

# TE MATA IRA—FACES OF THE GENE

---

## Developing a cultural foundation for biobanking and genomic research involving Māori

*Maui Hudson\**

*Khyla Russell†*

*Lynley Uerata‡*

*Moe Milne§*

*Phillip Wilcox\*\**

*Ramari Viola Port††*

*Barry Smith‡‡*

*Valmaine Toki§§*

*Angela Beaton\*\*\**

\* Associate Professor, School of Māori and Pacific Development, University of Waikato, Hamilton, New Zealand.  
Email: [maui@waikato.ac.nz](mailto:maui@waikato.ac.nz)

† Professor (Ret.), Otago Polytechnic, Dunedin, New Zealand.

‡ PhD Candidate, Māori and Psychology Research Unit, School of Psychology, University of Waikato, Hamilton, New Zealand.

§ Independent Researcher, Moerewa, New Zealand.

\*\* Senior Lecturer, Department of Statistics, University of Otago, Dunedin, New Zealand.

†† Independent Researcher, Forrest Hill, New Zealand.

‡‡ Researcher, Lakes District Health Board, Rotorua, New Zealand.

§§ Senior Lecturer, Piringa Faculty of Law, University of Waikato, Hamilton, New Zealand.

\*\*\* Director, Centre for Health and Social Practice, Waikato Institute of Technology, Hamilton, New Zealand.

DOI: 10.20507/AlterNative.2016.12.4.1

## Abstract

Te Mata Ira was a three-year research project (2012–2015) that explored Māori views on genomic research and biobanking for the development of culturally appropriate guidelines. A key component of this process has been to identify Māori concepts that provide cultural reference points for engaging with biobanking and genomic research. These cultural cues provide the basis for describing the cultural logic that underpins engagement in this context in a culturally acceptable manner. This paper outlines the role of two wānanga (workshops) conducted as part of the larger project that were used to make sense of the Māori concepts that emerged from other data-collection activities. The wānanga involved six experts who worked with the research team to make sense of the Māori concepts. The wānanga process created the logic behind the cultural foundation for biobanking and genomic research, providing a basis for understanding Māori concepts, Māori ethical principles and their application to biobanking and genomic research.

## Keywords

Māori, biobanking, genomic research, cultural foundation, ethics

*Me āta hāere mā ngā karu, kei tōtohu i  
te aroha o Tangaroa  
Tread carefully in challenging waters*

## Introduction

Indigenous participants are often placed in positions of vulnerability within a health and research system that generally doesn't acknowledge Indigenous worldviews or approaches to health and illness (Cram, 2001; L. T. Smith, 1999, 2012). In the context of biomedical research, highly specialized genetic (studies focusing on specific genes) and genomic (studies focused on groups of genes or whole genome) technologies create power imbalances between researchers/clinicians and participants/patients, and contribute to the low level of engagement from Māori communities (Wilcox, 2016). Māori reticence about the use of genetic or genomic technologies has been clearly articulated in the context of genetic modification most stringently in relation to cross-species manipulation involving food (Cram, 2005; Hutchings & Reynolds, 2005a, 2005b; Roberts, 2005; Roberts & Fairweather, 2004; Taupo, 2012;

Tipene-Matua, 2006). The picture is more nuanced with Māori support for genomic research and biobanking (Beaton, Smith, Toki, Southey, & Hudson 2015; Hudson, Ahuriri-Driscoll, Lea, & Lea, 2007; Port, 2009; Tawhara, 2006; Tipene-Matua, 2006; Wilcox, 2016) tempered by concerns that researchers may understate the risks and overstate the benefits of genomic research, with minimal contribution towards improving Māori health outcomes (Cram, 2005; Du Plessis et al., 2004; Rochford, 2012; C. Smith & Reynolds, 2000). With an increasing number of genetic/genomic studies being initiated by Māori families or communities, it will be important to create appropriate models to support engagement (Wilcox, 2016).

Key issues for Māori in relation to biobanking and genomic research, as identified through the Te Mata Ira project, include the protection of Māori rights and interests, a focus on Māori health priorities, the control of samples and data, expectations of consultation and consent, and a desire for greater feedback and communication (Hudson et al., 2016b). This paper describes Māori concepts relevant to biobanking and genomic research, creating a *cultural*

*foundation* upon which Māori communities can ground their discussions around appropriate kawa (principles) and tikanga (cultural protocols) with researchers. It contextualizes Māori concepts, identified through literature and hui (meetings) with Iwi and Māori stakeholders, as key reference points or *cultural cues* around which to describe aspects of a *cultural logic* underpinning the application of Māori ethical practices for this context. Through an explicit articulation of the cultural foundation for biobanking and genomic research we have been able to give the concepts practical meaning and a narrative that enhances understanding in both the Māori community and the research community.

## Methodology

A kaupapa Māori methodology was used for consistency with Māori worldviews and because of its focus on supporting Māori-inspired and Māori-led developments. Such a methodology is a preferred practice approach to research with Māori because it maintains Māori control of the research process, aligns with Māori ethics and development aspirations, and values Māori protocols within the research design (Cram, 2003; Hudson, 2004; Hudson, Milne, Reynolds, Russell, & Smith, 2010; L. T. Smith, 1999, 2012). Kaupapa Māori privileges Māori concepts, values, understandings and knowledge and has a focus on transformation by challenging systems and structures that limit opportunities for Māori development (Eketone, 2008). This does not limit the ability to question or challenge the information shared and ideas generated and is done in such a way that the mana (power) and integrity of participants and their views are maintained (Ahuriri-Driscoll, Hudson, Bishara, Milne, & Stewart, 2012). Framing research as kaupapa Māori gives credence and agency to a Māori epistemology which embeds Iwi cultural values and ways of knowing within the project (Tipene-Matua &

Wakefield, 2007). The principles of kaupapa Māori were embodied in the project in a number of ways:

1. The research was led by Māori researchers.
2. Participants were recruited through whānaungatanga (relationships).
3. The researchers spoke te reo Māori (Māori language) and integrated tikanga into the research process.
4. The research gave Māori a space to consider and define the issues.
5. The research raised Iwi awareness about genomic research and biobanking.
6. The research explored Māori rights and interests as they were defined by Māori.
7. A Māori lens was applied in the interpretation of the data.

## Methods

Research activities conducted after receiving ethics approval from the Northern B Health and Disability Ethics Committee (12/NTB/11/AM03) included literature searches, nine key informant interviews, five stakeholder workshops, five Iwi hui and four case studies. Significant concepts and ideas identified as cultural cues through these activities were analysed by the research team with the support of experts in two cultural wānanga workshops held in 2014 (January 22–23 and August 11–12) at the Waikato-Tainui College for Research and Development in Hopuhopu. The purpose of the wānanga, conducted after the initial data-collection activities, was to assist the research team to appropriately frame the cultural cues and consider how biobanking and genomic research might be informed by tikanga, kawa or other concepts that exist within mātauranga Māori (Māori knowledge). The two wānanga involved 14 participants (6 males and 8 females ranging in age from 20 to 70) comprising eight members of the research team and six external participants. The external participants were

purposefully selected by the research team as people with expertise in te reo Māori and tikanga Māori. They came from a range of Iwi and had expressed an interest in the kaupapa (project).

Wānanga in a traditional sense refers to a process of learning. Whare wānanga are “houses of learning” and are now used to describe Māori tertiary institutions. Wānanga and hui are often used to describe culturally safe or culturally appropriate group processes within research (Ahuriri-Driscoll et al., 2012). L. T. Smith et al. (2013) describe wānanga dialogue as “the adoption and adaptation of a traditional wānanga process . . . to culturally ground the discussion and provide space for mātauranga Māori to inform dialogue” (p. 25). Wānanga dialogue can be used in a variety of processes and formats to facilitate the dialogue and knowledge exchange “associated with traditional wānanga within the context of a contemporary workshop” (p. 25). This approach was utilized to bring cultural experts into a space where they could consider and debate how to position biobanking and genomic research in the context of Te Ao Māori (Māori worldview) and mātauranga Māori. The wānanga were facilitated by two members of the research team with others in attendance to take notes and aid the process of analysis, although all were free to contribute to the workshop discussions. According to Rycroft-Malone (2001) and Vinokur, Burnstein, Sechrest, & Wortman (1985), the use of one or two facilitators supports a smooth and successful meeting. The wānanga, conducted in both te reo Māori and English, were recorded, transcribed and analysed. Participant quotes emerged from the discussion within the wānanga and have been attributed to either the wananga tuatahi (first workshop) or wananga tuarua (second workshop) rather than a specific speaker.

The context of biobanking and genomic research was explained, and key Māori concepts identified from the literature, key informant interviews and stakeholder workshops were

presented to wānanga participants as the basis for semi-structured discussions. The key question for the data-collection activities was “What do Māori think about biobanking and genomic research?” Keywords and phrases that emerged included whakapapa (genealogy), whānau (family), whānaungatanga (relationships), tapu (sacred, free from restriction), mauri (life essence), mouri (variation of mauri shared by Huirangi Waikerepuru), mana (power), wairua (spirit), manaakitanga (caring), kaitiakitanga (guardianship), kotahitanga (unity), tikanga (protocols), karakia (prayer), Te Mata Ira (faces of the gene), he tangata kei tua (the person beyond the veil), te hau o te taonga (the spirit of the gift), he kōrero nō te ao kōhatu (a saying from the old world), he tapu te kaupapa (a sacred purpose), he aha te mea nui o te ao? He tangata! He tangata! He tangata! (what is the most important thing in the world? It is people! It is people! It is people!), ko te kura huna ki roto ki te toto (a precious gift within the blood). Through an iterative process of dialogue the wānanga participants identified which concepts provided the primary reference points for understanding, how they relate to each other and the logic behind those connections, and how they might be valued through the application of kawa and tikanga. The wānanga provided a space and process which allowed the research team to make sense of the information that had emerged from our previous research activities, and co-construct a cultural foundation for biobanking and genomic research which became the “straw man” for further consultation with Iwi and Māori stakeholders.

### **Developing the cultural foundation for biobanking and genomic research**

The purpose of the cultural wānanga was to make sense of the cultural cues in the context of biobanking and genomic research, and consider how they might inform issues of ethics and practice. The wānanga participants

recognized that genomic research and biobanking are potentially beneficial for Māori, and that it was important that Māori retain the ability to set the research agenda and control the process of donation. The differences between the scientific paradigm and Te Ao Māori and how intangible elements like wairua and mauri might be addressed were also considered. Participants expressed a desire to develop understandings and applications of Māori concepts and consider what aspects might be changeable (law) and what should remain constant (lore) within this kaupapa. Participants also recognized that increased knowledge on biobanking and genomic research was a key part of exercising control over these processes and that increasing knowledge was required at both individual and collective levels. Three ideas emerged as the most relevant cultural cues and narratives describing the cultural logic for this context:

- 1) The idea that tissue is a taonga (treasured item). As a taonga, human tissue has a tapu which must be addressed in both the physical and spiritual domains.
- 2) The principles or kawa that might inform the use of tissue should include:
  - Kia tau te wairua o te tangata, whānau, hapū, Iwi (To ensure a level of comfort)
  - Kia pūmau te mana o te tangata, whānau, hapū, Iwi (To maintain a level of control)
  - Kia hiki te mauri o te tangata, whānau, hapū, Iwi (To create a level of integrity)
- 3) There are three areas where tikanga needs to be developed:
  - Te tuku i te taonga (the sharing of the gift)
  - Te hau o te taonga (the spirit of the gift)
  - Te whakahoki i te taonga (the return of the gift) (Dewes, Hudson, & Southey, 2014)

These ideas provided the framework around which the research team was able to develop the cultural foundation for biobanking and genomic research through a series of research activities that followed the wānanga, including five Iwi feedback hui and seven stakeholder workshops (Figure 1).

The general narrative that describes the logic of the cultural foundation is as follows:

1. Protecting *whakapapa* is the primary concern for communities.
2. Tissue, DNA and data are *taonga* (valued resources).
3. Taonga have a *tapu* (spiritual importance).
4. *Tākoha* is a process that gifts responsibility for the taonga.
5. *Kawa* are the principles that inform those responsibilities.
6. *Tikanga* are the protocols that support those responsibilities.
7. *Mauri* (in this context) refers to the level of integrity in the system.
8. *Wairua* (in this context) refers to the level of comfort amongst donors and communities.
9. *Mana* (in this context) refers to the level of control that donors and communities retain.
10. Operationalizing these elements will create a culturally safe environment for Māori donors and communities to engage in biobanking and genomic research.

### Creating a narrative to describe the cultural logic

A key challenge in developing the narrative and logic behind the cultural foundation was to understand and reinterpret, when necessary, the meaning of concepts identified as key cultural cues. The concepts identified were consistently used as cues by participants across different Iwi and Māori stakeholders to orientate their responses to the question “What do

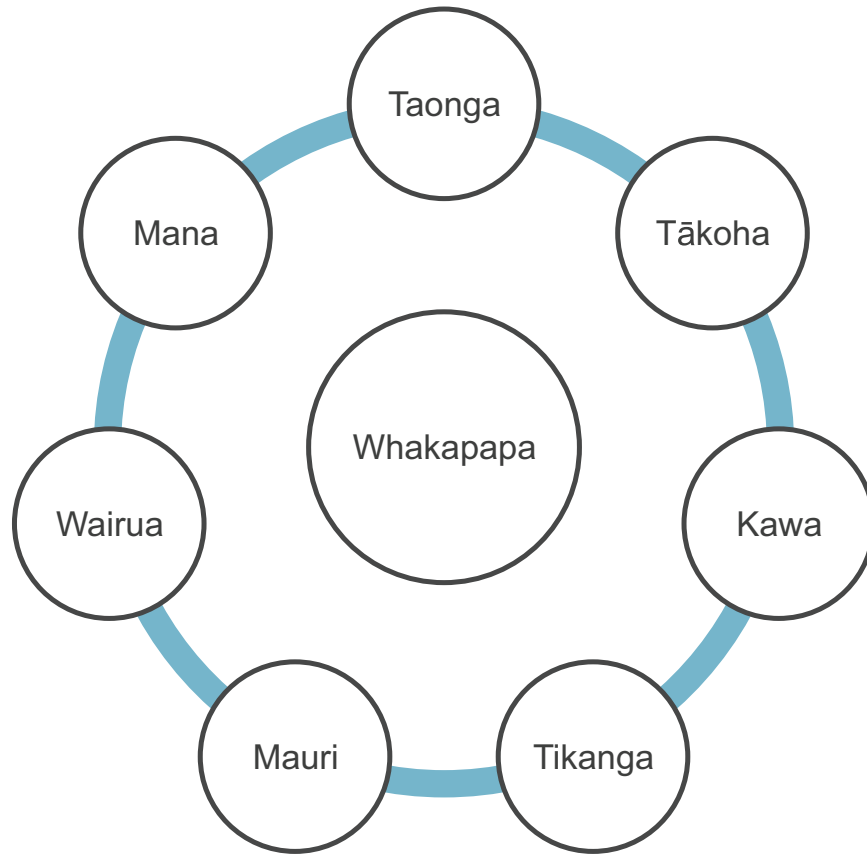


FIGURE 1 The cultural foundation for biobanking and genomic research

Māori think about biobanking and genomic research?” Wānanga participants also reiterated the importance of these cultural cues when they discussed this kaupapa:

Mauri is the life essence that ensures balance and harmony. It is protected through tikanga. (wānanga tuatahi)

It’s about taking proper care of the taonga, maintaining the tapu and mauri to make sure that it is not abused. (wānanga tuatahi)

Kia pūmau te mana. Na te tapu i puta mai te tikanga (Let the mana be retained forever. It is from tapu that tikanga comes through). (wānanga tuatahi)

Cultural cues were selected on the basis of their importance within a Māori worldview, relevance to the context of biobanking and

genomic research and coherence with the other models (Du Plessis et al., 2004; Tipene-Matua, 2006; Tipene-Matua & Wakefield, 2007). The cultural cues are outlined in more detail below.

### ***Whakapapa***

Whakapapa is a key reference point for Māori when talking about health and genetics. Whakapapa was described as the connection between people and as creating a responsibility for both future and past generations. Whakapapa is often used as a framework to describe 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; therefore, the storage and use of human tissue for research becomes a culturally significant activity.

But what part of my person will be of advantage in the future for my own progeny, my own descendants and/or all of what's left of me in the biobank? . . . Is there anything that will be best served in terms of preservation for my own whakapapa? (wānanga tuatahi)

A core responsibility for whānau, hapū and Iwi is to ensure that whakapapa is protected, in part by managing the access and use of information relating to whakapapa. Therefore, when individuals consent to participate in genomic research or biobanking, Iwi considered the contribution of biological material and personal information to be culturally significant.

Protection of whakapapa is the primary consideration, and Māori expressed a number of concerns about the potential for harm to whakapapa and a strong desire to protect it. Māori concepts of toto (blood), momo (type) and ahua (shape) demonstrated an understanding of genetics. Toto was associated with DNA and statements like “tō ana te toto” (he resembles his family) or “kei rō toto” (it's in the blood). Through statements such as “he momo tangata” (that type of person) or “nō taua whānau tera momo” (that type belongs to that family), momo was equated with genotype. Ahua, meanwhile, through statements like “titiro ki tona āhua” (look at his appearance), was linked to the genetic concept of phenotype, referring to differences in the expression of a gene. Whakapapa also informs systems of decision-making based on whānau, hapū and Iwi knowledge.

### **Taonga**

The concept of taonga as something precious or significant also emerged. Taonga can be applied to valued objects, significant resources or important entities. Taonga should be looked after in an appropriate manner to preserve their integrity and value as well as respect the tapu that has been imbued into them. The tapu creates an understanding that there will always be a metaphysical korowai manaaki (protective

cloak) placed over processes associated with looking after or managing that taonga. Through the subsequent discussions with Iwi it became clear that human tissue is considered a taonga, and that DNA from any genetic origin connecting to whakapapa is also a taonga. Participants recognized the cultural and spiritual significance of DNA as well as its usefulness as a resource for research. Data, as a representation of people's biological material, is also considered a taonga and participants recognized genetic information as a highly valuable strategic asset to Māori.

### **Tapu**

Tapu refers to the sacred or special nature of an object and implies that the object must be actively protected or managed. Wānanga participants spoke about the need to identify and make distinctions between tapu (sacred, restricted) and noa (free from restriction). Tapu refers to that belonging to Io-Matua-Kore (the Origin), a supreme spiritual being in Te Ao Māori. Participants associated research with human DNA as highly sacred and any transgressions could have major repercussions, including “he tangata te utu” (a life in exchange). Distinguishing the parameters of tissue collection—what can be taken, stored and researched—informs how this could be carried out safely. The important thing is to identify the right kawa and tikanga to allow people to whakanoa (remove restrictions) and whakatapu (impose restrictions) the tissue at appropriate times.

I think the question centres around tapu and noa. If you sort out tapu and noa then you'll know what you're talking about . . . what's going to the blood bank and what's tapu. (wānanga tuatahi)

My interpretation of that was that tapu is there to look after that te taha wairua, te taha mauri and we can whakanoa kikokiko stuff (tapu looks after the spiritual aspects and

we can deal with the physical components)  
(wānanga tuarua)

### **Tākoha**

Allowing one's tissue to be used in genomic research was considered to be akin to a koha (gift) rather than a donation. A koha is often conceptualized as an unconditional gift; however, for Māori the gift of tissue was thought to have restrictions. Tākoha emerged as a form of gifting that recognized the tapu associated with the gift, implying specific conditions of use should be applied. Tākoha demonstrates a fundamental repositioning of the gift from the object to the values and ethical expectations associated with looking after it. Te hau o te taonga supports tākoha as it is the responsibility of the original recipient of the taonga to ensure that subsequent users of the taonga respect the spirit of the gift (M. Henare, 2007). It also implies that the original recipient has the responsibility to communicate to the donor the uses and results of research conducted by other users of that tissue. While M. Henare (2007) uses this concept in the context of gifting land, it also made sense to participants when applied to the gifting of human tissue.

### **Kawa**

Kawa commonly refers to traditional principles that underpin tikanga and inform how people should act. The participants supported the adaptation of kawa to the context of biobanking and genomics research. Through the wānanga, new kawa were created to provide direction to scientists and researchers for appropriate use of taonga within research. Kawa created through the wānanga were aligned to English translations to facilitate understanding in the research context:

- Kia tau te wairua o te tangata: the “level of comfort” felt by both tissue donors and their communities.

- Kia pūmau te mana o te tangata: the “level of control” experienced by both donors and their communities.
- Kia hiki te mauri o te kaupapa: the “level of integrity” in the system and ensuring the right processes are followed.

### **Wairua**

Wairua, a core philosophical concept that pervades all aspects of Māori society and is a central element of cultural protocols, refers to the spiritual dimension within Māori models of health as a key component of a person's wellbeing (Ahuriri-Driscoll et al., 2012; Durie, 2004). Wairua—non-physical qualities, relational and connective qualities, and contribution to wellbeing and personal contentment—is of fundamental importance to Māori (Kingi, 2002; Mark & Lyons, 2010; McLeod, 1999; Palmer, 2004; Valentine, 2009). Wairua was frequently referenced within workshops and hui as a concept to consciously address as it could both influence relationships and outcomes of genomic research and be impacted by them. Injury to a person's wairua negatively affects the whole of their wellbeing, so ensuring whānau are comfortable with their involvement in genomic research is a key consideration, as is the need for wairua to be understood and respected by researchers. Wairua was identified as an intangible spiritual element that must be actively considered in the process.

They talk . . . with more concern about the tapu o ngā taonga rather than the wairua . . . The research process should be governed by tapu, who owns the information and [maintains] the spirituality of tissues and why tissues and parts are separated. (wānanga tuatahi)

I suspect the wairuatanga (spirituality) of our whānau knowledge will in time become more recognized as a fundamental part of that genomic experience and experimentation. (wānanga tuarua)



## **Mana**

Mana commonly refers to power, control or prestige and is referenced as an important concept in Māori ethical frameworks and research, including Te Ara Tika (Hudson et al., 2010), the Mana Atua framework (Tipene-Matua, 2006) and the Constructive Conversations/Kōrero Whakaaetanga project (Du Plessis et al., 2004). Different types of mana—mana atua (spiritual power), mana whenua (Iwi power), and mana tangata (personal power)—describe different levels of control and responsibility for decision-making in the context of genomic research and biobanking. Hui participants highlighted the rights of whānau to choose whether they engage in genomic research and/or provide samples for future biomedical research, and the role of Iwi in supporting them in the context of that relationship. Iwi assistance may be necessary and important 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 participant-researcher relationship, community members wanted their Iwi entity to use their mana whenua status to support and protect their interests. Mana whenua relates to the rights and authority that Māori associate with decision-making over resources, usually within hapū and Iwi boundaries. Through treaty relationships the concept of mana whenua reinforces Indigenous rights to participate and partner with agencies in the delivery of services, including research.

## **Mauri**

Mauri is the physical aspect of the taonga and is applied to both animate and inanimate objects. Ensuring that mauri is maintained or enhanced will be a challenge for genomic researchers and biobanks. Trees, mountains, rivers, lakes and oceans all carry their own form of mauri, as does all that inhabits them. In Te Ao Māori a birth is announced as a proclamation with the saying “tihei mauri ora” (sneeze forth the

breath of life). Te Ao Māori attaches mauri to all living things animate and inanimate, and in the context of biological samples the mauri of the donor remains with both the sample and associated data.

## **Tikanga**

With the establishment of kawa it was necessary to identify tikanga that can be applied to the key stages of the biobanking process to ensure expectations of reciprocity and the physical and spiritual dimensions of the process are met. At the point of te tuku i te taonga, a relationship is being established that creates expectations of reciprocity, the parameters of consent, and the level of comfort and safety for donors. Karakia may be used for whakawātea (spiritual cleansing) at an individual or project level to address the spiritual aspects of consent, while the physical aspects can be dealt with by addressing all the appropriate parameters within an informed consent process. Te hau o te taonga is concerned with the integrity of decisions about the use of the gift, ensuring respect for the spirit in which the gift was given and adhering to the parameters of consent. At a spiritual level, the use of kaitiaki (guardians) in the decision-making process, regular communication and updates on use provide ways to maintain a high level of comfort amongst donors and communities. The whakahoki i te taonga (the return of the gift) stage provides an opportunity to present back reports, provide access to data and re-consent communities. These actions contribute to demonstrating respect for the relationship, reporting on all uses and outcomes, and checking on satisfaction with process. The spiritual dimension of this process is addressed through the nature of the engagement, and Iwi expressed the desire for this to be done in a formal manner:

Kaua e haere tāhae mai mā ngā rārā, engari haere rangatira mai mā te upoko (Return like a chief through the front door, not like a thief through the side door) (wānanga tuarua)

## Validating the cultural foundation for biobanking and genomic research

While the wānanga only involved a small group of external participants, it played a critical role in the conceptualization of the cultural foundation. The cultural foundation and subsequent guidelines derive their mana from an extensive consultation and feedback process. Validating the cultural foundation within Māori and scientific communities was a key component of ensuring it was useful and had relevance, underpinned by the cultural authority of the participants and the cultural integrity of the process. As conceptual change is an emotional process as much as an intellectual one it was important that the internal logic and authenticity of the cultural foundation was validated across a broad spectrum of Māori society (L. T. Smith et al., 2013).

Feedback hui with Iwi, presentations to whānau and workshops with stakeholders ensured the framework was properly grounded in a Māori worldview. Each event was valuable for the description of cultural cues, refinement of the cultural logic narrative or refinement of the cultural foundation. Validation activities covered a broad spectrum of settings covering Māori, Iwi, hapū and whānau collectives, and the cultural foundation has also resonated well with other Indigenous communities when presented in international forums in Australia, Canada and the United States. The cultural foundation underpins the development of two guidelines which are under review: *Te Mata Ira: Guidelines for Genomic Research with Māori* (Hudson et al., 2016b); and *He Tangata Kei Tua: Guidelines for Biobanking with Māori* (Beaton et al., in press; Hudson et al., 2016a).

## The importance of accessing the cultural logic

This project adds a cultural dimension to ethical, legal and social implications (ELSI) of medical

genomic research and biobanking (Budimir et al., 2011). Cultural worldviews embody a logic that prioritizes values and concepts, providing an alternative pattern of thinking and shape for what is recognized as appropriate ethical behaviour. Positioning scientific concepts within a Māori worldview or vice versa is a challenge for those operating at the interface of these knowledge systems. According to Hudson et al. (2010), the difficulty arises in attempting to locate “new knowledge within different systems of meaning” (p. 55). Cultural cues, which act as stimuli for accessing cultural knowledge, facilitate shifts between different systems of meaning and provide a framework for the integration of new knowledge.

Wānanga discussions reiterated the Māori concepts as important constructs that form the cultural foundation which can be used to consider issues associated with biobanking and genomic research. Linking of concepts across scientific and Māori worldviews creates associations with approximate meanings to support conceptual understanding rather than direct translations of either set of words. The cultural foundation informs how cultural cues can be applied and the ways Māori might approach decision-making. Participants expressed the need to create more spaces for this type of wānanga or thought process:

What I should have said in the beginning is, “Ko tēnei te wā me wānanga tātou, e pā ana ki ngā kupu pērā me tapu (It is time for us to have a deep discussion about words like tapu).” (wānanga tuatahi)

Participants were able to ground their thinking about genomic research and biobanking in a Māori worldview by identifying a range of culturally relevant reference points. Cultural cues provided a way of framing the discussions, and a matrix of concepts that reveal a cultural logic informing decision-making in this area emerged (Hudson et al., 2010; Ramsden, 2002; Tupara, 2012). While the context of genomic research

and biobanking was unfamiliar to many of the participants, there was a consistent message about the importance of kawa and tikanga.

Māori cultural logic informs the principles for evaluation (kawa), and decision-making (tikanga) around genomic research and biobanking. Iwi recognized that biobanking and genomic research is an ongoing endeavour, that a range of decisions need to be made throughout the tissue consent period and that the context of those decisions might be different to those that exist for established kawa and tikanga. They reiterated the idea that “there is no tapu that humans are unable to address and/or mitigate given time to understand the situation, conscientize the process, and develop specific protocols to address any cultural, ethical or spiritual concerns” (Hudson et al., 2010). The importance of identifying and acknowledging cultural values and engaging with the community in the development of appropriate ethical boundaries was reinforced. The cultural foundation for biobanking and genomic research will be strengthened through experience, and enhancing the depth of thinking and levels of connectivity with the Māori worldview. Connecting with kupu (words), kōrero (concepts), whakataukī (sayings), kawa and tikanga to provide a range of cultural cues that create meaning and help Māori navigate the complex language and ethics of biobanking and genomic research is central to achieving this. Kawa and tikanga within the cultural foundation have been discussed with stakeholders in the fields of Māori ethics, Māori research, genomic science and biobanking, and they have begun to be operationalized in some of these settings (K. Henare et al., 2015).

### The value of creating new cultural cues

Te Ao Māori is an interconnected worldview weaving spiritual and physical dimensions through stories and whakataukī.

The reinterpretation of concepts within the cultural foundation has been enhanced by identifying a range of stories and whakataukī to reinforce and scaffold these ideas. “Te Mata Ira” translates to “the faces of the gene” and represents the multiple ways in which genetics is understood within the Māori community. This is reinforced by the messages contained within two whakataukī that have been linked to the context of the project.

The first whakataukī, which forms the epigraph to this paper, is “Me āta hāere mā ngā karu: Kei tōtohu i te aroha o Tangaroa.” This was created during the project and translates to “Tread carefully in challenging waters.” We have been reminded throughout the project of the care required when engaging in research which uses tissue or DNA from Māori communities. The whakataukī was created by kaumātua (elders) who participated in the Iwi hui. Huata Holmes (Ngai Tahu) offered the first part of the whakataukī, which was originally “me āta hāere tātou” (safely negotiate our journey). In suggesting the whakataukī, Huata metaphorically likened the research journey to negotiating the swells in the ocean and the care that must be taken whether you are on the crest of a wave looking out or the bottom of a swell. The second part of the whakataukī was suggested by Moe Milne (Ngati Hine), whose message was to be mindful of both the lure and risks of research.

The second is a traditional whakataukī: “Kei tua o te awe mapara he tangata ke, he ma”, which normally translates to “Beyond the tattooed face is another, one with clear skin”, and was commonly understood to be a prophecy about the coming of the Pākehā (Europeans). Awe mapara (soot) is used in tāmoko (tattoo) ink. Adapted to the context of biobanking, with the awe mapara as the ink in the pen, the whakataukī poses the question: “Beyond the consent process there is another who makes the decision, do you know who that is?” The reinterpretation of the whakataukī provides another way to connect cultural wisdom to new contexts by focusing attention on the role of

decision-making in the context of biobanking and genomic research.

## Conclusion

The process of developing a cultural foundation has been a valuable and enriching experience. Māori communities are interested in contributing to the development of policies and protocols that make the new contexts within which they find themselves culturally safe, and within mātauranga Māori there exists a range of concepts, values and knowledge that can be applied to meet the ethical challenges of emerging biorepository-based “omics” research. The cultural foundation’s key cultural cues and the logic behind their use in the context of biobanking and genomic research reinforce the protection of whakapapa as the overriding motivation or concern of Māori communities, outline the responsibilities that are transferred to researchers when they accept tissue for research, and describe the principles and protocols that inform decision-making and culturally safe practice. While it has been developed specifically for the biomedical context, the concepts and logic within the cultural foundation could be relevant to other types of genomic research and biobanking activities (e.g. environmental) and biotechnology. The processes adopted to develop the cultural foundation provide direction for maintaining cultural authority in the research process and ensuring the cultural authenticity of translational activities at the interface of science and Māori (or Indigenous) knowledge.

## Acknowledgements

The Te Mata Ira research team would like to extend our sincere thanks and gratitude to the wānanga participants, stakeholders and Iwi—Ngāti Hine, Ngāti Whātua ki Orakei, Ngāi Tahu, Ngāti Porou, Ngāti Rakaipaaka—who

generously contributed to the project. Thanks also to Kim Southey and Te Kuru o te Marama Dewes who contributed to the wānanga. Lastly, thank you to the Health Research Council of New Zealand, who funded the research project. Ngā mihi ki a koutou katoa.

## Glossary

ahua	shape
awe mapara	soot
hapū	subtribe
he aha te mea nui o te ao? He tangata! He tangata! He tangata!	What is the most important thing in the world? It is people! It is people! It is people!
he kōrero nō te ao kōhatu	a saying from the old world
he momo tangata	that type of person
he tangata kei tua	the person beyond the veil
he tangata te utu	a life in exchange
he tapu te kaupapa hui	a sacred purpose meetings
Io-Matua-Kore	the Origin, supreme spiritual being
Iwi	tribe
kaitiaki	guardian
kaitiakitanga	guardianship
karakia	prayer
kaumātua	elders
kaupapa	purpose/project
kawa	principles
kei rō toto	it’s in the blood
koha	gift
kōrero	concepts
korowai manaaki	protective cloak
kotahitanga	unity
ko te kura huna ki roto ki te toto	a precious gift within the blood
kupu	words
mana	power
mana atua	spiritual power
mana tangata	personal power
mana whenua	Iwi power

manaakitanga	caring
mātauranga Māori	Māori knowledge
mauri	life essence
me āta hāere tātou	safely negotiate our journey
momo	type
mouri	variation of mauri shared by Huirangi Waikerepuru
noa	free from restriction
nō taua whānau tera momo	that type belongs to that family
Pākehā	Europeans, New Zealanders of European descent
tākoha	gift of responsibility
tāmoko	tattoo
tapu	sacred, free from restriction
taonga	treasured item
Te Ao Māori	Māori worldview
te hau o te taonga	the spirit of the gift
Te Mata Ira	faces of the gene
te reo Māori	Māori language
te tuku i te taonga	the sharing of the gift
tihei mauri ora	sneeze forth the breath of life
tikanga	cultural protocols
titiro ki tona āhua	look at his appearance
tō ana te toto	he resembles his family
toto	blood
wairua	spirit
wairuatanga	spirituality
wānanga	workshops
wānanga tuarua	second workshop
wānanga tuatahi	first workshop
whakahoki i te taonga	the return of the gift
whakanoa	remove restrictions
whakapapa	genealogy
whakatapu	impose restrictions
whakataukī	sayings
whakawātea	spiritual cleansing
whānau	family
whānaungatanga	relationships
whare wānanga	house of learning

## References

- Ahuriri-Driscoll, A., Hudson, M., Bishara, I., Milne, M., & Stewart, M. (2012). *Nga Tōhu o te Ora: Traditional Māori healing and wellness outcomes*. Retrieved from [http://researchcommons.waikato.ac.nz/bitstream/handle/10289/9479/Nga%20Tohu%20o%20te%20Ora%20Research%20Report%20June%202012\\_FINAL%20pdf.pdf?sequence=2&isAllowed=y](http://researchcommons.waikato.ac.nz/bitstream/handle/10289/9479/Nga%20Tohu%20o%20te%20Ora%20Research%20Report%20June%202012_FINAL%20pdf.pdf?sequence=2&isAllowed=y)
- Beaton, A., Hudson, M., Milne, M., Port, R. V., Russell, K., Smith, B., . . . Wihongi, H. (in press). Engaging Māori in biobanking and genomic research: A model for biobanks to guide culturally informed governance, operational and community engagement activities. *Genomics in Medicine*.
- Beaton, A., Smith, B., Toki, V., Southey, K., & Hudson, M. (2015). Engaging Maori in biobanking and genetic research: Legal, ethical, and policy challenges. *International Indigenous Policy Journal*, 6(3), 1–19. <http://doi.org/bm54>
- Budimir, D., Polasek, O., Marusić, A., Kolčić, I., Zemunik, T., Boraska, V., . . . Rudan, I. (2011). Ethical aspects of human biobanks: A systematic review. *Croatian Medical Journal*, 52(3), 262–279. <http://doi.org/b7wbfw>
- Cram, F. (2001). *Rangahau Māori: Tōna tika, tōna pono*. In M. Tolich (Ed.), *Research ethics in Aotearoa* (pp. 35–52). Auckland, New Zealand: Longman.
- Cram, F. (2003). *Preliminary discussions with Māori key informants*. Paper prepared for the National Ethics Advisory Committee. Auckland, New Zealand: Katoa.
- Cram, F. (2005). *Māori and genetic testing, Part 1: Exploring issues*. Working paper developed for the Constructive Conversations/Kōrero Whakaaetanga Research Project. Auckland, New Zealand: Katoa.
- Dewes, T. K., Hudson, M., & Southey, K. (2014). *Te Mata Ira: Cultural constructs and biobanking*. Poster presented at the University of Waikato Summer Internship Poster Competition, Hamilton, New Zealand.
- Du Plessis, R., Scott, A., Phillips, H., Cram, F., Tipene-Matua, B., Parsons, M., & Taupo, T. (2004). *The social, cultural, ethical and spiritual implications of genetic testing: Preliminary findings* (Constructive Conversations/Kōrero Whakaaetanga Research Report No. 3). Christchurch, New Zealand: Social Science Research Centre, University of Canterbury.

- Retrieved from <http://www.conversations.canterbury.ac.nz/reportspapers.htm>
- Durie, M. (2004). Understanding health and illness: Research at the interface between science and indigenous knowledge. *International Journal of Epidemiology*, 33(5), 1138–1143. <http://doi.org/dd2kw2>
- Eketone, A. (2008). Theoretical underpinning of kaupapa Māori directed practice. *MAI Review*, (1), 1–11.
- Henare, K., Parker, K., Print, C., Hudson, M., Wihongi, H., Findlay, M., & Lawrence, B. (2015, November). *PUKUmahi! Kia whai te huarahi tika NETwork! Roadmap for safe travel: Ensuring health benefits flow on to Māori*. Poster presented at the New Zealand Society for Oncology, Christchurch, New Zealand.
- Henare, M. (2007, March 28). *Tikanga hau: The spirit of the gift* [PowerPoint slides]. Retrieved from [www.philanthropy.org.nz/files/Manuka%20Henare.ppt](http://www.philanthropy.org.nz/files/Manuka%20Henare.ppt)
- Hudson, M. (2004). *He matatika Māori: Māori and ethical review in health research* (Master's thesis, Auckland University of Technology, Auckland, New Zealand). Retrieved from <http://aut.researchgateway.ac.nz/handle/10292/151>
- Hudson, M., Ahuriri-Driscoll, A. L. M., Lea, M. G., & Lea, R. A. (2007). Whakapapa—a foundation for genetic research? *Journal of Bioethical Inquiry*, 4, 43–49. <http://doi.org/fp8kr9>
- Hudson, M., Beaton, A., Milne, M., Port, W., Russell, K., Smith, B., . . . Wilcox, P. (2016a). *He Tangata Kei Tua: Guidelines for biobanking with Māori*. Hamilton, New Zealand: Māori and Indigenous Governance Centre.
- Hudson, M., Beaton, A., Milne, M., Port, W., Russell, K., Smith, B., . . . Wilcox, P. (2016b). *Te Mata Ira: Guidelines for genomic research with Māori*. Hamilton, New Zealand: Māori and Indigenous Governance Centre.
- Hudson, M., Milne, M., Reynolds, P., Russell, K., & Smith, B. (2010). *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.
- Hutchings, J., & Reynolds, P. (2005a). *Māori and the “McScience” of new technologies: Biotechnology and nanotechnology research and development*. Retrieved from [http://www.rangahau.co.nz/assets/hutching\\_reynolds/maori\\_mcscienc.pdf](http://www.rangahau.co.nz/assets/hutching_reynolds/maori_mcscienc.pdf)
- Hutchings, J., & Reynolds, P. (2005b). *The obfuscation of tikanga Māori in the GM debate*. Retrieved from <http://www.kaupapaMāori.com/action/18>
- Kingi, T. K. R. (2002). *“Hua oranga”: Best health outcomes for Māori* (Unpublished PhD thesis). Massey University, Wellington, New Zealand.
- Mark, G. T., & Lyons, A. C. (2010). Maori healers' views on wellbeing: The importance of mind, body, spirit, family and land. *Social Science and Medicine*, 70(11), 1756–1764. <http://doi.org/fdwg2n>
- McLeod, M. K. (1999). *E iti noa nā te aroha: A qualitative exploration into the realms of Māori healing* (Unpublished master's thesis). University of Waikato, Hamilton, New Zealand.
- Palmer, S. (2004). Hōmai te Waioara ki Ahau: A tool for the measurement of wellbeing among Māori—the evidence of construct validity. *New Zealand Journal of Psychology*, 33(2), 50–58.
- Port, W. (2009) Māori culture and genetic technology. *MAI Review*, (3), 1–11.
- Ramsden, I. (2002). *Cultural safety in nursing education in Aotearoa and Te Waipounamu* (Unpublished PhD thesis). Victoria University of Wellington, Wellington, New Zealand.
- Roberts, M. R. (2005). Walking backwards into the future: Māori views on genetically modified organisms. Indigenous voices, Indigenous visions. *World Indigenous Nations Higher Education Consortium Journal*, 10, 1–10.
- Roberts, M. R., & Fairweather, J. R. (2004). *South Island Māori perceptions of biotechnology*. Lincoln, New Zealand: Agribusiness and Economics Research Unit, Lincoln University.
- Rochford, T. S. (2012). Ten reasons why genetics does not explain health disparities between Māori and non-Māori. *New Genetics and Society*, 31(1), 99–110. <http://doi.org/btvct6>
- Rycroft-Malone, J. (2001). Formal consensus: The development of a national clinical guideline. *Quality Health Care*, 10, 238–244. <http://doi.org/btpfnx>
- Smith, C., & Reynolds, P. (2000). *Māori, genes and genetics: What Māori should know about the new biotechnology*. Whanganui, New Zealand: Whanganui Iwi Law Centre.
- Smith, L. T. (1999). *Decolonizing methodologies*. London, England: Zed Books.
- Smith, L. T. (2012). *Decolonizing methodologies* (2nd ed.). New York, NY: Zed Books.
- Smith, L. T., Hemi, M., Hudson, M., Roberts, M., Tiakiwai, S., & Baker, M. (2013). *Dialogue at the cultural interface. A report for Te Hau Mihi Ata:*

- Mātauranga Māori, Science and Biotechnology*. University of Waikato, Hamilton, New Zealand.
- Taupo, K. (2012). Negotiating the interface of genetic testing, biobanking and Māori ontology and epistemology. *New Genetics and Society*, 31(1), 25–40. <http://doi.org/cjtwks>
- Tawhara, K. (2006). *Attitudes of Māori towards genetic research*. Report prepared for the Māori Indigenous Health Institute (MIHI) and the Cardioendocrine Research Group, Christchurch School of Medicine and Health Sciences. Dunedin, New Zealand: University of Otago.
- Tipene-Matua, B. (2006, June). *Having honest conversations about the impact of new technologies on Indigenous people's knowledge and values*. Paper presented at the Mātauranga Taketake: Traditional Knowledge Conference: Indigenous Indicators of Wellbeing: Perspectives Practices Solutions, Christchurch, New Zealand.
- Tipene-Matua, B., & Wakefield, B. (2007). Establishing a Māori ethical framework for genetic research with Māori. In M. Henaghan (Ed.), *Genes, society and the future* (Vol. 1, pp. 379–422). Wellington, New Zealand: Brookers.
- Tupara, H. (2012). Ethics and health research: Decision making in Aotearoa New Zealand. *AJOB Primary Research*, 3(4), 40–52. <http://doi.org/bm55>
- Valentine, H. (2009). *Kia ngāwari ki te awatea: The relationship between wairua and Māori well-being: A psychological perspective* (Unpublished PhD thesis). Massey University, Palmerston North, New Zealand.
- Vinokur, A., Burnstein, E., Sechrest, L., & Wortman, P. M. (1985). Group decision making by experts: Field study of panels evaluating medical technologies. *Journal of Personal Social Psychology*, 49(1), 70–84. <http://doi.org/db3phh>
- Wilcox, P. L. (2016). *New Zealand Māori community engagement with medical genomics research: A review*. Unpublished manuscript. University of Waikato, Hamilton, New Zealand.