

# ESTABLISHING A MĀORI ETHICAL FRAMEWORK FOR GENETIC RESEARCH WITH MĀORI

Bevan Tipene-Matua

Benita Wakefield

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## I EXECUTIVE SUMMARY

This report responds to trends around research on genetic variation and the potential for such research to reveal information linking genetic variation to common diseases amongst Māori.

This report focuses on what has been referred to as the “new genetics”, or the expanding nature of research on genetic variation that analysis the genetic links to common diseases (cancer, diabetes), as opposed to single gene disorders or purely genetic diseases such as Huntington’s disease. The ‘new genetics’ is a phrase developed to emphasise the expanding role and rapid development of genetics. Shickle defines it as “applications resulting from development in techniques for locating genes, their products and functions” (Shickle, 2000:3).

The key for this report around the term ‘new genetics’ is that it is specifically about studying and identifying genetics of more common diseases (not just a study of rare diseases), and the possibility of much more rapid and large-scale analysis of factors contributing to diseases which Māori and other indigenous peoples suffer from disproportionately (Peterson, 2002).

This report explores the broader context of Māori health by discussing Hauora Māori frameworks and knowledge systems for addressing health disparities and contrasts these against the philosophical and scientific ideals driving “new genetics”. As links between genetic variation and the health of certain populations, particularly indigenous and ethnic populations, continue to be made the issues arise that are primarily driven by ethical, cultural, social and political influences.

This research involved analysing relationships between potential health benefits from genetic testing of newborns and any cultural, spiritual or ethical issues this testing may raise. It looked at the tensions between Māori collective tribal responsibilities and individual rights with regard to the access to and use of human genetic material.

Finally, the report proposes that genetic testing research could have significant benefits for Māori and other communities particularly if a broad approach to establishing and implementing moral, ethical and spiritual frameworks to drive such research is adopted.

The final part of the report introduces the Mana Protocols for genetic research and outlines how such protocols could be developed and used to assist Māori (whanāu, hapū and iwi), researchers, funders and regulators of genetic research.

## 2 SETTING THE SCENE: HAUORA MĀORI AND GENETICS

### 2.1 Hauora Māori: Māori health and well-being

Holistic approaches to improving health and well-being consider spiritual, physical, emotional, environmental and socioeconomic influences as key factors contributing to the wellness of an individual within the community.

Such approaches are encapsulated by the term Hauora Māori and we suggest that it will be important that such approaches are understood and implemented if Māori are to benefit from genetic research on common diseases such as diabetes, cardiovascular disease and cancer.

Hauora Māori incorporates the wider aspirations of whānau, hapū and iwi development. The disparities in the status of Māori and non-Māori health reflect higher Māori mortality rates and rates of diabetes and other chronic health conditions. Consequently, Māori seek opportunities within the public health sector to respond to these challenges by initiating strategies to eliminate these disparities. The delivery of Māori-driven health programmes reflects a more holistic approach to the improvement of health and well-being within whānau, hapū and iwi.

Three models of Māori health that emerged from the late twentieth century to provide a more holistic understanding of Hauora Māori were He Whare Tapa Whā, Te Wheke and Ngā Pou Mana.

The Whare Tapa Whā model evolved out of several hui held with Māori health workers through the Māori Women's Welfare League Rapuora Research Project in the early 1980s (Murchie, 1984). The model has been widely recognised as portraying the four cornerstones of health reflected in the structure of a house, with each side representing a dimension of health required to ensure 'strength and symmetry' (Durie, 1994: 70). The first dimension is taha wairua or the spiritual side. Durie describes taha wairua as the, '... capacity to have faith and to be able to understand the links between the human situation and the environment' (Durie, 1994: 71).

Durie stresses the importance of mauri and inter-relationships with the land, ocean, waters and forests—all being integral to a person's health and well-being, sense of identity and connection with the whenua. The other sides of the house are taha hinengaro, referring to mental and emotional well-being; taha whānau extended whānau support; and taha tinana bodily health, or the physical well-being of the individual. Taha tinana also acknowledges the existence of tapu and noa and the importance of upholding tikanga, rituals and practices that provide safety and protection for the whānau. For example, partaking of food is often the most common practice after performing a sacred ritual (such as karakia, or incantations and appeasements to the Atua) in order to clear the way for the return to normal activities.

The integration and strengthening of all aspects of health and well-being as depicted by the four sides of the Tapa Whā house ensures balance and wellness for the whānau. Each aspect is dependent on the other: spiritual, physical, emotional and family. All walls of the Whare Tapa Whā must be intact in order to live a full and healthy life.

The Wheke model was presented by Dr Rangimarie Rose Pere in 1991. The model is perceived to be holistic, integrating eight dimensions symbolic of the tentacles of a wheke or octopus. The tentacles overlap and intertwine, symbolising inter-connectedness, and include the dimensions of wairua, tinana, hinengaro and whānau (represented as whanaungatanga) which are similar to the Whare Tapa Whā model. Another dimension includes the concept of mana, or life principle. The extensions given to the meaning of mana are: mana Atua – the divine right from Io-Matua, Supreme God; mana Atua ake – emphasising the development of positive identity and appreciation of absolute uniqueness both individually and within a group identity; and mana whenua – the mutual relationship between the people of the land and the land of the people. Pere also refers to the concept of tūrangawaewae, the footstool and place of belonging that is inter-linked with identity and the care and use of the land (Pere, 1991). The other dimensions comprise the mauri or life-sustaining principle within people and objects that also incorporates language; hā a koro mā, a kui mā, which is literally the breath of life and positive role-modelling provided by elders and ancestors in supporting whānau; and whatumanawa, which encourages the full expression of emotions that is vital for healthy growth and development. Te Wheke proposes that sustenance is required for each tentacle in order that the organism might attain wai-ora, the total well-being of the individual represented by the eye; the body and head of the wheke represent the whole whānau (hapū and iwi) unit.

The Pou Mana model was presented by the Royal Commission on Social Policy (Henare, 1988). The model includes four key interactive concepts or supporting values necessary to improve the health status and mana of the individual, and well-being of the whānau group. These include: whanaungatanga – inter-connections between whakapapa or sense of belonging, manaaki (hospitality), iwi, hapū, waka and tohatoha (fair distribution of material things); taonga tuku iho – taonga, te reo rangatira, ngā tikanga, ngā ritenga (behaviour and practices that are based on traditional knowledge, cultural heritage, protocols and customs); te ao tūroa or the environment – stewardship that is imbued with holistic beliefs, and interwoven with whakapapa linking all things both in the natural environment and in the social world; and tūrangawaewae – central to cultural identity and social and economic development for whānau, hapū and iwi.

The Royal Commission placed particular emphasis on te ao tūroa, recognising the inter-relationship with tūrangawaewae and the marae described by Durie as ‘the epitome of a collective identity’ (Durie, 1994: 76). Te ao tūroa is viewed as being inextricably connected with mana Māori, which is considered essential to the identity and integrity of people (Henare, 1988).

The inter-relationships between the natural world and health of people are integral to cultural identity, values, beliefs and practices. All three models reflect an integrated and holistic approach to understanding the various dimensions which comprise Hauora Māori, or health and well-being from a Māori perspective.

In the next section we explore genetic research in the context of Hauora Māori and working to improve Māori health outcomes.

## 2.2 Hauora Māori and research on genetic variation

Understanding the approach of Hauora Māori takes specialist knowledge and expertise and it is expected that few geneticists are likely to possess such skills. Conversely genetic science is highly technical and advancing rapidly leaving many Hauora specialists concerned about its utility to Māori health. We suggest that efforts from both parties to situating genetic research, particularly whānau or hapū-based research, within the Hauora Māori paradigm are necessary to increase the likelihood of Māori communities benefiting from genetic research.

*There are a whole lot of pharmaco-genetic interventions available to non Māori that we have not tested to see if they work on Māori. There is a huge role that genetics can do to stop victim blaming of Māori patients so I see there is this nice particular marriage but instead, geneticists are not being brought to the party about what Māori community health needs are and they are stuck in their little labs saying ‘oh that’s interesting’... (Research participant.)*

Hauora Māori seeks to respond to Māori health needs, and in so doing must explore a range of complex and diverse environmental, social, spiritual and cultural factors. Whilst there are many theories about the influence of genetics on health, the role of genes within this complex array of variables is not clear. For example, the potential to utilise genetic information to explain common health problems like diabetes is often over-emphasised, and this hyping up of genetics has raised significant issues.

Studies attempting to link single gene variants to complex psychosocial characteristics such as aggressive behaviour and alcoholism raise serious questions about the virtue of relying on purely genetic explanations for such complex matters. Whilst the presence of genetic variation certainly influences our lives and might provide some useful predictive features, genetics alone offers only one piece of the puzzle when

explaining complex characteristics such as aggressive, addictive or other antisocial behaviours. Despite this, media hype continues to overstate the role of genetics. As stated by Dr Sujatha Byravian:

*We don't have a genetic reason for criminal behaviour ... But it is interesting that genetics as the reason for criminal behaviour continues to appear ... Maybe you can repair (the problem) by changing the social circumstances in a person's life or doing other things, but you can't change it just by changing someone's genes (Russel, 2006: 2).*

A Hauora Māori conceptualisation of human health and well-being adopts a holistic approach which looks at physical and metaphysical factors, in contrast to a common perception of genetic science being able to explain complex human characteristics and health indicators solely by examining genetic variation.

Humans share 99.9 per cent of the same genetic material (ie. DNA), which leaves the remaining 0.01 per cent of our genetic makeup (about 3 million base pairs) to account for our different physical characteristics and risks for disease (Lewontin, 2005). Most of this variation explains differences among individuals, whilst only about 10% explains genetic differences among populations (Lewontin, 2005)

To most lay people this seems a small amount of genetic variation, however, geneticists see these variants as being far from trivial and could potentially provide significant health benefits.

*10% might sound trivial but it actually corresponds to ~300,000 points in the genome. It is plausible that any of these 300000 DNA variants could act individually, or together with other variants, to help explain different rates of genetically influenced disease among populations. Perhaps not so trivial after all! (research participant)*

The level of uncertainty and conjecture about which genes might or might not be associated with disease or other characteristics raises issues about the creation of unrealistic expectations. This is particularly pertinent for vulnerable communities who cannot be expected to understand the scientific implications or broader issues.

It is often said that race as a term to distinguish different communities, such as Māori, or Polynesian, or European race, has little scientific basis, i.e. there is no biological or genetic explanation distinguishing race, as these commonly used terms are far too broad a category to accurately define humans biologically

However, increased moves to focus research on specific “racial” groups culminated in the first race-based drug (BiDil), a treatment for heart failure in African Americans, in the United States in 2005. Despite the apparent success of BiDil to date it remains controversial in the fields of medicine and genetics and ethics.

Similar moves to focus research and develop drugs targeted at ethnic and indigenous communities are continuing and are also likely to spark debate about ethical impacts. For example, some geneticists, such as British biologist and author Armand Leroi, now promote the use of race by medical researchers as a proxy for genetic identity (Leroi, 2006). This approach has been criticised by some for promoting confusion, presenting arguments based on non-scientific propositions and raising contentious issues such as what race actually is and what relevance if any race has to genetic science.

*In his [Dr Leroi's] discussion, however he mixes up race with references to local tribes and or populations, managing only to confuse his audience. Demonstrating how antiquated notions about race continue to belie real scientific understanding (ibid.: 1).*

As stated, the causal link between genetic variations and specific diseases is uncertain. What is proposed is that the genetic variation traced through the origins and migratory patterns of a populations ancestors may impact on disease susceptibility. Some geneticists propose a technique known as 'admixture analysis', or the breakdown of a populations genetic lineage based on multiple geographic regions of origin, in order to collect data and inform health risks. It is important to distinguish between race and ancestral origins, as it is ancestry that provides potentially useful genetic information as opposed to details about race (ibid.: 3). To date several high profile scientific studies of the African American population have employed this admixture method to discover genes involved in modifying the risk of hypertension, multiple sclerosis and prostate cancer in people with African ancestry.

An argument might be made, particularly by supporters of genetic testing research focusing on ethnic and indigenous populations, that such approaches are necessary in order to achieve improved health outcomes and address social inequities for marginalised communities.

Health research focusing on racial groupings is re-emerging as a result of efforts to deal with complex health issues. Whilst this might result in benefits, there are also potential risks for those communities being tested. Moves to identify ethnic groups with genetic traits may compound stereotypes and prejudices held by some health professionals. It is important that the dangers of such research resulting in the persecution of ethnic and indigenous populations as it has done in the past are appreciated.

*There is a general sentiment that studying the connection between race and genetics this time around will not produce the sinister effects of the past but is this true? We may be trudging down an erroneous path, one that will lead to false notions of biological differences and the delay of efforts to remediate inequalities whose origins lie mainly in environmental and social factors (ibid.: 8).*

This view needs to be balanced against finding solutions to the immediate and severe negative health challenges facing ethnic and indigenous communities and the need to ensure opportunities are not lost, as illustrated by the following:

*“If we neglect to explore the science of “race “ and genetics and assume, despite evidence to the contrary, that all races have the same genetic background, or that the genetic differences are negligible, then we might end up doing ethnic and indigenous minorities a disservice in terms of health care (research participant)*

Māori are beginning to engage in the new genetics testing technologies seeking genetic explanations for complex diseases and this is likely to continue (Tipene-Matua, 2006). Importantly, the risks to Māori must be minimised and potential benefits maximised to ensure that genetic testing and research can make a significant contribution to Māori development.

### 2.3 Comments

As geneticists continue to research and hypothesise about Māori health the Hauora Māori/genetics interface will come under greater scrutiny and the lines between genetic and non-genetic health determinants will become increasingly blurred. Hauora Māori is a response to the poor state of Māori health, which is explained by complex variables. The role that genetic research has to play in providing better health outcomes for Māori communities is yet to be ascertained. Whilst it is unclear whether genetic testing will improve Māori health, this report argues that, working together, Hauora Māori and genetics have the potential to improve health outcomes for Māori.

The Hauora Māori approach and the place of genetic research within it need to be understood, acknowledged and respected. Pleasingly, scientists in New Zealand are beginning to accept that new genetics can only make a contribution to the Hauora Māori body of knowledge rather than provide the sole solution.

*... it’s about putting pressure on genetics that their findings have to contribute to the knowledge base and not be promoted as being the sole knowledge base and ... it needs to sit in the context with which the data is used within health and it needs to contribute to other research looking at the complexities. (Research participants.)*

### 2.4 Genetic research and indigenous DNA

Another aspect of genetic testing technology that has increased in prominence and use in recent times is that of testing to determine individual/personal ancestry and origins according to genetics (so called “recreational” genetics). The increased

popularity of these tests reflects a growing desire to connect with personal identity. People are looking to science for answers as to who they are and where they came from. Whilst the genetic studies regarding ancestry often have a vastly different driver from health-related technologies, the lessons and responses from indigenous communities are useful for predicting Māori responses to the new genetics.

The genetic tests available to those seeking to analyse ancestry and origins involve identifying whether a person's genome contains particular stretches of variable DNA inherited from their ancient ancestors(haplotypes). These haplotypes vary in frequency among populations and as such can be linked to specific regions around the world. Such information might provide clues as to the ancestral origins of a person.

DNA of indigenous peoples has been the subject of many theories about human migrations and the evolution of inherited characteristics. This section discusses how genetic researchers and corporate sponsors propose to collect DNA samples from indigenous peoples globally. Such discussions provide potentially valuable insights and comparative analyses in terms of Māori genetic testing in Aotearoa New Zealand.

In the early 1990s a research project known as the Human Genome Diversity Project (HGD Project) proposed to collect blood and tissue samples from hundreds of different indigenous groups worldwide for genetic study (Council for Responsible Genetics, 2006). The rationale provided by the proponents of this research was that the indigenous tribes being targeted for research were close to extinction and it was important to gather this data before they disappeared.

At the same time a film entitled *The Gene Hunters* was produced, that warned indigenous peoples of the serious potential risks of abuse from genetic researchers. The video depicted unethical scientific research practice by showing researchers arriving at the village of an indigenous tribe to conduct routine health checks, give advice and administer medicines for common ailments. The scientists were also removing hair and blood samples without the participants' consent. After the collection of such samples the research team promptly packed up and left, supposedly never again to have contact with the indigenous tribe. This video was widely shown at gatherings of indigenous communities. Tribal activists around the world were asking key questions and challenging scientists about why they were rushing to gather DNA samples of indigenous peoples. Why such interest in saving the 'genes' of indigenous peoples and not the indigenous peoples themselves? In addition, indigenous groups questioned the benefits of the research and the potential adverse impacts the scientific discoveries might have on the beliefs and traditions of indigenous people, and whether these new theories might be used to challenge indigenous rights. The HGD Project was

discontinued after widespread criticism and condemnation from indigenous and non-indigenous communities (Foster, 1998; Harry, 2003).

More recently computer giant IBM and the Wait Family initiated a project with the National Geographic Society to collect DNA samples from 100,000 indigenous peoples throughout the world over a period of five years. The Genographic Project seeks to provide insights into how people travelled across the globe. Unlike the HGD Project, this project focuses on migratory patterns and the drivers of this research have deliberately distanced themselves from health-related genetic research. Genographic Project proponents state that 6–12 per cent of the proceeds from the sale of genetic testing kits, costing \$US100 each, will be dispersed to indigenous community projects by an organisation called the Genographic Legacy Fund.

*Proceeds from the sales of the Genographic Public Participation Kits support the Genographic Legacy Fund, a primary component of the overall Project. Through the extension of grants, the fund aims to empower indigenous and traditional peoples trying to revitalize their communities on a local level while at the same time helping to raise awareness on a global level of the challenges and pressures facing traditional communities around the world. (Genographic Project Website, 2006)*

Unlike the Human Genome Diversity Project (HGDP), which sought public funding, the Genographic Project is privately funded and therefore not subject to the accountability demanded of publicly funded research. In its first eighteen months, the project's scientists have persuaded perhaps as many as 18,000 indigenous peoples from throughout the world to donate their DNA (*New York Times*, 10 December 2006).

Indigenous groups around the globe have drawn parallels between the HGDP and the Genographic Project, arguing that the projects and their concerns are the same. This is not surprising, as the Genographic Project seeks to provide insights and perspectives on traditions and beliefs that are of great importance to indigenous peoples and it delves into deeply sensitive issues such as 'Why do we appear in such a wide array of different colours and features?' (Genographic Project Website, 2006).

Furthermore, the imperative that drove the HGDP to collect genetic material from indigenous populations before they died out, or became 'too diluted', remains a key motivating factor for the Genographic Project.

*In a shrinking world, mixing populations are scrambling genetic signals. The key to this puzzle is acquiring genetic samples from the world's remaining indigenous and traditional peoples whose ethnic and genetic identities are isolated. But such distinct peoples, languages, and cultures are quickly vanishing into a 21st century global melting pot.... That's why the Genographic Project has established ten research laboratories around the globe. Scientists are visiting Earth's remote regions in a comprehensive effort to complete the planet's genetic atlas (Genographic Project, 2006).*

Debra Harry, who is a Northern Paiute Native American and Executive Director of the Indigenous Peoples Council on Biocolonialism (IPCB), describes the Genographic Project as 'a recurrent nightmare'. Comparing it to the HGD Project she stated that, 'it's essentially the same project we defeated years ago. Some of the actors are different, but also some are the same' (Debra Harry, 2006).

Members of the IPCB and other indigenous peoples stridently oppose such research projects as attempts by genetic researchers to access indigenous DNA for their own ends.

*It's interesting how in the past racist scientists, such as those in the eugenics movement, did studies asserting that we are biologically inferior to them; and now, they are saying their research will show that we're all related to each other and share common origins. Both ventures are based on racist science and produce invalid, yet damaging conclusions about indigenous cultures (Debra Harry, 2006).*

*These kinds of projects have to stretch to claim any tangible benefits to indigenous peoples. Somehow, the Genographic Project has led its indigenous participants to believe its work will insure their people's cultural preservation. There is a huge disconnect between genetic research and cultural preservation (IPCB Chairperson Judy Gobert (Blackfoot), 2006, cited in Debra Harry, 2006).*

In late 2006 an article by Amy Harmon of the New York Times reported that the multi-million dollar Genographic Project had 'hit a snag', as native peoples of Alaska raised questions around the stories told by geneticists clashing with indigenous stories (Harmon, 2006).

Harmon stated the key issue was whether scientists were 'underselling the risks' to the indigenous donors. Geographic origin stories told by DNA had the potential to undermine long-held beliefs and traditions and therefore threaten a world-view indigenous leaders saw as vital in the preservation of their culture.

At issue here is the role indigenous knowledge plays in providing the social, economic and political foundation of indigenous societies. Despite the potential for such indigenous knowledge to make a vital contribution to the Western world, the risk is that, instead, it will continue to be eroded.

*The evidence supporting the existence of diverse cultural models of sciences rather than any single Western European-derived universal model of science is remarkably strong, but largely unacknowledged ... This systematic overlooking of the richness and integrity of indigenous sciences leaves us all impoverished at a global level, as the problems of excessive consumption and lack of sustainability of the projects resulting from the West European-derived scientific tradition become apparent with each decade (Scott and Tipene-Matua, 2004).*

At the core of the tension between indigenous groups and scientists and corporations is suspicion amongst indigenous leaders that the primary beneficiaries of such research will not be indigenous peoples. The potential exists for increased discrimination and denial of indigenous rights. Indigenous leaders point to centuries of broken promises to explain why they believe their fears are not far-fetched. Scientific evidence that Native Americans or other indigenous groups came from elsewhere, they say, could undermine the moral basis for sovereignty and erode their collective legal claims.

The withdrawal of indigenous support for the Genographic Project in North America and from the United Nations Permanent Indigenous Forum has as much to do with the lack of real partnership with indigenous peoples to drive this project as with the merits of the science itself.

Despite the development fund, the lack of real ownership and benefits accruing to indigenous participants are unlikely to be outweighed by the apparent driver of this project: curiosity about ancestry. The Genographic Project genetic science leader stated:

*'I don't think humans at their core are ostriches,' Dr. Wells said. 'Everyone has an interest in where they came from, and indigenous people have more of an interest in their ancestry because it is so important to them' (New York Times, 2006).*

Issues about the storage and potential misuse of DNA samples were also cited as areas of concern amongst indigenous groups. The issues raised by indigenous peoples regarding the Genographic Project have also been fuelled by examples of unethical genetic research and abuse of genetic information.

*Some American Indians trace their suspicions to the experience of the Havasupai Tribe, whose members gave DNA for a diabetes study that University of Arizona researchers later used to link the tribe's ancestors to Asia. To tribe members raised to believe the Grand Canyon is humanity's birthplace, the suggestion that their own DNA says otherwise was deeply disturbing (New York Times, 2006).*

In January 2007 genetic science watchdog the Council for Responsible Genetics (CRG) released detailed information citing the Genographic Project as inadequately safeguarding indigenous rights. In supporting the concerns raised by the IPBC, the CRG challenged the proponents of the Genographic Project explicitly to inform participants that this was genetic research.

*Project scientists seem to be purposely obscuring the basic research nature of their project, and this is not ethically acceptable (Council for Responsible Genetics, 2006).*

Another key question asked of the Genographic Project researchers was whether the research participants' consent would be ethically defensible. It was stressed that there needed to be robust processes in place to explain the potential risks to participants. Other concerns included psychological risks; risks of increased political persecution and discrimination; breaches of confidentiality; and unknown or unforeseen risks, particularly considering that the data has the potential to be used for future research.

According to the CRG, the Genographic Project had failed to meet widely accepted ethical standards whereby research subjects must give voluntary, competent, informed and understanding consent to participate. The CRG argued that acquiring blood samples from indigenous peoples, who are often vulnerable, is onerous and requires a higher ethical standard to be met; and that there is a need for time to be taken to ensure that the consent gained is ethically defensible.

*Obtaining ethically defensible consent from research subjects in developing countries for research done primarily to benefit rich countries, like the U.S., always poses significant challenges and therefore warrants heightened ethical scrutiny. The project's researchers must consider the difficulty of adequately informing research subjects from these populations; cultural nuances in valuing autonomy and locating decisional authority; the appropriateness and utility of written consent documentation; and even the prospects for ethically defensible consent from vulnerable populations (ibid: 1).*

Despite its considerable criticisms of the Genographic Project, the CRG maintains that it is still possible to salvage the Project's credibility and achieve what it calls responsible genographics by paying attention 'to where we came from and how we got to where we [are] today' (ibid).

## 2.5 Summary

Parallels are easily drawn between the issues raised by the HGDP and the Genographic Project on the one hand and the positive and negative Māori experiences of genetics on the other. These issues include what entails informed consent, the rights and responsibilities of individuals and collectives, the potential for increased discrimination and the impacts of genetics on indigenous cultural or spiritual perspectives.

The use and misuse of DNA and potential benefits for indigenous groups attempting to improve general poor health are important issues to address. Māori responses to genetic testing are discussed broadly in Part B.

A major lesson to be learned from these projects on genetic research with indigenous peoples is the need for an indigenous ethical, moral and spiritual framework to

drive how genetic research is carried out within indigenous communities. Such a framework needs to be cemented into all aspects of genetic research; otherwise genetic science will fail to provide real benefits to Māori and to contribute positively to the transformation of Māori communities. This is discussed in Part C of this report.

### 3 MĀORI AND GENETIC TESTING

#### 3.1 Māori perspectives on genetic testing of newborns

##### 3.1.1 *Māori and genetic testing: Traditional perspectives*

Pinepine te kura

Hau te kura

Whanake te kura i Awarua

Ko te kura nui, ko te kura roa,

ko te kura o tawhiti na Tuhaipo

Tēnei i te tira hou, tenei i haramai nei

Ko te Umurangi na Te Whatuiapiti

Nau mai e tama ki te taiao nei

ki whakangunu a koe ki te kahikatoa,

ki te tumatakuru ki te taraongaonga

Nga tairo ra e nahau e Kupe

I waiho I te ao nei ...

Little tiny kura (precious), the kura of renown, The kura who came from below Awarua, A noble kura, a famous kura, The kura from afar off, The kura of Tu-hae-po, A strange visitor he is lately arriving here, He is Te Umu-rangi and Te Whatu-i-apiti is he, Welcome o son, welcome to this world of life. You are to be ritually strengthened with the kahi-katea, with the tu-matakuru and the tara-ongaonga, These were the obstructions that you o Kupe bequeathed unto this world...

This excerpt from 'Pinepine te Kura', Ngati Kahungunu oriori or lullaby, written on the Porangahau River by Hori Niania for his newborn son Te Umurangi (date unknown). These were used to transmit knowledge and wisdom and to help prepare the young for their lives ahead. Oriori outlined the whakapapa or genealogies of the young child, and also included the significance of the birthing process, rites of passage, make-up of the child's identity and future challenges and how the whānau might deal with such challenges. Oriori were used to sooth young babies to sleep and to instil confidence, self-esteem, identity and an improved sense of well-being for future generations.

Traditional Māori knowledge demonstrated sophisticated and effective explanations of the human condition from birth to death. This knowledge was holistic and provided a spiritual and cultural basis for living that was intimately connected to the spiritual and natural worlds. This had a basis in ancestral wisdom and community connectedness.

*From womb to tomb: we said right here is a healer, that person is going to be nurtured and we did that traditionally and we want to go back to that traditionally, so there are some mappings that are part of our society and for the betterment of the society (Rongoā health provider: Constructive Conversations, 2005).*

Throughout the Māori world are symbols, concepts, values and traditions that provide clues about how Māori may respond to genetic testing. Explaining traits, characteristics and ways of being by analysing the traditions, values and practices at the core of Māori society helps to remind genetic science that indigenous knowledge can play an important role in providing balance in the discussions about new genetics.

In the past coming to terms with new technologies and different cultural values has placed and continues to place pressure on Māori society. Māori leadership in the modern era is still confronted with challenges like the acculturation and subjugation of Māori cultural values and beliefs to the dominant culture. These leaders contemplate significant loss of language and culture, an increasingly urban and youthful population heavily influenced by American pop culture and a community disconnected and alienated from whānau, hapū and iwi structures and values. The challenge of negotiating and managing the interacting influences of traditional values and leadership principles on the one hand and complex contemporary issues such as new genetic technologies on the other brings both additional pressures and opportunities.

Since the first contact with Europeans, Rangatira Chiefs of the era would have sought to sustain their traditions, cultural values and way of life. However, they also took 'particular interest in new crops and technologies they were able to access as a consequence of European contact' (Petrie, 2006). Chiefs took risks and pursued knowledge and technologies that would benefit the collective and ensure their survival, grow their capacity and provide for the social, political and economic needs of whānau, hapū and iwi. Indeed, Māori welcomed contact with early explorers and settlers, especially the benefits of trade and new technologies. These technological benefits were of course offset against the significant negative impacts of colonisation including considerable mortality rates from introduced infectious diseases and a decline in the Māori population by a third or more during the nineteenth century (Reid, 1999). In fact many Europeans believed the Māori race would die out as a consequence.

In traditional Māori society there were no tikanga principles developed specifically to address the challenges raised by genetics. The Royal Commission on Genetic Modification Report (2000) refers to 'world views' concerning traditional cultural values and beliefs and the difficulty in linking these with specific decisions, particularly as they relate to genetics and complex life-threatening chronic health conditions and the preservation of life.

Of primary importance to the Māori world-view, tikanga values and beliefs is the continuity and survival of whakapapa for individuals, whānau, hapū, iwi and society as a whole. An explanation of te ao Māori refers to the views and perceptions of the world Māori live in and how (through storytelling for example) their belief systems and philosophical traditions have shaped their values and behaviours. World-views are expressed through stories, symbolism, imagery and metaphor in order to conceive an explanation for creation. The genealogical descent of all living things provides a framework for tikanga: understanding patterns of behaviour in relationships and linkages and connections between animate and inanimate things.

The creation narratives within te ao Māori provide some insight into potential Māori responses to genetic testing. Māori seek guidance regarding future actions from the wisdom and attributes of kaitiaki Atua, tīpuna, ancestors and mythical heroes. For example, we can learn from the mythical hero Māui in order to identify the various tikanga principles underpinning Māori cultural, ethical and spiritual perspectives. According to the whakapapa narratives on Māui, he was the last born of five brothers, the pōtiki; hence his name Maui-pōtiki. Despite his lowly ranking, Māui exhibited important characteristics. He was endowed with extraordinary qualities such as being intelligent, a risk taker, cunning, innovative, resourceful and imaginative (Walker, 1992). Māui the trickster hero undertook many dangerous missions, bringing new knowledge or technology to the world. Māui is recognised for being courageous in pursuit of the prized jaw bone and for other feats such as slowing down the sun and fishing up Aotearoa. Through the Māui traditions whānau are encouraged to pursue goals that might involve some risk taking in new technologies or entrepreneurial pursuits to obtain social, health, environmental and economic gains that will benefit the whole collective. The knowledge gained would benefit the collective and ensure the survival of future generations.

The Māui traditions provide an insight into a Māori entrepreneurial spirit and a willingness to push boundaries and take risks. A key message found in the Māui myths is one of caution, highlighting the dangers of wanting to control the natural order of things. The story of Māui seeking to become immortal and subsequently dying between the thighs of the Guardian of the Night, Hine-nui-te-Pō, sends a strong message that there are limits to what humans can and should do in the pursuit of knowledge. As the Ngāti Kahungunu people stated in their submission to the Royal Commission on Genetic Modification when using the Māui traditions to provide insight into genetic modification:

*For like much of the boosterism of gene research he (Māui) saw the opportunity to unravel the mysteries of life, to prolong it, and even change it. Yet in the excitement of new opportunity he neglected the wisdom of the past and did not take the time to properly assess the risks. He knew that there might be dangers,*

*but assumed that he could minimize or control them. And he failed, because in a very basic sense he had not asked of death why do we need to know? (Ngāti Kahungunu, 2001: 11).*

The increased numbers of whānau and hapū choosing to engage in genetic research to gain health and economic benefits indicate such decisions might be influenced by a Māori entrepreneurial and risk-taking spirit. These sentiments were also expressed by other presenters to the Royal Commission, who stated that they believed traditional Māori approaches to new technologies were more risk seeking than risk averse.

*We do not believe that Māori were reluctant developers of technology; the overwhelming anthropological and customary evidence weighs against this interpretation of tikanga Māori ... We contend that ... [the assertions] that man cannot subdue or engineer the world are based on a very surface level understanding of the Māori cosmos (Ammunsen, 2001).*

Although there is little data to support this, the following statement from one research participant supports the notion that the early explorers were risk takers when they left to come to Aotearoa:

*Our people didn't leave Hawaiki unwillingly ... you don't leave paradise willingly ... there were some real events affecting their wellbeing so they left and that was a conscious decision, a leap, and I say we are faced with those decisions all the time to make that leap (to take risks), the people who left Hawaiki on the Takitimu ... made the decision willingly, knowingly ... that is what we should do now, we shouldn't cocoon ourselves in what we know.... There was a sense of adventure but there was also a sense of need and urgency ... if we stay where we are in the status quo we are going to die.... (Research participant.)*

### **3.1.2 Māori and genetic testing: Contemporary perspectives**

Current research with Māori about the acceptability of genetic testing of newborns, and the increasing numbers of Māori embracing these health biotechnologies, indicate willingness to engage (Tipene-Matua, 2006). The Constructive Conversations: Kōrero Whakaetanga is a five-year research project looking at the ethical, social and cultural impacts of emerging health biotechnologies, including genetic testing, on communities. Over a three-year period, at least thirty focus groups and workshops were conducted with a broad range of groups on the impacts on communities of genetic testing, screening of newborns and biobanking.

From this research diverse perspectives emerged about genetic testing and the potential impacts of these new technologies on Māori who, like non-Māori, were heavily influenced by the potential to achieve positive health outcomes for whānau, hapū and iwi (Du Plessis et al., 2004).

*I know that if it comes down to it and I see somebody that I love suffer, I would do everything in my power to alleviate that suffering and that's what really determines my decisions at the end of the day ... It makes it really personal. And if it is somebody I love and if genetic testing is going to help then I would do everything in my power to convince them to take that track if it is going to alleviate their suffering and that's where I'm at (research participant cited in Tipene-Matua, 2006: 7).*

Altruism, generosity, love and experiencing the joy of helping others in need are humanistic ideals common to all peoples. For Māori they are enshrined in concepts such as manaakitanga, aroha, mana and kaitiakitanga. These values are found on all marae, the modern expression of the traditional Māori village. The overarching manaakitanga philosophy driving all marae dictates that people are to be looked after at all costs and that the mana or prestige of the marae is determined by the how well visitors are cared for; the literal translation of 'marae' is 'generous'. The manaakitanga philosophy influences all aspects of Māori society and, when applied to the well-being, including potential health risks, of the collective whānau, the desire to make a positive contribution to help others is strong. The point here is that enshrined within Māori society are values and traditions that are likely to influence decisions regarding emerging health-related biotechnologies such as genetic testing. Often whānau or hapū members participating in research projects are driven by the perceived needs of the collective.

*I came home to a tangi and they were all talking about this research project that was being conducted by a whānau member who won an award and that it would contribute to helping the health of (the iwi). (Research participant.)*

Increased pressure on Māori communities to make decisions in favour of genetic research might grow out of tikanga Māori values such as manaakitanga and the Māori entrepreneurial spirit to push boundaries and take risks.

Providing clear and balanced explanations of genetics to those Māori communities contemplating engaging in genetic testing is essential and calls for people with the skills to understand and critique genetic research projects and convey the risks and benefits clearly and objectively.

It is important for research scientists to consider the increased pressure to participate in genetic testing research when promoting such projects to Māori communities. It is sometimes difficult for individuals to decline participation in such research, as expressed by a participant describing how she felt compelled to contribute to a mainstream research project:

*... you had a doctor there who provided all your care ... so I felt kind of obliged and kind of agreed at the time but just didn't do what I was supposed to do as part of the study.... it was a really long information sheet ... you can just imagine doctors saying this is really going to help us and we are going to find a cure etc and you can just imagine a lot of Māori just signing it (research participant).*

Often expectations of gaining diagnostic health benefits from genetic research have been raised to the point of being unrealistic as evidenced by the following statement:

*Yeah, I am quite 'pro' to a point, because I would certainly like them to DNA my whānau because we have certainly got some pretty strong traits in our whānau. To be straight up – one of them is alcoholism and depression and I would really like to know is, surely, is it truly genetic in my whānau or is it just crap that happened? (Research participant cited in Du Plessis et al., 2004)*

In researching the impact of genetic testing on Māori, the Constructive Conversations project focused primarily on diseases that had an obvious genetic component (e.g. Huntington's Chorea) as opposed to the more multifactorial diseases that the new genetics seeks to address.

The new genetics focus on common diseases raises new and complex issues for Māori communities. The focus on diseases with complex contributing factors, which are highly prevalent amongst Māori (such as diabetes), raises the question about whether Māori who engage in such research are realistic about the potential health benefits. Concerns were raised during the Royal Commission on Genetic Modification process about claims that genetic science can provide explanations as to why Māori suffer from non-genetic diseases.

*We particularly reject the blanket claims made in linking genetic research to certain diseases that are known not to have genetic causes, such as various cancers. That claim is as despicable as those made by the old snake oil fraudsters (Ngāti Kahungunu, 2001: 12).*

The view that genetic science is unlikely to assist in improving Māori health is particularly relevant to the new genetics, which focuses on multifactorial diseases. It is therefore essential that Māori participants in these research projects are well informed and aware that genetics alone will not provide the answers to their health problems.

Moreover, the likelihood that people will change their lives and lifestyles as a result of findings from genetic testing raises other issues for Māori communities, which receive constant messages about being unhealthy. These messages rarely result in behavioural or lifestyle change, which begs the question: would Māori respond to health predictions based on genetics? Will it make a difference to peoples' lives to

learn that they may have a genetic predisposition to a certain disease? If it is not likely to change how people live, as put by Moana Jackson in the Ngāti Kahungunu submission to the Royal Commission, ‘why do we need to know?’ (Ngāti Kahungunu, 2001). It might be more likely that parents would make changes to their child’s lifestyle, rather than their own, as a result of a genetic test:

*... if my baby was there and they took DNA and told me that something serious was going to happen to it, then I definitely would do something about it straight away ... if it was my baby there I would do that. (Research participant, cited in Du Plessis et al., 2004.)*

There is a real danger that health-predictive genetic information passed on to Māori communities could cause more harm than good as it may place additional stress on whānau.

*I saw that about DNA and I thought my DNA, my whānau DNA, my tīpuna DNA and I thought who are these people to lay claim to a DNA strand that they don’t even know who it is ... and to identify a disease that might possibly be in my family, who again has that right to expose that for future generations as well as past generations? (Research participant, cited in Du Plessis et al., 2004).*

It will be important to consider carefully the potential of unnecessarily increasing burdens on whānau by passing on information about being genetically predisposed to certain diseases. However, there is also potential for such ‘burdens’ to alleviate suffering and anxiety: ‘Having genetic information in some cases can reduce ‘victim blaming’ of Māori. It has a lot to contribute’ (research participant).

*I was actually thinking it would be nice to have that DNA thing done, but not telling us. Maybe the doctors can have it and let us know ‘hey there’s a problem here and we’ll deal with it in maybe another 5 years time’ ... (Research participant, cited in Du Plessis et al., 2004.)*

The support for genetic testing from Māori who have chosen to engage has not been unconditional, and is often driven by the potential for health benefits.

Issues have also been raised regarding the amount of information to be given to whānau in order for informed decisions to be made, and the potential abuse of information resulting in increased discrimination, stigmatisation and reification of racist stereotypes.

Evidence exists that data from genetic studies targeting Māori have the potential to be used and abused by mainstream media and politicians to concoct provocative media headlines and feed existing stereotypes. In 2005, a speech given by a politician, the now infamous ‘Orewa speech’, did just that, resulting in racist hysteria across the

nation as a result of which some Māori lost their jobs and were harassed (Pelkowitz, 2004). How the media and politicians could use and interpret information that might emerge from genetic research about Māori should be considered before such information is released.

Another example of mainstream media supporting and fuelling existing negative stereotypes about Māori was the media response to a geneticist's hypothesis in 2005 that Māori might be genetically predisposed to addictive behaviour as a result of a higher presence of the MAO gene dubbed the 'warrior gene' (*New Zealand Herald*, 2005; Merriman and Cameron 2007).

These two examples clearly illustrate how information from genetic research, particularly if negatively focused, will be used against Māori by an unsympathetic mainstream media and by politicians looking to gain votes. The 'warrior gene' debate raised key issues in terms of how Māori are defined, and the potential impact of research looking to genetics to explain characteristics and traits specific to Māori people.

The role of the media and its influence on how science is communicated to the public has an important effect on how genetics are perceived. In searching for the groundbreaking story, media coverage of genetic research often fails to challenge the reliability of the science involved or to point out that research can be merely a hypothesis, theory or pilot study, or can possibly be based on limited data. The combination of enthusiasm on the part of the media for attention-grabbing headlines and captivating 'sound bytes', alongside the enthusiasm of geneticists in promoting their research, has culminated in poor reporting and considerable misinformation about the potential benefits of genetic research. Coupled with the mainstream media's preoccupation with negative portrayals of Māori and the pre-eminent place of Western science in our society, the likelihood of abuse of Māori through media coverage of genetics is high. According to some observers, it is unlikely that this will change as pressure increases on geneticists to deliver:

*Editors wanted breathless stories about ever-grander discoveries; they certainly didn't want stories about theories that didn't pan out or the limits of genetic research. The net effect of all these trends was the development of ever-more PR-savvy 'science' (I enclose the word in quotation marks because there was nothing very rigorous or scientific about much of what was passed along for public consumption) and a relaxation of standards of reportage. (Lancaster, 2005: 4 quoted in Tipene-Matua, 2005.)*

One view emerging from this research is that, if there is any risk of research data being extrapolated or misinterpreted by the media in a negative way resulting in adverse impact on Māori, the research should not be conducted.

What is most important is that the risks of mainstream media picking up on genetic research on Māori and giving it a negative twist should not be underestimated, but rather managed carefully. The ‘warrior gene’ controversy exemplified the way in which Māori can be adversely impacted upon by genetic research when the risks of releasing data from ethnically based genetic research are not anticipated or well managed.

The problem with debating genetic theories through the mainstream media is that often the subtle nuances and complex issues lose out to negative or sensationalised portrayals of Māori. This particular controversy served as a warning, to both Māori communities and genetic researchers contemplating Māori genetic research, regarding the risks of research data being abused and misinterpreted by the media, or even used for political gain.

Another key issue for the future will be how genetic material collected from Māori populations might be used – particularly if it is to be taken overseas.

*... I was asked to be a participant in some research ... and ... it ... didn't ask me if my samples could go overseas. It told me that in participating in the study I was consenting to my samples going overseas so I didn't participate (research participant).*

As well as the issue of how genetic material is obtained from Māori communities, questions arise regarding how long genetic researchers should be allowed to continue to collect DNA samples for unspecified purposes. The term ‘gene trawling’ emerged to describe how research into the relationships between genetic variation and disease often involves searching for genes that may or may not be there. The term also refers to a search for genes that are unspecified from the outset, rather than starting with a hypothesis related to one particular gene and health condition.

*... Geneticists just keep looking and you just cannot just keep looking for something with the hope that you might find something without understanding the context in which it sits (research participant).*

Is it ethically defensible for a genetic research team to engage in community research projects when they don't really know what they are looking for? Should limits be placed on geneticists that require them to provide specific details about the nature and extent of the research and the actual outcomes that will be achieved for communities?

Māori communities are becoming more aware of how to deal with health-related research projects, including genetic research; and with this increased experience come increased expectations regarding what they want from researchers.

These expectations include the desire to use research results to assist broad iwi development goals. It is likely that Māori want autonomy within research projects, working in partnership with those geneticists who want to access their DNA rather than being mere bystanders.

*The things they talked about that they wanted to have actually come down to basic ethics and research practice ... heaps of our Māori communities had research conducted on them, they used words like methodology ... they had been involved a lot in research and they said research never ever comes back and tells them what they got out of it ... they were simply getting lay reports like a one page thanks for participating and ... they wanted more ownership over the research data so that they could use that data as a community or whānau ... to advocate for their own needs as well ... they wanted to not be just bystanders in the research ... they all understood genetic testing and they all talked about it for the benefits of their children and grandchildren (research participant).*

#### 4 ESTABLISHING A MĀORI ETHICAL FRAMEWORK FOR GENETIC RESEARCH

Much of the research to date has dealt with the ethical, cultural and social impacts of genetic testing in isolation from the whānau, hapū and iwi engaging in the technologies. Therefore in much of the discussion about these issues hypothetical or theoretical scenarios are posed for community contemplation.

Increasing amounts of genetic studies engaging with Māori communities provide valuable opportunities to learn lessons and to ground the issues raised earlier in this report. Such opportunities include invoking more effective frameworks that acknowledge Māori systems and ensure Māori communities maximise benefits and minimise risks when engaging genetic testing technologies.

Often genetic research conducted in Māori communities is driven by the overarching need to develop long-term strategies to strengthen the capacity of the whānau, hapū and iwi.

*A realisation that we need to understand why we're dying so young. Why we have all these prevalent diseases? What was the buy-in for them? They're salt of the earth people. No use feeding them the fruits of the lofty tree.... I do believe that because our health status is so out there to be seen it's almost that we are at the desperation stage ... (research participant).*

Addressing poor health is considered important to the wider aspirations of social, political, environmental and economic development encapsulated by the iwi strategy development plans. This strategy seeks to provide knowledge, protect iwi taonga,

address iwi social and economic issues and ensure that the tribal identity “...is restored and strengthened, is inclusive of all our whānau and results in benefits for our people’ (research participant). If the time is taken to connect genetic studies to the needs of the community, there is potential for significant short-term and long-term benefits.

*I think neat. Good because that’s an iwi using modern technology for its wellbeing. As our people did when they first arrived here because they arrived here and found a whole pharmacy, they found a whole storehouse of healing, new medicines and they went out there and found them. And they created all the tikanga necessary to embrace. Then they created the mātauranga, all the knowledge about it. ... So there’s an awesome base for new mātauranga, for tikanga to be developed as you apply that mātauranga for the wellbeing of the people ... (research participant).*

Research participants’ views varied in this research about the use of genetic material for associated and other projects, for which those supplying genetic material have not given explicit consent. Some thought that it was sufficient for an ethics committee in consultation with the relevant iwi authority to give consent regarding how genetic material was used. Another view emerged that DNA samples should be destroyed once the primary research project concludes.

#### 4.1 Collective consent, partnership relationships

It is difficult to fully determine how collective obligations to whanau, hapū or iwi influences individuals who choose to engage or not engage in genetic testing research. An important aim for the future will be to understand what extent participants in genetic research focussing on Māori consider individual and/or collective responsibilities when consenting to participate in this genetic research.

Establishing partnership relationships with Māori, as well as discussing and resolving issues to do with decision-making, authority and access in relation to genetic material, is crucial when determining how best to engage Māori in genetic testing.

All those interviewed for the purpose of this report agreed that the collective entities of whānau, hapū and iwi are the foundations of Māori society and for genetic research to engage effectively with Māori communities there must be recognition of this:

*... individualism globally is a key value to the controlling interest so it is in conflict with the value of collective participatory Māori processes and I think as a consequence of colonisation we probably have been left with other values ... that have penetrated the culture and affected the culture very much across the board, and in the journey of reclaiming we reclaim that which was in terms of who we are.... Individualism is a product of pākehā rule, socio-economic paradigm, it must colonise, people and the environment (research participant).*

Ownership of and authority over DNA was viewed by some to lie with individual Māori 'donors,' although all believed that for Māori there are also obligations to the collective:

*... with DNA it's a collective thing.... So it's not for me to say that well I have the right to all of that whakapapa and the DNA and every other aspect contained within it ... you've got to respect the individual mana of people, of your own. You've got to nurture that too because in nurturing the mana of the individual you've actually enhanced the mana of the collective (research participant).*

The authority to make decisions about the DNA of collective whānau groups was thought to rest with the hapū as opposed to the broader iwi authority. Participants considered that such decisions entailed an obligation to consult other hapū and iwi in order to take account of the overall implications.

Although decision-making with regard to DNA was thought to reside most appropriately at the local level, such rights were discussed in relation to associated obligations to others, with iwi seen as playing a role in assisting and supporting hapū by establishing broad policy and creating opportunities.

All participants saw the way forward, in terms of genetic researchers effectively engaging Māori communities, as being projects that are established and driven by the communities themselves, based on whānau and hapū needs.

*... that's the thing about this....study. Everyone that becomes involved with the study, they are not just the client, they are also the owner so we've got to go back to all of them, we've got to keep them informed, we've got to get their consent or whatever ... one of the biggest challenges for Māoridom especially with our younger generation is re-installing our values and our beliefs ... they should feel confident as individuals that within a collective they're still going to have rights, there are still going to be pathways for them to move forward individually (research participant).*

Some of the key factors influencing decisions to support genetic research were the immediate community benefits, such as having access to a doctor for general medical advice and employment opportunities that are often part of such projects. The importance of ensuring short-term benefits for communities being researched was often stressed as being critical to the success of such projects. The question of the validity of finding a genetic solution to Māori health issues will only be answered by the people themselves, as they choose to explore such issues in partnership with geneticists.

*Well they are conscious of the fact that this will only provide some of the answers but it's better than what we've got at the present, which are no real answers. We can point to things and say, 'Oh yeah, yeah. Māori die of diabetes because of the way they live' and all the rest of it but really that still doesn't answer what we want to know inherently within ourselves....What we're not trying to do with the thing is come up with some kind of genetic definition for it all because we realise that's only one part of it. There are other implications. There are social implications. There are educational implications (research participant).*

*... What it is really about for us is re-educating ourselves on how we can better look after ourselves moving forward. If we are to carry on at the same mortality rates as we are now, most of our....affiliates are bloody dying before they are 60 ... This research was in the first instance going to benefit us ... That was the overriding influence ... it was that there were short-term gains for us. It suited where we were at as a people... (research participant).*

These sentiments provide some early insight into how genetic research projects should be conducted in future if they are to be successful. It is primarily through the establishment of significant partnerships between researchers and 'researched' communities that this will be achieved. The next section discusses how such relationships might be established.

## 4.2 Establishing a Māori ethical and cultural framework

This section will explore whether a Māori framework is needed to assist in the resolution of ethical and cultural issues arising in the course of genetic research. First, we outline the views from research participants on the need for a Māori ethical and cultural framework. Secondly, we discuss various conceptual frameworks developed for assessing the impact of genetic research on Māori.

The need for a Māori-specific framework was viewed as important by the research participants as it could potentially fill a gap in the current regulatory and conceptual frameworks:

*... ethics committees sometimes miss things and they have a small Māori membership and you tend to get lay people as opposed to researchers ... we pretend we don't have the resources but I think we do. Unless you do it study by study it's too hard because there are no generic guidelines as each study is so different and they develop, evolve and change and you need input into that evolving process ... everyone has the HRC guidelines but who reads them? Not very many people, everyone fills out that responsiveness to Māori thing, it's all pretty standard, they cut and paste it ... it has all been about ticking the box (research participant).*

When asked about the need for a mechanism to deal with Māori ethical and cultural issues regarding genetic research, participants were generally supportive regarding the potential benefit to Māori and other indigenous peoples. In discussing genetic testing research on Māori communities, one participant was conscious of the need to set in place effective models of engagement with Māori for the benefit of other indigenous communities:

*If we are going to continue to push the boundaries and in doing so we need to set up models and frameworks that are not just beneficial to ourselves but also to our brothers and sisters around the world to help them to get up to speed. He tohu rangatira tērā (research participant).*

Support for a Māori ethical framework for genetic research was driven by the need to ensure that Māori benefit from the science, and that geneticists are 'put on notice' regarding their research with Māori being run effectively and constructively.

Overall there was a general consensus supporting the development and implementation of a Māori conceptual framework that would regulate how genetic research could be better conducted to ensure Māori communities benefit. However, work needs to be done to determine the content of such a framework, and then time taken for application, testing and refinement.

#### *4.2.1 Developing a moral, ethical and spiritual framework for genetic research with Māori*

Conceptual frameworks have been developed to assess the impact of genetics on Māori, in relation to specific biotechnologies ranging from genetically modified organisms to preimplantation genetic diagnosis (PGD) (Durie, 2005; Mead, 2005, Guyatt, McMeeking, Tipene-Matua, 2006).

In the first year of the Human Genome Research Project, a tikanga framework was proposed to assess the impact of PGD on Māori. It used the tikanga Māori framework for assessing new technologies developed by Mead (2005). It involved a series of questions or tests to be analysed against the new technology at hand. Test 1 focused on how PGD might breach tapu and Test 2 looked at the impacts on mauri, particularly as it related to the embryo. Test 3 involved analysing the reasons for the breach of tapu (the 'take' test) and the consequences and necessary responses (the 'utu test'), to ensure satisfactory outcomes or maintenance of relationships (the 'ea test'). The tikanga framework then proposed that examples or precedents within Māori knowledge systems should be analysed to help understand the new technology and the technology should be measured against key Māori principles including whanaungatanga, manaakitanga, mana, tika and noa (Guyatt, McMeeking, Tipene-Matua, 2006).

The tikanga Māori framework for assessing new technologies is best suited to those with a strong knowledge of Māori world-views and values. It is unlikely that most

geneticists could use such a framework, although one research participant was clear that genetic research involving Māori should be overseen by Māori.

*... that's why I don't think any research should be done external to Māori researchers being involved because only Māori researchers will be able to engage and then it's only Māori researchers who have had involvement with Māori communities ... it can set the non-Māori researchers up as well (research participant).*

Similarly, Mason Durie, in responding to the debate on genetic modification, challenged the appropriateness of the risk management framework for assessing the impacts of new genetic technologies on Māori. He suggested a framework based on three domains: the *natural environment*; the *human condition*; and *procedural integrity* (Durie, 2004).

Māori values or concepts relevant to the domain of the natural environment include *mauri* (integrity), *whanaungatanga* (relationships) and *kaitiakitanga* (guardianship); the domain of the *human condition* encompasses *wairua* (spirituality), *tapu* (safety), *hau* (vitality) and *whakapapa* (intergenerational transfers). The third domain, *procedural integrity*, includes *tikanga* (protocols).

Durie's framework for assessing the impacts of new genetic technologies would result in a series of research outcomes. For example the *whanaungatanga* concept might require that research contributes to the integrity of ecological systems; or an outcome stemming from *tikanga* might be the development of a clear set of protocols, consistent with Māori values (Durie 2004).

The frameworks put forward by Durie and Mead were developed primarily in response to GM technologies and require users to have strong knowledge of Māori traditions and values. Adaptation would be required for use or application by geneticists. These frameworks were in all probability not intended to assist geneticists embarking on longitudinal population genetic studies with large cohorts of *whānau* to locate cures for common diseases.

Guidelines and protocols exist at the national and international levels to assist genetic researchers when engaging with communities, and these provide useful templates for Māori and other indigenous peoples to develop and build upon.

The World Health Organization (WHO) has produced protocols to guide genetic researchers. These protocols have mainly focused on the rights of individuals and do not specifically account for the unique position of indigenous peoples. For example, WHO proposed international guidelines on ethical issues in medical genetics and genetic services in 1998, which discussed appropriate protocols relating to genetic counselling, confidentiality of data, issues around justice and demands for equitable access to services. Table 1 outlines the ethical protocols envisioned in the WHO international guidelines.

The guidelines ask researchers to give a prediction as to the results of research and to indicate potential impacts on individuals and families. Such guidelines do not fit overly well with new genetics research involving Māori, particularly in terms of providing predictions about results and impacts. Ascertaining exactly what might be 'discovered' or result from such research and the complex interplay between genetics, lifestyle and environment is extremely difficult.

Furthermore, the guidelines do not encompass or consider unique world-views held by indigenous peoples, or collective entities such as whānau, hapū and iwi, severely limiting prediction of impacts on culture, spiritual values and communities.

**Table 1:** *Proposed Ethical Guidelines concerning Autonomy and Informed Consent (World Health Organisation Human Genetics Programme, 1998).*

Other examples of professional ethical behaviour expected of researchers in general are captured in the WHO guidelines for participatory health research and include the following:

- When conducting genome and genetic research involving humans, the guiding ethical principle for researchers is respect for persons which is expressed as
- regard for the welfare, rights, beliefs, perceptions, customs and cultural heritage, both individual and collective, of persons involved in research.
- The culture and traditions of the group to which the participant belongs must be
- respected. It is desirable that a group be consulted prior to undertaking
- research on the group with the purpose of understanding whether implementation of the proposed research protocols may cause disrespect or harm to them in any way.
- In human genome and genetic research no participant or group must be exposed to more than a minimum acceptable risk. If it is anticipated that research will expose a participant or group to a specific risk, this should be disclosed.
- Each participant must have the right to demand compensation from the investigator for any injury or harm arising from his/her participation. Appropriate liability agreements should be drawn up between the researcher and the participating individual and/or group before commencement of the research (WHO, 2006).

The 2006 Operational Standards for Ethics Committees (Ministry of Health, 2006) state that the National Ethics Advisory Committee is currently developing a Māori framework for ethical review of health and disability research ([www.newhealth.govt.nz/neac](http://www.newhealth.govt.nz/neac)). The standards outline three Treaty principles which will inform the standards:

- *Partnership* – working together with iwi, hapū, whānau and Māori organisations to ensure Māori individual and collective rights are respected and protected;
- *Participation* – involving Māori in the governance, design, management implementation and analysis of research, especially research involving Māori;
- *Protection* – actively protecting Māori individual and collective rights, Māori data and Māori culture, values, norms, practices and language in the research process.

Whilst these guidelines are useful to ensure researchers working with Māori adhere to ethical standards, adaptation and extension is required if they are to address Māori spiritual, cultural and socio-political perspectives.

Such guidelines do not specifically deal with genetic research involving Māori, which requires a targeted response. The wide spectrum of genetic science that is emerging and rapidly developing makes tracking the ethical, cultural and spiritual impacts on Māori very difficult within the existing ethical and regulatory regimes.

The stigma attached to genetics, due largely to media hype, accentuates the need for an ethical framework targeting genetic research involving Māori communities.

The next section will further develop the concept of a kaupapa wairua Māori ethical framework as a tool to assist genetic science to make positive contributions to Māori development.

### **4.3 Genetics as a tool for whānau transformation – Towards a kaupapa wairua Māori ethical framework**

This section discusses the potential for genetic research as a process to assist in transforming whānau and proposes the establishment a Māori ethical, moral and spiritual framework to achieve this.

For new genetics to have any significant positive impact on Māori communities a broad approach must be adopted that looks at establishing research relationships and processes that are based on sound ethical, moral and spiritual principles.

The amorphous manner in which new genetics research might contribute to health benefits for Māori dictates a broader focus on benefits accruing to Māori communities.

For new genetic research to have a transforming effect it must promote, invoke and develop an ethical, moral and spiritually driven approach to the research process with a view to influencing and assisting Māori community transformation. Invoking such a framework has the potential to influence and transform a community, which would be hugely beneficial irrespective of any long-term health benefits, which may or may not eventuate, as a result of the research. The contribution that Māori could make to the new genetics debate is potentially to broaden the focus and ‘raise the bar’ in terms of dignity and integrity in an ethically contested research agenda fraught with much difficulty and uncertainty.

Creative and innovative research methodologies that consider broader socio-economic benefits, both short and long term, accruing to communities need to be implemented by principal investigators when developing research proposals. Scholarships, employment opportunities, seminars and wananga, getting people interested in and excited about community health and development, history, whakapapa and identity or merely getting people thinking generally about their lives and livelihoods and being spiritually connected to the natural world, their ancestral origins and each other are the types of benefits which a kaupapa

wairua Māori framework supports. Such an approach to new genetics research will not only take pressure off genetic scientists immediately to produce health outcomes but it will also ensure real benefits accrue to communities in need.

The first step towards establishing a Māori framework is to accept that new genetics research is heavily influenced by politics, values and assumptions about the status of science. Genetic research, focusing on whānau and hapū, will always be interpreted and extrapolated for other Māori based on people’s cultural assumptions, values and politics.

#### 4.4 Ethical, moral and spiritual frameworks

Transforming Māori whānau and hapū means invoking broad innovative approaches to research and recognising how it might contribute to the development of Māori health and well-being. Understanding ethical, moral and spiritual perspectives and analysing Māori spiritual and cultural dimensions enhances and drives Māori development. Ohia argues that invoking a Māori ethical framework will give an organisation an ‘edge’ or the ‘X factor’ to achieve what he terms ‘exponential growth.’ The theory of exponential growth asserts that an organisation based on moral, ethical and spiritual elements, with the same amount of input into a project (energy, time, effort, skill, materials, investment, equipment etc.) as another organisation, will record positive achievements beyond what could logically be expected (Ohia, 2006).

This paper proposes that only through the establishment of an ethical, moral and spiritual framework (kaupapa wairua Māori) for new genetics will this research be successful in contributing to Māori development and whānau transformation. Ohia espouses that such a framework is likely to inspire support and be more likely to succeed; he views the alternative route of development, or as some may argue the route currently followed by the majority of iwi, as a pathway to continued oppression and marginalisation of Māori communities.

*... failure due to corrupt behaviour is a natural consequence with the outcome being 'exponential decline' or rapid decline ... (Ohia, 2006: 34).*

Corrupt behaviour in terms of genetics research extends to the enrolling of Māori communities into projects that yield little or no short-term or long-term benefit, and includes unethical research that does not connect with the cultural or spiritual heart of the community being researched. Kenneth Pimple, a commentator and teacher of research ethics, states that:

*Unethical conduct is a social problem not merely because it has a negative social impact but because social forces shape our personal ethical standards. There are at least two standards of right conduct ... one is ethical or moral conduct, and the other is success, whether measured in terms of wealth, popularity, power, or some other coveted social good. Ethical conduct and success are not necessarily at cross-purposes, but they are often perceived to be, and we worry that the latter is likely to drive out the former (Pimple, 1995: 3).*

The idea of invoking a kaupapa wairua Māori framework to drive genetic research is that whānau, hapū or iwi could have collective buy-in regarding the ethical, moral and spiritual dimensions of the research; and the success of such projects would be bolstered by adherence to moral and ethical values. This would constitute a huge contribution to a community regardless of the results of the science.

Bringing such integrity back into genetic science research, which is widely perceived as 'captured' by corporate agendas and untrustworthy, is ambitious but worth attempting. Without such integrity or mana, genetic research will always stumble. Genetics will continue to be criticised by Māori and other indigenous peoples globally as another tool with which to oppress communities, with little or no benefit to those communities at most risk. Macrina (1995: 1) states:

*Integrity conjures images of wholeness, totality, and completeness. Scientific and lay communities alike have recognised that science includes some practitioners who are capable of reprehensible behaviour. They sometimes fall prey to self-deception and may rationalise in ways that mislead themselves and others. Terms like 'sloppy science' are frequently used to describe such behaviour, but the distinctions between 'sloppy science' and 'scientific misconduct' are nebulous.*

*The knowledge that guides scientists' decision making processes is obviously interwoven with their moral principles, yet they learn about standards of conduct for scientific research in varying ways. Awareness of and adherence to accepted standards of conduct is the basis of scientific integrity.*

The questions asked of genetic researchers, rather than merely conferring benefits, should extend to fundamental questions such as, 'Is Māori culture and identity at risk?' and 'Are fundamental Māori values and ways of doing things being threatened in any way?'; this will help ensure that Māori world-views remain intact. The first step to realising this goal is an acceptance that Māori identity and purpose is essential to survival and that science, politics and laws brought by and coupled with colonisation have had and will continue to have significant impacts on Māori identity. In support of this stand, Durie emphasised three points in his address to the Royal Australian and New Zealand Association of Psychiatrists congress. He declared that:

*All are linked to identity and more specifically to the conditions which promote security of identity. The first point recognises that the alienation of people from their land and their culture subjects them to a fragmentation of identity and, along with loss of possessions, a loss of spirit. The second point is that although the law does not create an identity, laws have the capacity to enhance identity or at the very least not to destroy a sense of positive identity. And the third point is simply that identity can be secured more firmly if people are able to feel a sense of participation in the affairs of the nation and can relate to the symbols of nationhood (Durie, 1996).*

It is important to realise that invoking a kaupapa wairua Māori ethical framework is consistent with tikanga Māori and upholds Māori knowledge systems, values and philosophies. However, invoking such an ethical framework involves using aspects of both Māori and non-Māori knowledge:

*It is a matter of Māori reclaiming them in some cases from the ancient world, and of incorporating others (from other sources outside of the 'Māori world' if need be) to build this package of values and principles that will inform Māori behaviour and development. Arguably, this is not a new phenomenon as Māori, over the years, have constructed their set of human values that inform their ethics, integrity and morality (Ohia, 2006).*

Focusing on a holistic approach that emphasises the spiritual dimension is more likely to inspire people, and particularly indigenous peoples, to achieve to the very best of their abilities and model the finest example of humanness. Mead asserts that:

*... a person is far more than a mere biological self. There are other aspects of the self and one of these has to do with the spiritual self, the tapu of the person, the sanctity, the special attributes that we are born with and that contribute to defining our place in time, locality and society (2003: 35).*



The mana-based protocols reinforce the importance of specifying the unique position of Māori and other indigenous peoples throughout the world. They recognise the need to take into account basic professional practices as well as accounting for the cultural, spiritual and political uniqueness of indigenous peoples.

#### *4.5.1 Mana tangata (human dignity)*

Mana tangata demands that researchers adhere to principles of respect, integrity and dignity in their dealings with tangata whenua. For example, genetic research involving Māori must be conducted by qualified researchers, who have at least some knowledge of the indigenous language and culture of the research participants.

The mana-based framework incorporates ethical standards of research that insist on research being quality and safety-assured prior to implementation. Such standards are captured by the WHO guidelines for participatory health research discussed earlier (WHO, 2006).

These ethical standards are incorporated into mana tangata, which requires respect for human rights, dignity and the well-being of participants. Such matters are to take precedence over the expected gains in knowledge. Mana tangata also incorporates robust informed consent procedures, privacy protocols as safeguards against discrimination and stigmatisation, benefit sharing and appropriate counselling services (Tipene-Matua, 2006).

#### *4.5.2 Mana whenua (political authority)*

The mana whenua research protocol affirms the right to self-determination and the unique place of the Māori people and their language and culture. It distinguishes Māori research participants from other groups and acknowledges the right of Māori to control all components of research within their communities.

Key questions include: Are there broader social or political implications arising out of the research being conducted? How does it affect the ability of the indigenous participant to be kaitiaki or environmental guardians? What is the balance of power between researchers and those being researched and how can any imbalances be addressed? Are there opportunities in the research to establish partnership agreements and to encourage a unified response from the indigenous group involved?

The mana whenua component of the research protocol imposes an obligation on the Māori research participants to consider the impact of the research on others including non-Māori. As Mead (2003) argues, ideally an event or technology should maintain, enhance or improve mana, and lift everybody who participates. Will the genetic research impact on other groups in society (Māori and non-Māori) and how can such impacts be minimised? (Tipene-Matua, 2006).

Mana is bestowed by others and is essentially about what you can do for others; it is about looking after the well-being of people. Making decisions based on individual needs to the detriment of others is contrary to this concept, as is the commodification or privatisation of collectively held interests (e.g. whakapapa) without the consent of the collective. What options for collective decision-making or responsibility are available and how can these be supported? (Tipene-Matua, 2006).

#### 4.5.3 *Mana Atua (spiritual integrity)*

Mana Atua is integral to the development of any moral, ethical or spiritual framework for genetic research. Mana Atua might mean providing space for contemplation of the research. Is the research driven by a desire for the public good (as opposed to knowledge for knowledge's sake or purely financial considerations)? Is there a place for karakia (prayer) or ritual to ease any anxieties or allow room to reconsider whether the research should continue? Are there opportunities to contemplate the potential for humility that might avoid causing spiritual imbalances or transgressions of spiritual integrity? Is there an inner consciousness of uneasiness or anxiety about the research or does the research have a good wairua, a good feeling? What are the impacts on Māori cultural concepts such as whakapapa, mauri and wairua?

Māori spiritual perspectives have the potential to add much value to genetic research protocols. They are the antithesis of empirical science and impose parameters for constraint that are sometimes necessary. Spiritual perspectives are indigenous perspectives and, whilst they are difficult to define, often avoided, put in the too hard box or dismissed as being unscientific 'mumbo jumbo', we as indigenous peoples must remain vigilant in presenting such perspectives as a legitimate and valuable part of this debate (Tipene-Matua, 2006).

Initial feedback from researchers on the mana protocols has been positive. There have been valuable suggestions made for improvement, such as perhaps using mana tipuna (ancestral authority) as opposed to mana whenua, as the former could be more relevant to genetics research. Another interviewee stressed the need to incorporate short-term benefits for communities as a standard to assess genetic research. Another view that emerged was the importance of incorporating into the protocols a question on how technology contributed to fragmenting a community, to ensure that genetic technologies do not result in internal disunity as has happened in the past with GMOs (genetically modified organisms). The greatest test of these protocols will be whether they are useful to both Māori and the scientific community.

Rapid increases in genetic technologies drive a need to develop robust protocols to ensure that research participants and researchers are protected from harm. Developing ethical procedures specific to Māori community-based genetic research is groundbreaking, and potentially of significant community benefit.

Key questions to be asked in the future of genetic testing research projects will be: What are the contributing factors that led participants to enter into such projects (e.g. age, gender, education and economic or health status etc)? What expectations do participants have of how researchers should analyse genetic data? Do research participants draw boundaries around what research they consider appropriate and what research should not be conducted? Is there a 'sliding-scale' for research into common, life-threatening conditions such as heart disease, cancer and diabetes and polymorphisms for 'antisocial' behaviours such as gambling, criminal behaviour and alcoholism? How do participants conceptualise the 'therapeutic gap' between the collection of samples and the development of new treatments or health interventions? Do participants want to know or be further informed about the science and broader social issues explored through such research and what short-term benefits could result from genetic testing research on Māori populations (e.g. increased awareness of and interest in health and research)? What issues are specific to Māori as opposed to the general population regarding genetic studies?

#### 4.6 Conclusion

This report has covered a broad spectrum of issues, perspectives and responses regarding genetic testing and research and the potential impacts on whānau, hapū and iwi. The expansion of the 'new genetics' to include the investigation of common diseases raises significant ethical, cultural and spiritual questions and has the potential to provide broad benefits for Māori.

A Māori ethical framework for genetics to be administered by a Māori ethics committee or similar body should be established. Whilst legitimate concerns have been raised about the genetic testing of ethnic and indigenous communities, equally strong sentiments have been expressed warning that we should be careful 'not to throw the baby out with the bath water'. The key is to ensure that the approach to genetic research is balanced in terms of its risks and benefits, and that we do not give genetics more negative or positive spin than is justified. The need for honesty is essential (Tipene-Matua, 2006). There are many talented and committed Māori and non-Māori genetic researchers who believe their science can make a significant contribution to the improvement of community well-being. If genetic research is to be conducted with kaupapa wairua Māori as its foundation, the benefits will be significantly enhanced.

*Am I going to really improve lives? Is it really going to impact and help people? – if I don't believe in the science, I won't do it ( researcher).*

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## APPENDIX

### Methodology

#### **Kaupapa Māori philosophy**

This kaupapa Māori research project acknowledges and recognises Māori epistemology and Māori cultural values and takes for granted Māori ways of knowing and being. The project is viewed in the wider context of tino rangatiratanga and the active pursuit of whānau, hapū and iwi self-determination; the reclamation of our Māori traditions; restoring the tapu and mana – wellness amongst whānau; improving the sociopolitical status of Māori; and achieving economic independence.

#### **Research focus**

The focus of this research study was to analyse relationships between Māori perceptions of the health benefits of genetic testing of newborns with Māori ethical, spiritual and cultural concerns, and the tensions between Māori collective tribal responsibility and individual rights with regard to the access and use of genetic material. The study sought to generate protocols that might be relevant and useful for specific stakeholder groups for effectively interfacing with indigenous Māori communities. All participants were given an information sheet and consent was obtained by individual signature. A draft copy of this report was also circulated for final comment to Te Iwi o Ngati Rakaipaaka before the report was finalised.

#### **Interview process**

Māori participants were asked a range of semi-structured and open-ended questions:

#### **Tikanga Māori**

Participants were asked to give their perspective on tikanga Māori and examples of when their tikanga may be conflicted; weighing tikanga against the potential to gain health benefits from new technologies such as genetic testing; Māori collective decision-making; and the right of individuals to choose how their human genes are utilised.

#### **Rakaipaaka Health and Ancestry Study**

The next set of questions focused on the Rakaipaaka Health and Ancestry Study to ascertain what knowledge participants had of the study and to seek their responses as to what the broader impacts of this research project might be for Rakaipaaka and Māori in general. This included balancing any ethical concerns with the potential impacts on the health of a child or mokopuna; the possibility of a taonga species or traditional food source being impacted upon; and the rights and responsibilities of individuals, whānau, hapū and iwi.

## **Whakapapa, DNA**

These questions examined the notions of who owns DNA and whakapapa and the patenting of whakapapa. Participants were also asked to comment on existing monitoring bodies and whether there was a need for establishing a national body to manage the utilisation of genetic resources from an iwi/Māori perspective, and how this monitoring body might look (i.e., representation, kaupapa, resourcing, etc).

### **The mana protocols**

Participants were asked to comment on the mana guidelines under development by the research team to assist genetic researchers when engaging with Māori communities and to ensure researchers adhere to principles of respect, integrity and dignity in their dealings with tangata whenua. These included:

#### **Mana tangata (human dignity)**

- Respect begins with researchers having at least some knowledge of the indigenous language and culture of the research participants. (Ensuring researchers are culturally safe is likely to require training – e.g. knowing how the Treaty applies to the research being conducted.)
- It is important to have regard for the welfare, rights, beliefs, perceptions, customs and cultural heritage, both individual and collective, of persons involved in research.
- It is desirable that a group be contacted prior to research being undertaken on the group to avoid disrespect or harm being caused in any way. It is important to develop strong relationships and engage communities through honest communication based on mutual trust and benefits.
- If it is anticipated that research exposes a participant or group to a specific risk, this risk must be disclosed.
- Each participant must have the right to demand compensation from the investigator for any injury or harm arising from his or her participation.
- Appropriate liability agreements should be drawn up between the researcher and the participating individual and/or group before commencement of the research (World Health Organization, 2006).
- Informed consent procedures and privacy protocols should be in place.
- Safeguards against discrimination and stigmatisation should be in place.
- Benefit sharing, appropriate counselling services and access to kaumātua advice should be offered.

### **Mana whenua (political authority)**

- Do Māori have the right to veto the release of any research data and are there opportunities to vest any resulting intellectual property in the Māori collective?
- Are there broader social or political implications arising out of or influenced by the research being conducted?
- How does it affect the ability of the indigenous participant to be kaitiaki?
- What is the balance of power between researchers and those being researched and how can any imbalances be addressed?
- Will the genetic research impact on other groups in society (Māori and non-Māori) and how can such impacts be minimised?
- What options for collective decision-making or responsibility are available and how can these be supported?

### **Mana Atua (spiritual integrity)**

Mana Atua – spiritual integrity – means providing space for contemplation regarding the proposed research.

- Are there opportunities to consider the potential for humility that might avoid causing spiritual imbalances or transgressions of spiritual integrity?
- Is the research motivated by the public good (as opposed to knowledge for knowledge's sake or a purely financial imperative)?
- Is there a place for karakia (prayer) or ritual to ease any anxieties or to enable reconsideration of whether the research should continue?
- Is there an inner consciousness, uneasiness or anxiety about the research or does the research have a good wairua, a good feeling?
- What are the impacts on Māori spiritual values (e.g. whakapapa, mauri and wairua)?

### **ENDNOTE**

- 1 Mead (2003) describes tapu as 'the most important spiritual attribute' (at 45) and a 'state of being set aside' (at 367). Hiroa (1948 (1982)) regards tapu as a restriction (at 347) and as prohibitions and sanctions (at 349).