



He Tangata Kei Tua

Guidelines for Biobanking with Māori

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He Tangata Kei Tua: Guidelines for Biobanking with Māori Tissue

Kei tua o te awe māpara he tangata kē, he mā?

Introduction

Māori ethical frameworks recognise that all research in New Zealand is of interest to Māori and outline community expectations of appropriate behavior in research to deliver the best outcomes for Māori. Research contributes to the broader development objectives of society and this endeavor is being supported by biobanking infrastructure. Ethics has a specific role in guiding key behaviours, processes and methodologies used in research.

This document outlines a framework for addressing Māori ethical issues within the context of biobanking. It draws on a foundation of mātauranga (Indigenous knowledge) and tikanga Māori (Māori protocols and practices) and will be useful for researchers, ethics committee members and those who engage in consultation or advice about biobanking with Māori in local, regional, national or international settings.

Biobanking

In practice, a biobank is an organised collection of biospecimens used for health research. The Organisation for Economic Co-operation and Development (2009) definition specifically describes two components of a biobank: (1) human biological materials and/or genetic information generated from their analysis; and (2) extensive associated demographic and health information (references).

Biological tissue can include blood and blood products (plasma, serum or bone marrow aspirates), saliva, tissue or pathology biospecimens (tumour tissue collected during operations or diagnostic tests). The value of the biobanks depends on the quality of the stored tissue itself, but also on the information collected about biobanks donors (reference). This information may include medical, lifestyle or family history information, risk factors, outcome information (for example; tumour stage and grade, operation date and type, treatment received, date of death), and specific clinical information such as radiological results and images, or diagnostic

test results. This information may be stored in separate cancer registries, or in another information technology system linked to the sample data. Researchers may access hospital information systems and clinical notes to collate this information. New data from specific studies (e.g. genetic test results) and long term follow up data may be added to the clinical information over time.

Common features of biobanks include: (1) an ongoing and open-ended nature, which often involves unspecified future research that challenges the traditional practice of informed consent, allowing for the donation of biospecimens that are stored for definite or indefinite periods of time; (2) that biospecimens and data need to remain potentially re-identifiable, even if they are coded. This is because a biospecimen and associated data may need to be linked to other sources of health information for studies in the future, or to follow up information added over time; and (3) a focus on the common good, more concerned with future public benefit than individual benefit for the participants themselves. Currently, there is often no direct or immediate benefit to individual donors.

There is no formal register of New Zealand biobanks. However, a range of biobanks exist including research biobanks (often targeting types of cancer or specific diseases); transplant biobanks (cord blood, fertility, eye and placental tissue); and other population biobanks (to store Guthrie card/newborn heel prick test cards, and biospecimens from longitudinal studies).¹

Te Ara Tika

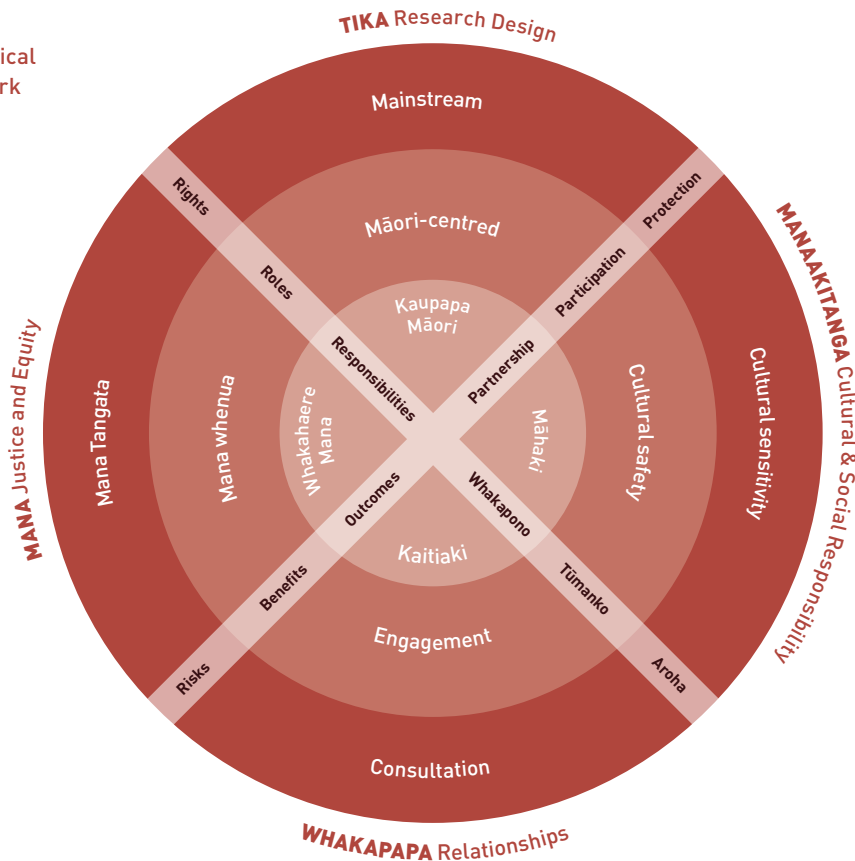
Te Ara Tika Guidelines for Māori Research Ethics: A framework for researchers and ethics committee members (Hudson, Milne, Reynolds, Russell, & Smith, 2010) brought together various strands connecting tikanga Māori, the principles of the Treaty of Waitangi, Māori research ethics, and the health research context in a way that could be understood and applied in a practical manner by researchers and ethics committees (Hudson et al., 2016).

The purpose of the Te Ara Tika guidelines was to explain key ethical concepts for Māori to support decision-making around Māori ethical issues, to identify ways to address Māori ethical concerns, and to clarify the roles of Māori ethics committee members.

1 Guthrie Card Repository, Melanoma Tissue Bank, Neuroendocrine Tumour Collection, Fertility Tissue Banks, Cord Blood Bank, Brain Bank, Middlemore Tissue Bank, Pancreatic Cancer Bank, Eye Bank Auckland, Cancer Society Tissue Bank, Colorectal Cancer Tissue Bank, Arthritis Sample Bank, Glioblastoma and Wilms Tumour Bank, New Zealand Organisation for Rare Disorders, Placenta Bank, and banked samples from the Growing up in New Zealand study (Bartholomew, Wihongi, & Stewart, 2014).

The Māori ethics framework within Te Ara Tika references four tikanga based principles whakapapa (relationships), tika (research design), manaakitanga (cultural and social responsibility), and mana (justice and equity) as the primary ethical principles in relation to research ethics. Te Ara Tika provides the framework for researchers to engage with Māori communities and issues that are important to them.

Figure 1:
Māori Ethical
Framework



Te Ara Tika also identified a range of areas that required special ethical consideration including the collection and use of human tissue, genetic research, ongoing storage in tissue banks, the establishment of cell lines, tissue being sent overseas, and future unspecified use.

Te Mata Ira

Given the increasing prevalence of genomic research, shifts towards creation of research biobanks, and the international nature of research collaborations, it was timely that the Health Research Council funded the Te Mata Ira research project to explore Māori views on genomic research and biobanking.

Te Mata Ira translates to ‘the different faces of a gene’ and acknowledges that Iwi or Māori groups would have different ways of understanding or relating to genetic and genomic research. The project sought input from Māori across a diverse range of settings including whānau, hapū, iwi⁵, Māori health workers, Māori researchers, social scientists, biomedical scientists, and Indigenous researchers⁴.

General Māori objections to genetic research² are tempered in the context of health research when there is direct benefit to Māori whānau³. While not all whānau or Iwi will agree to participate in genomic research there are an increasing number that are choosing to engage with genomic researchers. The aim of the Te Mata Ira project was to identify ways to protect the interests of Māori participants and groups that choose to participate in genetic or genomic research and agree to the storage of their samples/DNA/data in biobanks⁴. The project identified key themes relevant to biobanking for Māori, and for Iwi⁵.

Māori	Iwi
Protection of Māori rights and interests	Tissue removed for a range of reasons (clinical and research)
Focus on Māori health priorities	Whānau make decisions, hapū and Iwi support interests
Robustness of genomic research methods	Experience loss of control (over time)
Control over samples and data	Accountability of research organisations
Expectations of consultation	Iwi governance over projects is expected
Expectations of consent	Communication about progress and results is essential
Ongoing feedback and communication	Outcomes for participants, iwi and communities
	Education is important

Table 1: Key Themes Relevant to Biobanking

Purpose

The purpose of the He Tangata Kei Tua Guidelines for Biobanking with Māori tissue is to describe the cultural foundation informing ethical approaches to biobanking, to inform decision-making around ethical issues when conducting biobanking with Māori tissue, and outline best practice approaches for addressing Māori ethical concerns.

2 Cram (2005), Hook (2009), Rochford (2011).

3 Durie (2008), Du Plessis et al. (2004), Roberts & Fairweather (2005), Tipene-Matua (2006), Tipene-Matua & Wakefield (2007), Tupara (2012).

4 The information collected through the Te Mata Ira research project informs the content of these guidelines.

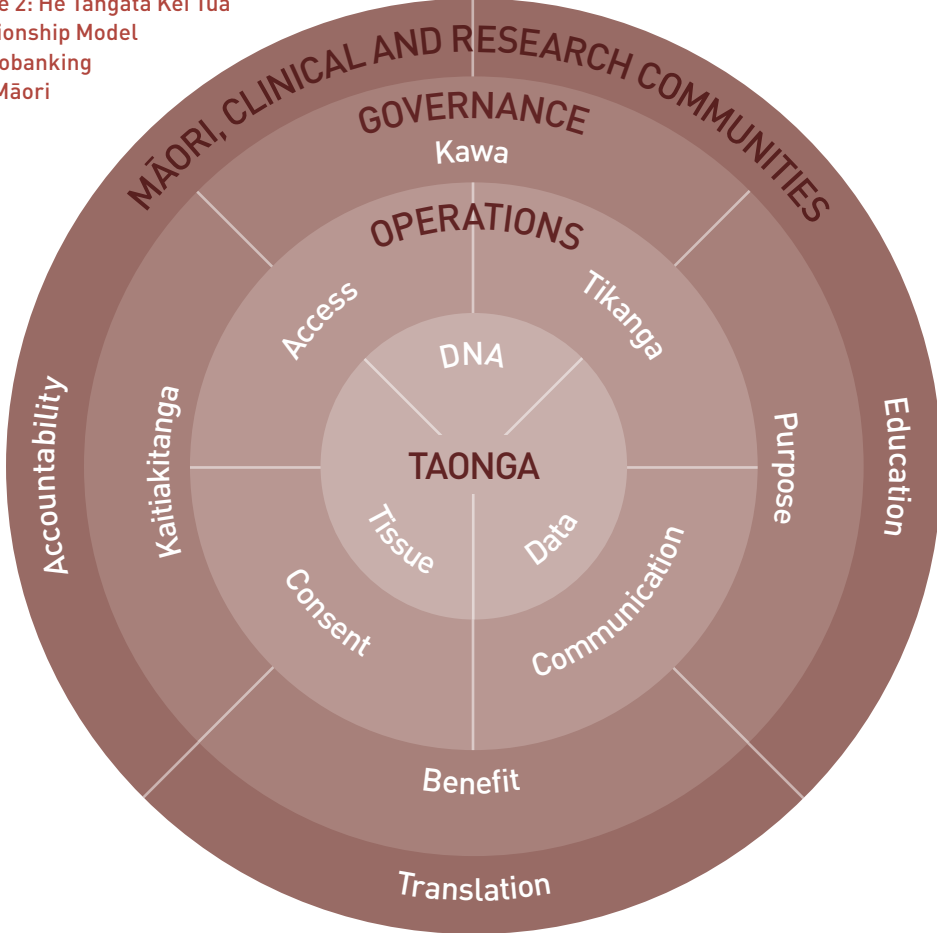
5 Iwi that provided input to the Te Mata Ira project included Ngāti Hine, Ngāti Porou, Ngāti Rakaipaaka, Southern Runaka o Ngāi Tahu, and Ngāti Whātua ki Ōrakei.

These guidelines on Biobanking with Māori tissue are designed to be read in conjunction with the Te Mata Ira Guidelines on Genomic Research with Māori, and the Te Ara Tika – Guidelines for Māori Research Ethics (Hudson et al., 2010). Te Ara Tika provides generic advice for all health research and the Te Mata Ira guidelines provides more specific guidance for the context of genomic research and other 'omics' related to biomedical research.

Background to the Guidelines and the Model

The He Tangata Kei Tua Relationship Model is designed to build on the guidance provided by Te Ara Tika and Te Mata Ira because the Māori ethical issues identified in that document relevant to research are also relevant to biobanking. The He Tangata Kei Tua Relationship Model aligns with the key issues from the Te Mata Ira framework and considers their application to three spheres of activity: Operations, governance and community engagement (including with Māori, clinical and research communities). To facilitate further Māori engagement in biobanking and provide distinct opportunities to engage Māori communities in decision-making, several key themes identified by Māori should be considered to ensure biobanking policies, procedures and practices are culturally acceptable.

Figure 2: He Tangata Kei Tua Relationship Model for Biobanking with Māori



Cultural Foundation

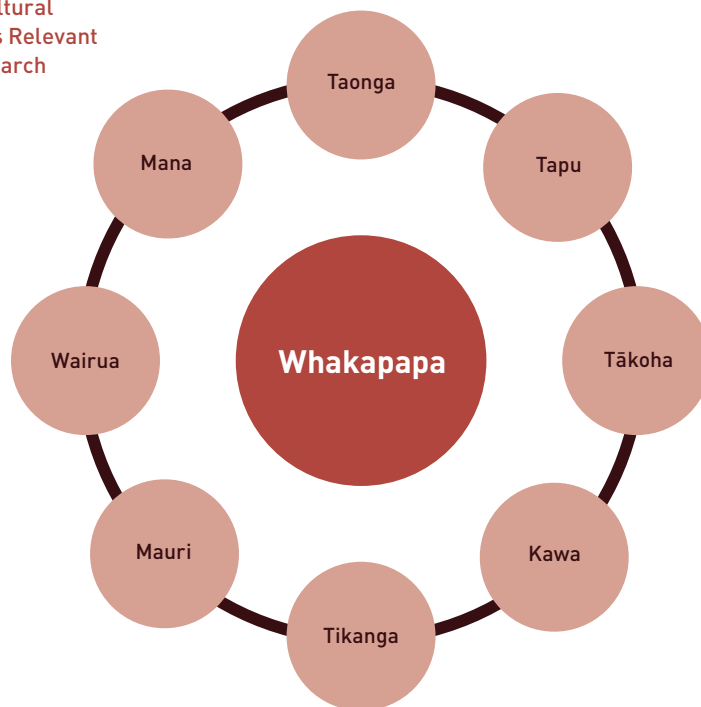
Cultural worldviews are embedded with a logic that prioritises specific values and shape appropriate ethical behaviour. Māori ground their thinking about genomic research and biobanking in a Māori worldview through a range of culturally significant reference points reinforced through kawa and tikanga.

Ethics is about values, and ethical behaviour reflects values held by people at large. For Māori, ethics is about 'tikanga' – for tikanga reflects our values, our beliefs and the way we view the world.⁶

Māori recognise that biobanking is an on-going endeavor and that a range of decisions need to be made throughout the period that the tissue is held. Māori reiterated the importance of identifying and acknowledging cultural values and concepts, and engaging with the community in the development of appropriate ethical boundaries for biobanks.

The cultural foundation outlines key cultural concepts that inform Māori understandings of genetics and how they apply to the context of biobanks. The descriptions will also support initiatives to improve genetic literacy within Māori communities.

Figure 3: Key Cultural Values/Concepts Relevant to Genomic Research



⁶ Te Puni Kokiri, 1994.

The **whakataukī** that informs these guidelines is '**Kei tua o te awe mapara he tangata ke, he ma**'. The common translation of this whakataukī is 'beyond the tattooed face is another, one with clear skin' which is taken as a prophecy about the coming of the Pakeha. The awe mapara is the soot used in the tāmoko ink. In this context we think of the awe mapara as the ink in the pen and translate the whakataukī to ask the question 'Who makes the decisions after consent has been given? This recognises that most decisions in the context of biobanking are made by people other than the donor.

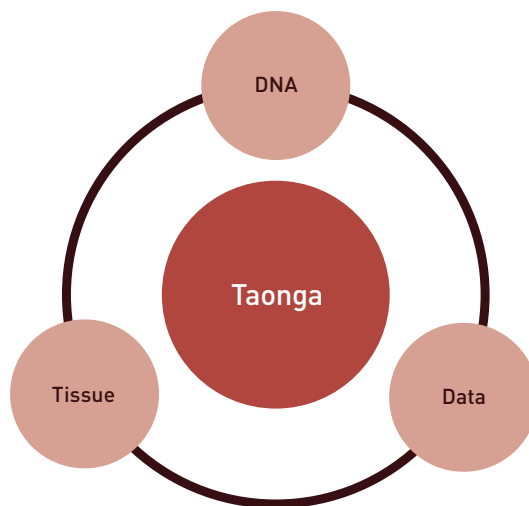
*Kei tua o te awe mapara he tangata ke, he ma?
Who makes the decisions after consent has been given?*

Protecting Whakapapa

Whakapapa is a key reference point for Māori when talking about health and genetics. Whakapapa was described as the connection between people and creates a responsibility for both future and past generations. Whakapapa is often used as a framework to describe a range of connections including genealogy, social and ecological relationships, cultural histories, family traits, and ancestral inheritances. At a physical and spiritual level, whakapapa is embodied within the DNA of a person and therefore the storage and use of human tissue for genetic/genomic research becomes a culturally significant activity. When individuals consent to store their biological material and personal information in a biobank, Māori consider this to be a culturally significant activity. As such, a core responsibility for whānau, hapū and iwi is to ensure that whakapapa is protected, in part, by managing the access and use of the tissue and information relevant to whakapapa. The protection of whakapapa is a key consideration for Māori especially when engaging in biobanking.

Whakapapa is used to explain both the genesis and purpose of any particular kaupapa (topic, purpose). Whakapapa is an analytical tool for not only understanding why relationships have been formed but also monitoring how the relationships progress and develop over time (mai i te whai ao ki te ao mārama). Within the context of decision making about ethics, whakapapa refers to quality of relationships and the structures or processes that have been established to support these relationships. In the context of biobanking, the development and maintenance of meaningful relationships between the biobank and donor/communities forms another axis of consideration for evaluating the ethical tenor of a biobank and its associated activity.

Figure 5: Components of Human Tissue that are Considered Taonga



Tākoha

Koha is often conceptualised as a gift. Tākoha is a form of gifting that recognises the tapu associated with a gift and indicates that conditions are to be applied to the taonga being gifted. Tissue consented for storage in biobanks and use in genomic research is considered a gift or donation however when applying the concept of tākoha the gift refers to 'responsibility' to look after the tissue rather than the tissue itself. This responsibility is borne by the biobank and the researchers they share the tissue/DNA/data with.

Kawa for Biobanking

Kawa and tikanga provide the primary interface for accessing repositories of cultural knowledge and experience that can be used to inform ethical deliberations. Kawa refers to the core values and ethical principles that underpin a Māori worldview. The creation of kawa to inform biobanking (and genomic research) provides biobanks with a set of statements to inform the decisions they make once they have been gifted the responsibility to look after Māori tissue and DNA. The kawa have a dual function in that they represent both ethical principles that can inform decision-making as well as desired outcomes for the participants and communities.

I. Kia tau te wairua o te tangata

Wairua is a core philosophical concept that pervades all aspects of Māori society and is a central element of cultural protocols. It refers to the spiritual dimension and within Māori models of health it is a key component of a person's wellbeing (Ahuriri-Driscoll et al, 2012). Wairua is a concept to consciously address as it could both influence relationships and outcomes of genomic research as well as be impacted by them. An injury to a person's wairua negatively affects their wellbeing so ensuring whānau are comfortable with their involvement in genomic research is of importance here.

'**Kia tau te wairua o te tangata**' refers to the '**level of comfort**' that participants and communities have in the research project.

The level of comfort changes over time so a variety of different actions contribute to achieving this outcome. These actions might include engagement with iwi, use of cultural protocols during consenting process, encouraging whānau support, communicating uses of the tissue including research results, and transparent governance.

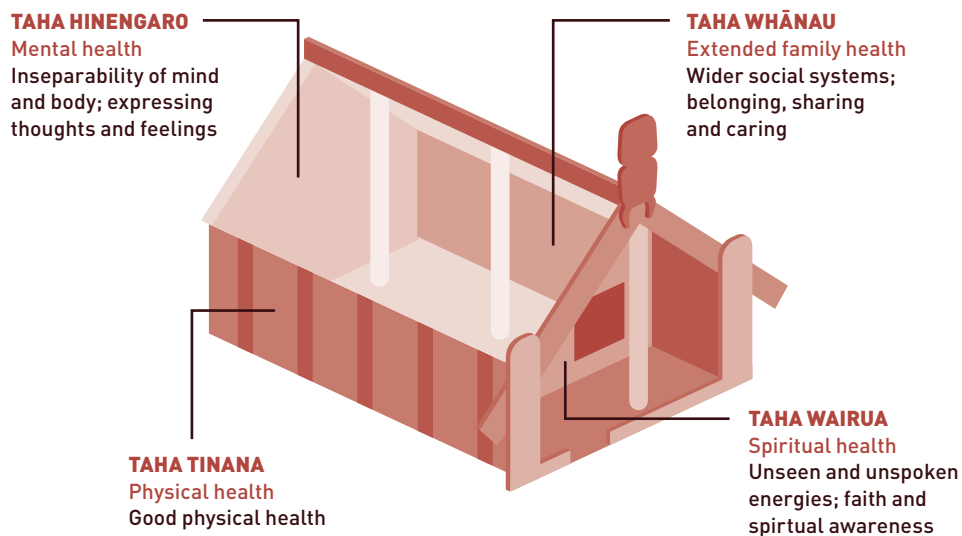


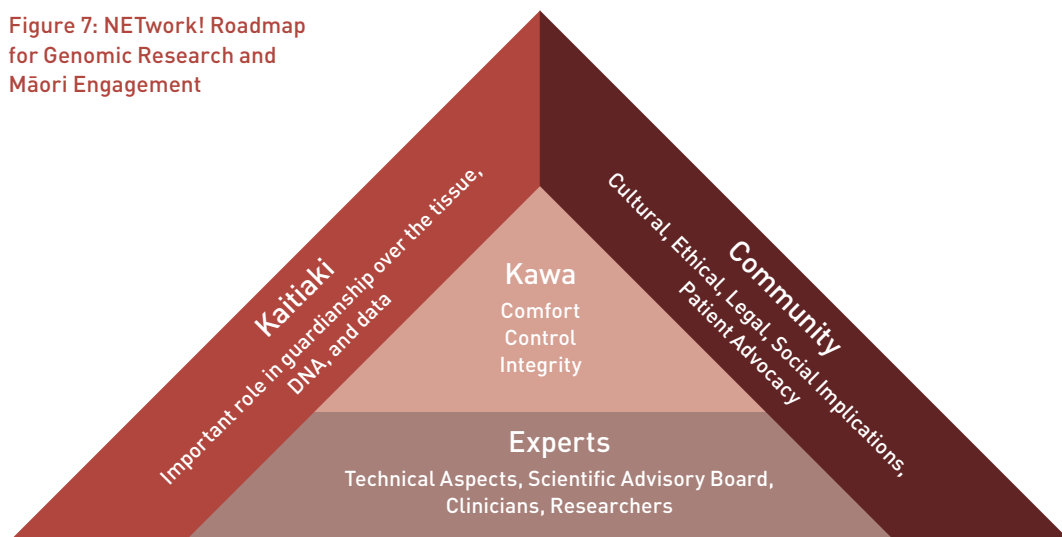
Figure 6: Te Whare Tapa Wha – Māori Model of Health and Wellbeing

Examples

Dr Melanie Cheung led work at the Neurological Foundation Human Brain Bank to look at how core Māori values can guide the process of working with human tissue. One of the cutting edge methods used on tissues samples in the laboratory involves growing cells from post-mortem and post-operative brain tissue. The development of appropriate tikanga for the laboratory supports culturally safe practice for both researchers and whānau. The process of seeking guidance of kaumātua, kuia, whānau, hapū, and iwi resulted in the use of specific karakia, waiata, kai and wai to whakanoa samples as they enter the laboratory environment.⁷

The NETwork project brings to together patients, clinicians and researchers to advance understanding of Neuro-Endocrine Tumours. Dr Kimiora Henare has been supporting the team to develop culturally appropriate processes and structures to support their on-going programme of research including work to operationalise kawa and utilise kaitiaki.⁸

Figure 7: NETwork! Roadmap for Genomic Research and Māori Engagement



7 Cheung, M. J. (2011). *Cellular and Cultural Studies of Human Neurodegenerative diseases*. (PhD Thesis, University of Auckland).

8 Henare, K., Parker, K., Print, C., Hudson, M., Wihongi, H., Findlay, M., Lawrence, B. (2015). PUKUmahi! Kia whai te huarahi tika NETwork! Roadmap for Safe Travel: Ensuring Health benefits flow on to Māori. Poster presented at NZSO conference 2–3 Nov 2015. Christchurch, New Zealand.

II. Kia pumau te mana o te tangata

Mana commonly refers to power, control or prestige. Different types of mana (mana atua, mana whenua, mana tangata) describe different levels of control and responsibility for decision-making. There are recognised rights for Māori collectives (whānau, hapū or Iwi) to engage with biobanks and consult around the purpose and parameters of the biobank. Whānau have rights to choose whether they engage with research and/or provide samples for biobanks and expect that hapū/iwi will support them as required in the context of those relationships. Iwi assistance may also be necessary to ensure whānau can access research information, access services, or provide cultural support as whānau make difficult decisions. To address the power imbalance inherent in the donor-biobank relationship, community members see hapū/iwi entities using their mana whenua status to support and protect their interests.

‘Kia pumau te mana o te tangata’ refers to the **‘level of control’** that donors and communities have in relation to the use of tissue in biobanks.

The level of control that communities and participants have in the context of their relationship with the biobank changes over time. Their level of influence tends to be greater during the consultation (in the case of communities) and consent (in the case of participants) phases of a biobank, and reduces over time. Efforts should be made to engage and empower participants and communities of interest throughout the life of the biobank to achieve this outcome.

Examples



The Queen Lili'uokalani Hospital in Hawaii has developed a dual consent process to ensure that patients are able to give free prior and informed consent to their tissue being stored in a biobank and used for research. As invitations to consent tissue into biobanks often occur when patients are undergoing surgery it was felt that this context distracts attention away from full consideration of the potential uses of the tissue in research. The process now used by the hospital consents the storage of tissue prior to the surgical procedure and then does a follow up six months later to request consent to use the tissue for future research.



Ngati Porou Hauora have been designated by the Iwi as the entity responsible for consultation with health researchers. They have established a research co-ordinator position, a stakeholder policy for health research and evaluation, as well as a research agreement on the use, storage and protection of Genome-wide Sequence Data.

III. Kia hiki te mauri o te kaupapa

Mauri is a core concept underpinning the Māori worldview. It can be described as the 'life essence' and is applied to both animate and inanimate objects. Maintaining the mauri can be thought of as maintaining the genetic or biological integrity of an organism or system. Ensuring that mauri is maintained or enhanced improves the level of public trust and accountability between genomic researchers and Māori communities.

'**Kia hiki te mauri o te kaupapa**' refers to the '**level of integrity**' present within the systems that contribute to the research endeavour.

The level of integrity in the systems that support research and the transformation of services – research organisations, ethics committees, funding bodies, and the health system – is integral to the level of support and trust that Māori communities have in research. Biobanks have a responsibility to build an understanding of their purpose and role within the research endeavour and develop trust with Māori communities through their activities and actions. Greater levels of transparency and communication about their activities and the research projects they support will contribute to the realisation of this outcome.

Examples

Recent changes in the process of ethical review for Health and Disability research led the Māori Research Review Committees to develop a framework for Māori review of research in DHB's. Standardisation has several potential advantages including increased efficiency of time, energy and resource, as well as improved national consistency while still allowing for consideration of local context and collaboration with mana whenua. The framework (Simmonds, 2015) makes an important contribution to ensuring the rights of Māori are upheld in the research setting.

The Ngai Tahu Research Consultation Committee is an Iwi entity that ensures research conducted within the University of Otago (including Wellington and Christchurch Schools of Medicine) or DHB's within the Ngai Tahu region is ethically sound and culturally appropriate. The NTRCC provides a clear and transparent process to facilitate research as well as support Iwi to know what's going on, when research is complete and the results of the projects.

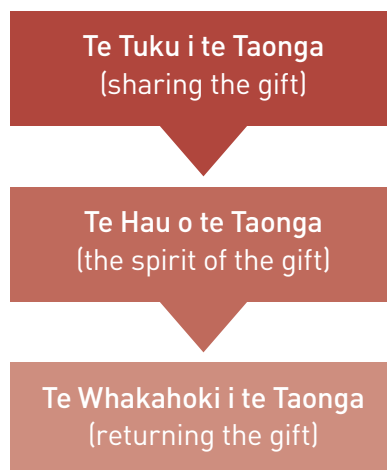
Tikanga for Biobanking

Tikanga refers to the specific protocols or processes that people follow to ensure that their values and principles are maintained. Tikanga provides a framework through which Māori can actively engage with ethical issues and consider the effect biobanks may have on their values or relationships.

Na te tapu i puta mai te tikanga⁹

As a taonga, the protocols for dealing with human tissue, DNA and data in research should address both physical and spiritual components within the research process. Tikanga will ensure that the kawa (principles) outlined above are operationalised by biobanks and the relationships between the biobanks and the donors/communities as well as researchers and the participants/communities are enhanced. There are three key stages where different tikanga could be applied to address cultural and ethical expectations of biobanks.

Figure 8: Key Stages
Where Tikanga can
be Applied



I. Te Tuku i te Taonga (sharing the gift)

Te Tuku i te Taonga refers to the point in time when a donor consents to their tissue/DNA/data being stored in a biobank. At a fundamental level the consent process establishes a relationship between the biobank and the donor. The process creates expectations of reciprocity, determines the parameters of the consent and also establishes levels of comfort and safety across both physical and spiritual dimensions.

9 The protocols for the context emerge from the spiritual nature of the activity.

Consent in the spiritual dimension relates to the process of wātea or whakawātea. In the biobanking context it might involve the use of karakia by cultural experts (tohunga) to clear the way by removing anxieties that participants and communities might have about the process of biobanking. This could happen at a institutional level (similar to the use of karakia to open a new building) or at the donor level (similar to the use of karakia by a hospital chaplain for a person before a significant operation). Addressing the spiritual dimensions of consent can also be supported by access to whānau support, as well as the use of Māori language and protocols during the consent process.

Consent in the physical dimension builds on existing practices involving the use of patient information sheets and consent forms. It is important that these documents address the full range of important issues (e.g. use of tissue, use of data, conditions of consent, benefit sharing, governance and future use arrangements) and that these are communicated in easily understood formats.

Example

Karakia are used as part of the process of whakawātea to address the cultural and spiritual significance of the activity. It is commonly used to transition from one state to another, acknowledging contributions and reflecting a transfer of responsibility. For a new building the process acknowledges the expertise and contributions of the people that have created the structure, and imbues the responsibility for future actions with the building itself and the people that will work there. Karakia provide a mechanism to enhance culturally safe practices for the context of biobanking and may be useful support for individuals providing samples or the establishment of new infrastructure.

II. Te Hau o te Taonga (the spirit of the gift)

Te Hau o te Taonga is a concept that refers to the expectations associated with the use of the tissue, DNA and data. Te Hau o te Taonga has been written about in the context of gifting land¹⁰. In the context of biobanking it supports the notion of tākohā and the responsibility to make decisions about the use of the taonga in a way which adheres to the parameters of consent, and respects the spirit in which the gift was given. Most decisions about the use of tissue, DNA and data occur after the point of consent so it is important to give consideration to the ways in which the kawa for biobanking will be operationalised.

The spiritual dimension of Te Hau o te Taonga relates most directly to principle 'Kia tau te wairua o te tangata', the level of comfort that participants and communities have in the biobank and the research projects it chooses to support. Identification of a kaitiaki (guardian) to support decision-making is one way to ensure the spirit of the gift is maintained as different research projects request samples from the biobank. Providing participants and stakeholder communities with updates is a way to ensure they are informed about the use of samples from the biobank. This addresses the issue where participants feel that they lose connection and control over time.

The physical dimension of Te Hau o te Taonga relates most directly to the principle 'Kia pumau te mana o te tangata', the level of control that participants and their communities have over their samples within the biobank. At a donor level it relates to the level of information and ability to withdraw consent. At a community level it relates to roles in the governance of the biobank and ability to track and audit the use of tissue/DNA/data.

¹⁰ Land was often gifted to settlers to support the establishment of schools, hospitals or churches with the understanding that if it wasn't used for that purpose it would be returned.

Example

An Aboriginal Governance Committee for a research project looking at genetic contributions to rheumatic heart disease in Aboriginal communities established a Living Protocol to ensure that the cultural and spiritual significance of tissue was being recognised as the samples, DNA and data was shared between the research partners. The Living Protocol outlines 'good manners' in relation to the use of samples, DNA and data and provides statements that can be included in material transfer agreements and data use agreements.

Tissue is considered by Aboriginal and Torres Strait Islanders to be sacred as it is a physical manifestation connecting collective stories of origin, identity and authority with aspirations for the future. A person's uniqueness arises from their connection to country and kin. The rights and obligations created with community through the gift of tissue extends to every recipient [user] of that tissue.

III. Te Whakahoki i te Taonga (return of the gift)

Te Whakahoki i te Taonga refers to the point in time when the consent for use has finished, the samples are disposed, and the responsibility for looking after the gift is returned to the community. This process is an expression of respect for relationship and provides an opportunity to report on all uses of the tissue/DNA/data. It also allows the research biobank to check in with the community about their level of comfort and satisfaction with the processes of the biobank and openness to continuing the relationship.

The spiritual dimension of Te Whakahoki i te Taonga relates to the communities level of comfort with the biobank and assesses the integrity of the biobanks decision-making and how it has managed the responsibility gifted to them. The metaphor of a 'kawe mate', where photos/taonga of a recently deceased person are taken to marae for whānau to grieve over, is associated with the acknowledgement and return of whānau members. The idea of a 'kawe taonga' emerged to recognise that often the actual tissue/DNA would not be able to be returned to participants/communities but a representation of those taonga in the form of reports or other information could be returned.

The principle 'kia pumau te mana o te tangata' can be enhanced by biobanks ensuring researchers provide access for donors to research reports or raw data, as well as providing opportunities for them to reconsider their consent and 'exit' the relationship with the biobank.

Example

A kaumatua from Ngāti Whātua spoke about the instructions given to the 28th Māori Battalion, a group of Māori soldiers that fought in World War 2. The elders realised that not all of them would return from the battles and were told that it was okay to bury the fallen on the other side of the world but that they should bring back a memento or something that belonged to the person so that the whānau could grieve for them. This is not unlike a kawe mate where a person is buried in a urupā in one region but a photo of them is taken to other regions so whānau from those places can also express their grief in a culturally appropriate manner.

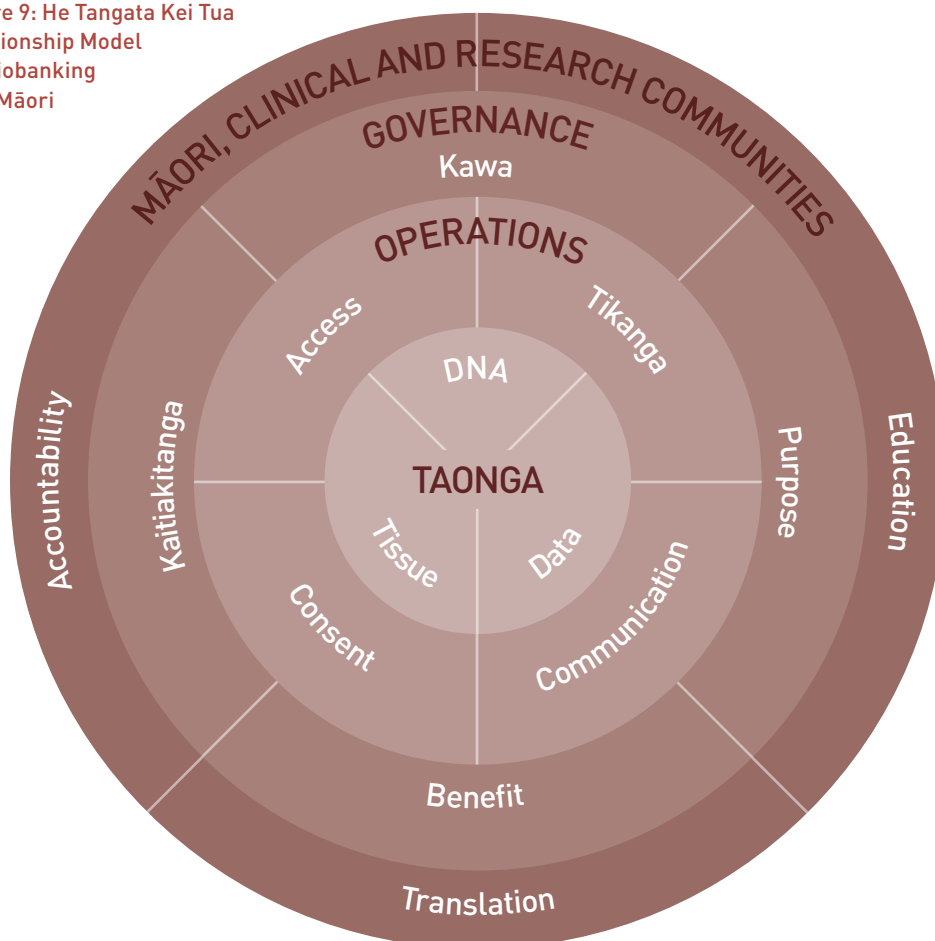
The kaumatua used this story as an analogy for the taking of tissue for research and suggested that while it may not be possible to return biological material to participants it was important that something came back. This might be the results of the study and he reiterated the importance of it being done in the right way. If discussions about the project had taking place with whānau or hapū then it should be in a formal manner on the marae.

*Me hoki rangatira mai mā te upoko, ehara mā te rārā.
One should return through the front door, not the
side door.*

He Tangata Kei Tua Relationship Model for Biobanking with Māori Tissue

It is important that biobanks actively build relationships with whānau, hapū, iwi, or Māori groups. The kawa and tikanga outlined above as part of the cultural foundation provide some guidance around decision-making in the context of biobanking. This section outlines the context and key issues¹¹ that Māori have interests in discussing in relation to biobanking.

Figure 9: He Tangata Kei Tua Relationship Model for Biobanking with Māori



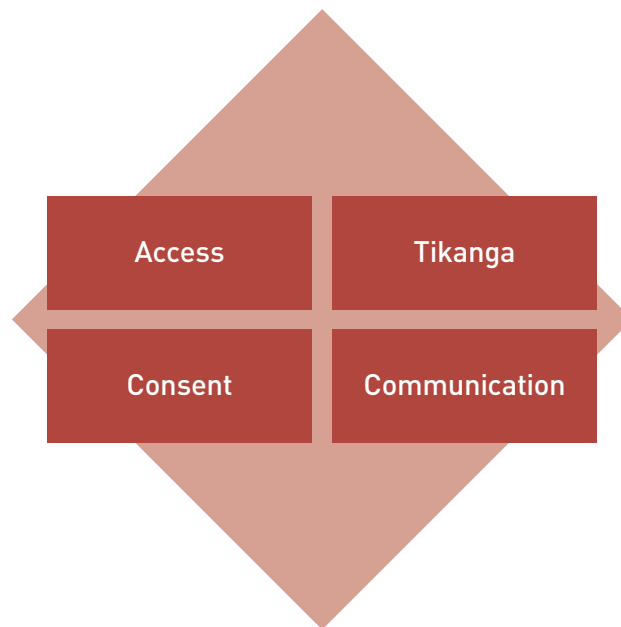
11 These issues were identified through the HRC funded Te Mata Ira research project.

Relationship Between Biobanks and Researchers

A biobank is a key part of the biomedical research infrastructure. They exist to support research and facilitate the ethical use of tissue consented by donors. As the main interface with donors they have a primary responsibility to ensure that the taonga of responsibility associated with a person's tissue/DNA/data (clinical and genomic) is upheld.

Operations

There are four key areas of the operations sphere within which key issues of relevance to Māori may be considered; tikanga (protocols), access, consent, and communication.



a) Tikanga

Tikanga (cultural protocols) should inform the research practices within the project to ensure the cultural safety of participants and their communities. For example, tikanga can be applied in the context of engagement with communities, the collection and disposal of samples/DNA/data, the future use of samples/DNA/data. Tikanga might also be applied to issues of data security and inform material transfer or data use agreements.

The types of questions to expect from Māori entities relevant to tikanga include:

- What happens to the samples that are collected?
- Can we track where the samples are and what they are being used for?
- What other whānau, hapū and iwi samples are part of the same project?
- Can we visit the research facility?
- How long are samples kept?
- What is the process of discarding samples?
- What tikanga could be applied and how?

Overall, tikanga (cultural protocols) should inform policy and practice within all spheres of biobank activities (operational, governance and community engagement). For example, the collection and disposal of biospecimens, engagement with communities, the future use of biospecimens and data, and community consent/mandate in support of the biobank and research project(s).

Tikanga, or protocols for research with tissue, should include 'na te tapu i puta mai te tikanga' (physical and spiritual components). In an operational sense, 'he take-utu-ea' (a circle of reciprocity) must be established. Firstly, 'he tuku i te taonga' (sharing the gift) involves establishing of relationship through consent. With this comes expectations of reciprocity, the need to define clearly the parameters of consent (conditions of consent, use of tissue, use of data and benefit sharing), and the need to establish a level of comfort and safety for the participant and community. From a spiritual perspective, this may involve wātea (consent) involving karakia, whakawātea (a form of karakia to remove a restriction before a state of tapu is returned) and access to tohunga (experts).

Secondly, 'he hau o te taonga' (the spirit of the gift), takes into account integrity of decisions about use, respect for the spirit in which the gift was given, adhering to consent parameters and may have spiritual and physical aspects. Spiritual aspects include kaitiaki, communication and updates on use, living protocols (that is, a statement that reflects 'te hau o te taonga' within Material Transfer Agreements); and physical aspects include the governance role; operating within consent parameters; and tracking and auditability for biospecimens and data.

Thirdly, te whakahoki i te taonga (return of the gift), requires expression of respect for the relationship, reporting on all uses and outcomes, the need to check on satisfaction with process and outcomes, access to raw data and reports, re-consent for future use and participation and consent to 'exit' the relationship.

More broadly, less specific consents may be acceptable when balanced by stronger governance arrangements and/or dynamic re-consenting models that support a focus on participation in projects that support Māori health priorities.

b) Communication

Communication was identified as a key issue for iwi and should take place within all spheres of biobank activities and engagement with individuals through to communities. There can be multiple pathways for communication with both active and passive channels (for example; letters, newsletters and websites). Returning results (for example, if through a defined process incidental findings are found to be significant and/or clinically actionable) should be communicated in an appropriate manner (to participants/whānau and/or general practitioners) with due regard for issues of privacy and confidentiality. Access to genetic counselling should also be facilitated and issues for biological relatives considered (by clearly communicating any level of risk).

The types of questions to expect from Māori entities relevant to communication include:

- How will updates and results be reported back?
 - When?
 - Who?
- How do iwi access the results?
- Can individual participants access their results?
- How will you contact participants about incidental or clinically actionable findings?
- Who will be the primary contact for the project? And biobank?

Communication was identified as a key issue for iwi and should take place within all spheres of biobank activities and engagement with individuals through to communities. There can be multiple pathways for communication with both active and passive channels (for example; letters, newsletters and websites). Returning results (for example, if through a defined process incidental findings are found to be significant and/or clinically actionable) should be communicated in an appropriate manner (to participants/whānau and/or general practitioners) with due regard for issues of privacy and confidentiality. Access to genetic counselling should also be facilitated and issues for biological relatives considered (by clearly communicating any level of risk).

More generally, there are clear expectations around Māori consultation and communication at the iwi level as iwi governance over projects is expected. Biospecimens and data should be used with due regard to the individual donors and iwi consent to undertake research that supports Māori health priorities. Communities should be acknowledged when their data is included in secondary studies and there is an expectation that study results from any secondary use of their biospecimens or data are communicated back to communities. In this way, re-contact options may facilitate re-consent for secondary use as research organisations/biobanks should be accountable to the donors for their decisions around future use of biospecimens.

c) Consent

The scope and specificity of the consent is a key consideration from a Māori perspective. There is a preference that participants consent for every use but discussions in the consultation phase may allow for specific project use, disease-specific use, or broad unspecified use. There is an expectation that there will be specific consents for genetic/genomic analyses, access to clinical records, and use for possible commercialisation. Consideration should also be given to whether specific consents are required for return of results (research, individual, incidental findings), anonymisation of biospecimens, and putting genomic information on open data sharing platforms. Broader, less specific consents may be acceptable when balanced by stronger governance arrangements and/or dynamic re-consenting models that support a focus on participation in projects that support Māori health priorities. Similarly, the timing of consent could be staggered to allow people to consent to clinical trial/sub-study in the first instance and to consent for future use at the end of the initial study.

The types of questions to expect from Māori entities relevant to consent include:

- What choices do participants get to make?
- What are the parameters of consent?
- Would you like participants to consent for unspecified future use?
- Do you want access to clinical information?

Scope and specificity of the consent is a key consideration from a Māori perspective (and may include broad unspecified use; disease-specific use, unspecified use; specific project use; use for genetic/genomic analyses; access to clinical records; and/or use for possible commercialisation). Similarly, return of results (research, individual, incidental); anonymisation of biospecimens; putting genomic information on open data sharing platforms; and timing of consent (for example, relating to clinical trial/sub-study/future use).

d) Access

At the operational level, access to tissue/DNA/data stored within a biobank should be consistent with principles and purpose established in conjunction with the community. Access to tissue/DNA/data from Māori donors should only be used for research projects that;

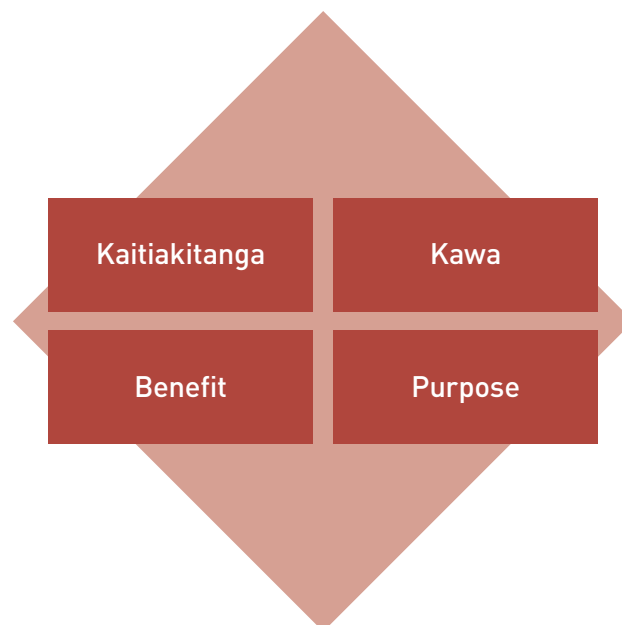
- a) focus on Māori health priorities,
- b) protect Māori rights and interests,
- c) use robust analytical tools and interpretive frameworks,
- d) provide feedback and communications to donors/communities, and
- e) operate within the parameters of the donors consent.

The types of questions to expect from Māori entities relevant to access include:

- Who is able to access the samples?
- What criteria is used to assess them/their projects?
- Are Māori part of the approval process?

Governance

There are four key areas of the governance sphere within which key issues of relevance to Māori may be considered; kawa (principles), kaitiaki (guardianship), biobank purpose (the aims and values of the biobank and the projects it supports) and benefit.



e) Kawa

Respect for kawa (principles) for research with human tissue emerged as a key issue for iwi. First and foremost that tissue is taonga (precious), tapu (sacred/restricted); and by extension, that data is a representation of tissue. Commonly, the only decision that a donor makes is whether or not to participate by donating a bio-sample to a biobank. With the donation of a bio-sample comes tākoha (a gifting of responsibility). Therefore, it is essential that kawa apply to every decision making point within a biobank's range of activities to create for Māori:

- 1) kia tau te wairua o te tangata (a level of comfort);
- 2) kia pūmau te mana o te tangata (a level of control); and
- 3) kia hiki te mauri o te kaupapa (a level of integrity).

The types of questions to expect from Māori entities relevant to kawa include:

- What type of relationship are you looking for?
- What principles are used to make decisions about the use of samples and data?
- How will Māori rights and interests in intellectual property be recognised?
- How can we ensure our tikanga is upheld?

f) Purpose

A key discussion with Māori stakeholders in relation to biobanks is around purpose. The purpose, values and mission of the biobank, its intended outcomes, and the make up of the team will all contribute to the level of comfort a community has in a biobank. They will look more favourably on biobanks that support research projects contributing to Māori health priorities. It is also important to differentiate and be clear about the range of studies or limitations on studies that the biobank will support.

The types of questions to expect from Māori entities relevant to purpose include:

- He aha te putake o te rangahau / What is the purpose of the biobank and the research it will support?
- Who is funding the biobank?
- Why is the biobank important for our community and for Māori generally?
- What impact will the biobank have on Māori health?
- What outcomes is the biobank aiming to achieve?
- Who is involved in the biobank?
 - Are there any iwi/Māori members of the team?
 - What experience does the team have working with Māori communities?

g) Benefit

The benefits of any research project should outweigh the risks to Māori and the biobank should ensure they only support projects that benefit Māori donors and their communities. Equity and justice are ethical principles underpinning the importance of benefit-sharing. Research will also have a range of outcomes and part of the ethical deliberation is to consider the nature of the outcomes (risk versus benefit, short versus long term) and their relative distribution (researchers, participants, communities, society). Researchers will legitimately benefit from being involved in research but biobanks should consider how donors and their communities might also benefit from participation. This might include capacity building and pathways for benefit sharing should commercialisation opportunities arise.

The types of questions to expect from Māori entities relevant to benefit include:

- What benefits will come from participating in the research?
- How will we benefit from supporting the biobank?
- What opportunities are there for our people to be involved or employed?

h) Kaitiakitanga

Kaitiakitanga is a form of guardianship with responsibility to look after specific resources. Guardianship implies respectful conduct in relation to the use of biospecimens and all forms of data/information. Indeed, individuals and/or communities should retain veto rights over how their biospecimens and data are used, which needs to be considered by biobanks at the governance and operational levels. Ideally, data sharing (for secondary use and open platforms) should only occur with the express permission of the participants (consent) and, at an overall project level, should be mandated by representatives from the community. It is important to clarify who holds the role of kaitiaki within the biobank and the community, and that they are aware of the responsibilities of that position to maintain 'te hau o te taonga'.

For Māori, data is a representation of tissue. Genetic information is a highly valuable strategic asset to Māori and with this comes some concerns and expectations. For instance, there is an expectation of control/influence over use of raw data and concern at linking of datasets across different domains. Nevertheless, it is possible to address 'wairua' (comfort) aspects of data through governance procedures and effective communication. Anonymisation removes the possibility of maintaining 'mana' (control) and of providing direct benefits. Processes to approve linking of data should be transparent to enhance 'mauri' (integrity) and trust in the integrity of the system; and may be supported in a practical sense through the use of material transfer and data use agreements, and data security and audit trail expectations.

The types of questions to expect from Māori entities relevant to kaitiaki include:

- Ma wai e tiaki?
- Who will be responsible for the samples, information and data?
- What options are there for storing the samples?
 - Is there a Māori or Indigenous biobank?
- How long can samples be used before renewing consent?

Māori, Clinical and Research Communities

The Community Sphere is the period post-project where the impact of the research project can be realized. Improved outcomes for Māori health motivates the engagement of whānau/hapū/Iwi in genomic research projects and there should be active mechanisms to deliver on this goal. Key issues to discuss with Māori entities as part of the planning for the community sphere include accountability, translation, and education.



i) Education

Māori recognise that genomic research will become an important part of the health system in the future. Improving levels of genetic literacy amongst Māori communities and levels of cultural literacy amongst science communities is necessary to ensure beneficial outcomes for Māori health. A component of this is to better understand how genomic research translates to health interventions and what the steps are to developing clinically relevant outcomes. Similarly, when a genetic basis for disease is discovered, how do whānau talk about this and what support is available to assist with this process?

The types of questions to expect from Māori entities relevant to education include:

- What support is there for educating the community about genomic research and biobanking?
- Where can we access information to help us make decisions?
 - Whether to engage
 - What to do with the results
- What information and advice can we access to support our whānau

j) Accountability

Accountability in this context relates to the relationship between the research team and communities that supported the research project. Expectations for ongoing feedback and communication with participants and Māori communities are key ways in which research teams can demonstrate accountability. Samples and data should be used with due regard to the donors consent and for studies which contribute to Māori health priorities. Communities should be acknowledged when their data is included in secondary studies (with their approval) and they should receive study results from any secondary use of their samples or data. Research organisations are accountable to the participants and their communities for their decisions around future use of samples and facilitating benefit sharing mechanisms for commercialisation opportunities. Re-contact options that facilitate re-consent for secondary use may be one avenue to demonstrate this responsibility.

The types of questions to expect from Māori entities relevant to accountability include:

- How will researchers be accountable to the community?
- How are decisions made around which organisations can access the samples?
- Will there be any restrictions around access or use?
- Will donors be informed about use of their samples?
 - Use in projects / Results of projects?
- Is there a mechanism for benefit sharing?
- If there is a problem, who can we talk to about the research and/or the researchers?

k) Translation

Knowledge translation informs resource allocation and can support service development. These are key outcomes for Māori communities from research. The challenge for genomic researchers is to articulate how genomic research translates to improved health outcomes across the spectrum of public health and personalised medicine. The relevance of the research results should be shared with participants and their communities, and clinically actionable results should be shared with clinicians and service providers using an ethically defensible plan.

The types of questions to expect from Māori entities relevant to translation include:

- What are the steps to developing a clinically relevant outcome?
 - Diagnostic tools
 - Education and health promotion
 - Pharmaceutical interventions
- How does genomic research translate to health interventions?
 - Health service delivery
 - Clinical decision making
 - Type and dosage of medication
 - Public health messages
- When a genetic basis for disease is discovered, how do whānau talk about this?
 - What support can be accessed?

Special Ethical Considerations

Benefit Sharing

Equity and justice are ethical principles underpinning the importance of benefit-sharing. Research will also have a range of outcomes and part of the ethical deliberation is to consider the nature of the outcomes (risk versus benefit, short versus long term) and their relative distribution (researchers, participants, communities, society). Researchers will legitimately benefit from being involved in research but consideration should be given to how participants and their communities might also benefit from participation through research, education and translational activities.

Research	Education	Translation
Participant/community access to additional health resources <ul style="list-style-type: none"> • tests • screening • expertise • genetic counselling 	Feedback to participants to <ul style="list-style-type: none"> • provide information about the contribution of genetic & environmental factors (i.e. consumption and exercise) to health incidence • increase levels of understanding about genetic conditions • information about whakapapa 	Improvements to health service delivery <ul style="list-style-type: none"> • access • screening • clinical decision making • personalised medicines
Capacity building <ul style="list-style-type: none"> • internships • scholarships • research positions • research workshops • relationships/partnerships with research providers 	Community workshops and hui to <ul style="list-style-type: none"> • provide information about the contribution of genetic & environmental factors to health incidence • increase levels of understanding about genetic conditions • make informed consent processes more robust 	Improvements to health literacy in community <ul style="list-style-type: none"> • Supports conscious decision-making around genetic conditions (genetic literacy) • Activating healthy communities (health promotion)
Information for community <ul style="list-style-type: none"> • Research reports • Baseline data for future Iwi studies/interventions • Shared intellectual property 	Develop project resources (print/website) <ul style="list-style-type: none"> • Genetic literacy • Health promotion 	Support Information Sovereignty <ul style="list-style-type: none"> • Māori stewardship of data and information • Māori research capacity

Table 2: Benefits for Communities

Benefits to researchers

- Status and reputation
- Qualifications (Masters and PhD theses)
- Personal advancement
- Increasing networks

Benefits to participants

- Access to interventions
- Opportunity to share experiences
- Koha
- Acknowledgement in publications
- Copies of reports

Benefits to participant communities

- Research capacity – research skills, understanding research processes
- Access to interventions
- Collection and protection of existing intellectual property
- Knowledge advancement
- Copies of reports
- Sharing of new intellectual property

Benefit to Māori

- Community development, for example health promoting events
- Researcher development for example qualifications and research experience
- Knowledge advancement, for example research outputs, hui (meetings/ seminars) and wānanga (workshops/teaching sessions)
- Development of mātauranga Māori

Benefit to society

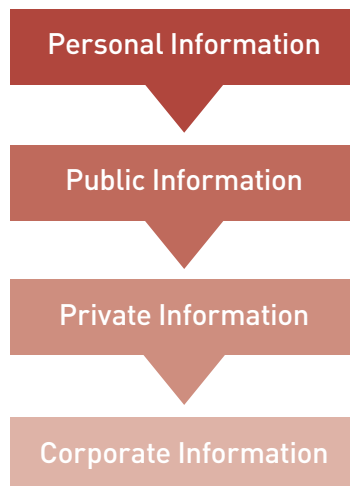
- Knowledge advancement for example research outputs, hui and wānanga
- Inclusiveness and diversity within the research system

Data Rights and Interests

Internationally, human tissue samples and associated genomic data from Māori and Polynesian sources are becoming an increasingly valuable resource. Opportunities for benefit-sharing with Māori communities is connected to an acknowledgement that they have an inherent right to derive benefits from the use of their taonga. These rights have been articulated in the Mataatua Declaration and the United Nations Declaration on the Rights of Indigenous Peoples and also underpin recent discussions on Indigenous Data Sovereignty.

Māori have expressed a belief that they have rights to tissue and the genomic data associated with it, as well as an interest in the outcomes of research and applications of their data. There is also a belief that genomic data, like their clinical data, was personal information. Its use in the public domain as part of supporting research is to improve health outcomes for their community. While many recognise that the pathway to the delivery of benefit often involves commercial entities there are concerns about their personal information becoming corporatised through research activities. There is an expectation that those who contribute to research should receive direct benefits over and above those delivered to the public.

Figure 10:
Information Flow



Data Linkage

Data is a representation of tissue and genetic information is a highly valuable strategic asset to Māori. There is some concern about the linking of datasets across different domains and there is an expectation of Māori involvement in governance over access to and linking of data.

The kawa developed for genomic research can also be applied to data governance, addressing 'wairua' through regular communication, 'mana' by providing direct benefits, and 'mauri' through transparent processes that enhance trust in the integrity of the system.

Incidental Findings

Tissue, DNA and data stored within biorepositories often ends up as a sample within a research project that produces an incidental finding. Incidental findings are results unrelated to the primary focus of the study but which may be significant for the individual's health. The nature of genomic research, which analyses a vast number of genes across the genome, will frequently produce incidental findings. The challenge is to determine whether the finding is statistically significant, clinically significant, and/or clinically actionable. Māori communities expect to be notified of any clinically significant or actionable findings. It is the responsibility of the research team to develop an ethically defensible plan¹² of how they will address incidental findings that emerge through their study.

12 National Health and Medical Research Council (NHMRC). National statement on ethical conduct in human research. Canberra: NHMRC, Australian Government; 2007. Available from: <https://www.nhmrc.gov.au/guidelines-publications/e72> [Verified 21 May 2015].

Glossary of Māori Terms

Disclaimer: Many of the descriptions used in this glossary are specific interpretations for the purposes of this document and do not denote the fullness of meaning normally associated with the word or term.

Awe māpara	Ink used for traditional tattoo
Hapū	Kinship group
Hui	Meetings, seminars
Iwi	Tribe
Kai	Food
Kaitiaki	Guardian/advocate
Kanohi ki te kanohi	Face to face
Karakia	Prayer, incantation
Kaumātua	Elder
Kaupapa	Topic, purpose
Kawa	Principles
Kuia	Female elder
Māhaki	Respectful conduct
Mana	Justice and equity, power and authority, control
Mana akiaki	Empowerment
Mana tangata	Autonomous individual
Mana whakahaere	Shared power and control of outcomes and dissemination
Mana whenua	Regional authority, customary title over land
Manaakitanga	To look after, care for
Mātaawaka	Māori living within the area not related to local iwi
Mātauranga	Traditional knowledge
Noa	Unrestricted

Tāmoko	Traditional tattoo
Tangata whenua	People of the land
Taonga	Precious, resources
Tapu	Restricted
Te Ao Māori	Māori world
Te Mata Ira	Faces of the gene
Tika	Right, correct
Tikanga	Protocols and practices
Wai	Water
Waiata	Song, singing
Wānanga	Workshops, teaching sessions
Whakanoa	To free from restriction,
Whakapapa	Genealogy, relationships
Whakatauki	Proverb
Whakawātea	To remove tapu
Whānau	Family, extended family, kin network

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Appendix A: Additional Resources

- Critique(s) of genetics-based research in Indigenous populations
<http://www.conversations.canterbury.ac.nz/documents/FINAL%20NGAPAEAPER.doc>
- Māori protocols
<http://www.katoa.net.nz/kaupapa-Māori/Māori-protocols>
- National Congress of American Indians Genetics Resource Centre
<http://www.ncai.org/policy-research-center/initiatives/projects/genetics-resource-center>
- Research consultation with Māori (Otago University policies)
<http://www.otago.ac.nz/research/Māoriconsultation/>
- Te Aroturuki
<http://www.dabhand.co.nz/tap/index.html> (draft)





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