. Merriman T, Cameron V. Risk taking: Behind the warrior gene story. *Journal of the New Zealand Medical Association*. 2007; 120(1250): U2440.
 56. Whittle PM. Darwinism and the nature of Māori. *MAI Review*. 2009; 3(2):1–12.
 57. Hudson M, Roberts M, Smith L, Tiakiwai S, Hemi M. The art of dialogue with indigenous communities in the new biotechnology world. *New Genetics and Society*. 2012; 31(1):11–24. PubMed PMID: 67343901.
 58. Morrin H, Gunningham S, Currie M, Dachs G, Fox S, Robinson B. The Christchurch Tissue Bank to support cancer research. *New Zealand Medical Journal*. 2005;118(1225):U1735.
 59. Tawhara K. Attitudes of Māori towards genetic research. Dunedin, New Zealand: University of Otago., 2006 Contract No.: Prepared for The Māori Indigenous Health Institute (MIHI) and the Cardioendocrine Research Group, Christchurch School of Medicine and Health Sciences.
 60. Cunningham EH, Cameron VA, Evans J, Irvine V, Pitama S, Robertson P. The development of guidelines for handling samples and specimens collected for research involving Māori. *New Zealand Medical Journal*. 2007; 120(1264):U2785.
 61. Taulii M, Davis EL, Braun KL, Tsark JU, Brown N, Hudson M, et al. Native Hawaiian views on biobanking. *Journal of Cancer Education* 2014; 29(3):570–6. Epub
 62. Hiratsuka VY, Brown JK, Hoeft TJ, Dillard DA. Alaska native people's perceptions, understandings, and expectations for research involving biological specimens. *International Journal of Circumpolar Health*. 2012; 71(1):18642–7.
 63. Anderson H, Kowal E. Culture, history, and health in an Australian Aboriginal Community: The case of utopia. *Medical Anthropology*. 2012; 31(5):438–57.
 64. Taniguchi NK, Taulii M, Maddock J. A comparative analysis of indigenous research guidelines to inform genomic research in indigenous communities. *International Indigenous Policy Journal [Internet]*. 2012; 3(1). Available from: <http://ir.lib.uwo.ca/cgi/viewcontent.cgi?article=1069&context=iipj>.
 65. Wee R. Dynamic consent in the digital age of biology. *Journal of Primary Health Care*. 2013; 5(3):259–61.
 66. Wee R, Henaghan M, Winship I. Dynamic consent in the digital age of biology: Online initiatives and regulatory considerations. *Journal of Primary Health Care*. 2013; 5(4):341–7.
 67. Tupara H. Ethics and Health Research: Decision Making in Aotearoa New Zealand, *AJOB Primary Research*. 2012, 3:4, 40–52. Available from: <http://dx.doi.org/10.1080/21507716.2012.714834>