Chapter 3 MĀORI PERSPECTIVES ON PRE-BIRTH GENETIC TESTING WITH PARTICULAR FOCUS ON PGD

PROLOGUE

To gain a full appreciation of a likely Māori response to pre-birth genetic testing it is necessary to contextualise the discussion within broader debates regarding emerging health biotechnologies.

For example, we were quickly reminded by research participants that power and control and the potential for social disparities to be accentuated were as much of an issue for pre-birth genetic testing as it is for other biotechnological innovations. Māori responses to genetic engineering biotechnology, the domination of genetic science by corporate agendas, and suspicion of health professionals and innovations resulting from successive negative colonial experiences, are factors likely to influence how Māori might respond to pre-birth genetic testing. This is articulated by Jessica Hutchings[1]:

> *But because this area is, not so much about helping people, it's more about making money and doing high profit driven sciences, that's driven by a multi-national and a free trade agenda and globalisation ... I know why it is, from my perspective it's about money, it's about profit and it's about power.*

This chapter situates the discourse on Māori perspectives of pre-birth genetic testing within broader issues confronting Māori as a result of the biotechnology explosion in the last ten years and the completion of the human genome project. It details Māori values, concepts, cosmology and traditions to provide a platform to analyse the implications of genetic testing on Māori people and Māori culture.

Broader issues around equality of access to health services, discrimination, and the potential erosion of cultural and spiritual values will need to be addressed if biotechnological innovations emerging from the mapping of the human genome are to be met with anything but suspicion and scepticism by Māori.

Similarly, in order to understand how pre-birth genetic testing may influence Māori, it is necessary to have some understanding of Māori cultural values, beliefs and perspectives. Literature on Māori responses to genetic engineering is useful to assist with this understanding particularly as there is limited literature and information on Māori views about pre-birth genetic testing.

The study conducted for this project is reported in Part B of this chapter where we reproduce and discuss the findings gathered from a selected group of Māori interviewees with relevant experience and knowledge (see the appendix to this chapter for an outline of the research process undertaken). The interviews both supplement and fill gaps in information gained from research literature and other sources, and provide depth and breadth for Māori perspectives of pre-birth genetic testing. Participants were chosen because of their broad range of expertise in matauranga Māori (Māori knowledge), Māori health, and socio-political issues regarding genetic engineering. Whilst participants were, for the first time, asked to consider the impact of pre-birth genetic testing on Māori they were able to draw heavily on their own knowledge base and considerable expertise.

With responses being considerably diverse, we have found that there is no clear single Māori world view on the possible impacts of pre-birth genetic testing on Māori. They range from a deep seated suspicion of the technology as merely another tool for powerful corporations and health professionals to increase societal inequities, to an acceptance based on the potential health benefits for whanau and tikanga Māori.

Pre-European Māori used social controls to protect and maintain the collective wellbeing of whanau and hapu. Arranged marriages, surrogacy, abortions and infanticide were practised and the importance of whakapapa paramount. Whilst these practices sometimes seem consistent with Māori cultural norms and values, there are diverse opinions about how and why they are carried out today. For example, one participant stated that abortion is not acceptable unless absolutely necessary and another felt it is important to distinguish between those Māori who want to participate in this discussion from a general perspective or from a Māori perspective. This is a classic example of the diversity in Māori views. We do not seek to homogenise Māori and present a singular Māori world view on pre-birth genetic testing. Rather, as a participant states below, we seek to explore the diverse perspectives from a particularly Māori point of enquiry.

> *So there's not a clear picture one way or the other about where Māori today might be. There's such a mix but I think the task that is becoming clearer is that where we as Māori are actually engaging with like abortion or birth, as Catholics or Christians as Scientists or as just someone out in the suburbs ... It's that "Kia Ora", well really you just happen to be a Māori Catholic, you're a Catholic actually and your views are Catholic ... and so that's where it's coming from. So what is this Māori view...there is a challenge to distil out what is distinctively Māori and that will only be a part of the answer because it doesn't mean to say that we all should or even can embrace [it].*[2]

Māori acquiescence of genetic testing is by no means universal or absolute. Caution has been expressed regarding the need to maintain the integrity of the process as unborn foetuses have a mauri and wairua that must be respected. The spiritual and emotional concerns of parents and whanau need to be accounted for as well as issues of equity and access to effective pre-birth genetic testing services.

Identifying how to respond to Māori cultural values and practices in a regulatory regime is challenging. Regulation in any area must command popular support and be guided by principles of proportionality, certainty, clarity, accountability, efficiency and accessibility. As a Māori values system is distinct from that of the majority population, protecting its integrity, holism, nuances and institutions within a regulatory framework is difficult.

The Treaty of Waitangi ('the Treaty') affirms the ethical and legal basis for striving to appropriately recognise Māori values, and is supported by four other legal doctrines: international human rights standards, aboriginal title, the fiduciary duty imposed on the Crown, and the status of tikanga Māori as a system of customary law. The Treaty and supporting legal doctrines also establish the founding principles which must guide any regulatory response. The essential factor is ensuring that Māori retain the right and ability to define and redefine the application of Māori customary values to pre-birth genetic testing. This means that Māori who wish to engage with pre-birth genetic testing should be able to do so with confidence that their cultural preferences and customary values and practices will be respected and maintained.

PART A: SETTING THE SCENE

1 MĀORI CULTURE, SPIRITUAL ETHICS AND GENETIC SCIENCE

A discussion about Māori culture, practices and perspectives can be understood through exploring stories of cosmology and creation. Māori cosmology provides not only an understanding of how tupuna (ancestors) viewed the world and their place within it, but also informs contemporary understandings, attitudes and concerns towards birth processes and the use of technology.[3]

> *[M]yth and legend in the Māori cultural context are neither fables embodying primitive faith in the supernatural nor marvellous fireside stories of ancient times. They were deliberate constructs employed by the ancient seers and sages to encapsulate and condense into easily assimilated forms their view of the world, of ultimate reality, and the relationship between Creator, the Universe and man ... These conceptualisations form what is termed the 'world view' of culture ... a systematisation of conceptions of reality to which members of its culture assent and from which stems their value system. This 'world view' lies at the very heart of the culture, something interacting with and strongly influencing every aspect of the culture.*[4]

Māori customs, values and attitudes are derived from an indigenous[5] body of knowledge which seeks to understand the universe and its origins. Māori cosmology looks deeply into the infinite darkness of eternity that existed before life began. The two fundamental principles in this cosmology are whakapapa (genealogy) and the personification of natural phenomena. Māori developed complex genealogical constructs through metaphorical language and poetic imagery to explain the universe and its origins, and the creation of life itself.[6]

Most accounts of the universe and creation itself are arranged in genealogical order. Some start with a description of Te Kore (the realm of 'chaos', 'nothingness' or 'potential being'). In this realm lived Io, a supreme being whose ihi (essence) bore Te Po (the night realm) and Te Ao Marama (the full light of day). Io then created a single ancestor from whom came Rangi and Papa, who after separation came to be known as Ranginui the 'sky father' and Papatuanuku the 'earth mother'.[7]

The three cosmological realms of Te Kore (the realm of potential being), Te Po (the realm of becoming) and Te Ao Marama (the realm of being) are all linked together to form the continual progression of life from conception, birth, life and death. Along this pass, in the opposite direction, the departing spirits descending to Hawaiki, and 'that which is in the process of becoming, ascending to the world of being.' Thus, the universe is holistic and dynamic; there is within it an ongoing process of continuous creation and re-creation.[8]

Furthermore, a traditional Māori view considers everything in the universe to be linked in some way to Ranginui and Papatuanuku through whakapapa. There is no separation between the cosmology or whakapapa of the natural world and the supernatural. Both are part of a single system, creating a fixed and unalterable bond between humans and the physical world. All Māori therefore are descendants from gods, goddesses, guardians and super-humans.[9]

One must first have an understanding of Māori cosmology and te ao Māori, in order to understand traditional Māori relationships with the land and the subsequent spiritual and cultural concepts, values and beliefs that stem from this relationship.

In this report, pre-birth genetic testing is analysed based on te ao Māori and matauranga Māori. This report situates perspectives provided by the 'research participants within a Māori worldview to avoid any watering down or misunderstanding of these concepts'[10]. Within this context, the participants raised concerns with genetic modification stemming from the paradigmatic differences in te ao Māori and the Western science tradition from which genetic science developed. Reconciliation of Māori spiritual, cultural and ethical concerns is often at odds with the reductionism on which genetic modification is based.

2 MĀORI RESPONSES TO GENETIC TESTING - A COMPARATIVE ANALYSIS

There is now an established body of literature and research documenting Māori responses to genetic modification. Whilst this research literature remains relatively new and the discourse evolving, it is useful to examine what Māori have said about genetic modification to gain deeper understanding of views about the potential implications of pre-birth genetic testing.

Articulation of Māori cultural perspectives and concerns about genetic modification came to prominence as a result of a high profile application to the Environmental Risk Management Authority (ERMA) in 1998 seeking to genetically modify cattle using human genes. Significant submissions were also provided to the government's Royal Commission on Genetic Modification in 1999.[11] Further information from the Royal Commission revealed two areas of concern. The first is primarily political and based on the Treaty of Waitangi. The second relates to cultural realities and values, most of which are regarded as being antithetical to genetic modification and particularly transgenics.[12] It is therefore very important when investigating potential Māori responses to pre-birth genetic testing to look and gain some insight into the bases for Māori cultural, spiritual and ethical perspectives and concerns.

3 WHAKAPAPA, MAURI, WAIRUA, TAPU AND NOA

The following discusses Māori responses to genetic modification with the aim of gaining understanding and insight into the potential impact of pre-birth genetic testing on key Māori concepts such as whakapapa, mauri, wairua, mana, tapu, noa, rangatiratanga and kaitiakitanga. These key concepts are outlined below not necessarily as a definitive classification but rather to provide a lens through which to analyse the implications of pre-birth genetic testing on Māori.[13]

The Māori world view has its roots deeply entrenched in whakapapa with a focus on the importance of relationships between tangata whenua (people of the land) and the natural world that reflect the links between Māori, the universe and the environment.[14]

Whakapapa is the genealogical descent of all living things from the gods to the present time.[15] 'Papa' is anything broad, flat and hard such as a flat rock, a slab or a board. 'Whakapapa' means to lay upon one another and is used to describe both the recitation of genealogies, and

also to name the genealogies. When a child is born, the child is born into a kinship system which has been in place for many generations. Whakapapa provides identity within a tribal structure and can be traced right back through to the beginning of time.[16] Māori cosmological narrative, previously outlined, in which the origins of the world and all living and non-living things are inter-connected, is essential in understanding discussions surrounding whakapapa. Whakapapa enables Māori to be located within the context of all that exists in the world and articulates a specifically Māori identity.[17]

Whakapapa is one of the fundamental ways in which Māori come to see and think about the world. Whakapapa is also a way of learning, a way of storing knowledge, and a way of debating knowledge. It is inscribed in virtually every aspect of te ao Māori (the Māori world).[18]

The continuity, values and practices of Māori societies began with whakapapa[19]. Whakapapa is the 'determinant of mana rights to land, to marae, to membership of a whanau, hapu, and collectively the iwi, the whakapapa determines kinship roles and responsibilities to other kin, as well as one's place and status within society'.[20] All in the Māori world can be seen to connect back to a founding ancestor through whakapapa.

Whakapapa accordingly plays an important role within whanau. Access to genealogical knowledge is integral to the functioning of a whanau in a number of ways. Birth order and generational level affect patterns of behaviour between whanau members and provide the basis for deciding issues of precedence and leadership. Whakapapa enables whanau members to establish links with one another, with wider hapu and iwi, and with a wide range of whanaunga.

Understanding whakapapa is essential to gaining insight into Māori concerns about genetic modification. As Roberts[21] states, it is through whakapapa that everything from a rock, a tree, the ocean and humans are all balanced intricately. Māori therefore have voiced concerns with the potential that genetic science has in threatening this delicate balance.[22] This is reiterated by Gibbs:

> *It is clear therefore, that genetic manipulation of the human genome may be seen by Māori as interference with the basic structure of relationships between generations and between species, which is central to both the practical and spiritual aspects of Māori life.*[23]

Recent research relating to genetic testing has highlighted Māori concerns about protecting Māori ways of defining and explaining the world and the cultural traditions and interpretations that are bound up in whakapapa.[24] Issues also remain not only for the potential disruption of whakapapa, but the subsequent breach of tapu that such disruption may engender. Some of the Māori concerns around genetic modification focus heavily on whakapapa and mauri and the impact on Māori spiritual values (wairua). In contrast, lesser emphasis is placed on genetic testing that does not involve the mixing of whakapapa through transgenics and therefore does not involve mixing of genes between species or, as some Māori have put it, 'mixing whakapapa'.

Understanding mauri is important when exploring the potential impact of pre-birth genetic testing on the Māori world.[25]

Mauri is a special power possessed by Io that makes it possible for everything to move and live in accordance with the conditions and limits of its existence. Everything has mauri including people, fish, animals, birds, forests, lands and rivers; mauri is the power which permits these things to exist within their own realm and sphere.[26]

Mauri can be thought of as the life force of humans. Mauri is the spark of life, the active constituent that indicates a person is alive. 'Tihei mauri ora' is the sneeze of life which signals the independence of the child from the womb, and is a manifestation of mauri existing as an essential and inseparable part of that particular person. Life is extinguished with the last breath, the body stops and becomes cold -this is when mauri leaves the body and the person dies.[27]

Humans are regarded as possessing a 'higher order' mauri, compared with other forms of life. Along with the obligations inherent in kinship relationships, this notion confers on people a responsibility to protect whanau, hapu, iwi and the environment.[28]

The importance of mauri in debates about genetic modification concern the transfer of genetic material from one organism to another and subsequent impact upon mauri:

> *In the Māori conception all life forms – animate and inanimate – have diverse origins as all have a genealogy back to the gods; the source of their life and being. Each life form, including each person, is therefore imbedded with its own mauri and each makes a substantial contribution to the cosmos and all things that live within. This mauri and the life forms are linked together, including humanity, by whakapapa, through mutual descent. As the mauri of all living things is connected by these kinship ties, acts that change or degrade the essence of one life form have an impact on the integrity of all other life forms.*[29]

Māori concerns relate to the impact of biotechnologies on whakapapa, mauri and the natural order of the universe. These concerns are also linked to the potential for changes in the essence of human beings and other living things, whose genes have been manipulated.

Manipulation of mauri is also seen to have implications for the nature of relationships between people and other living organisms. Genetic modification is considered by some to be tampering with the very spiritual essence of being Māori, which is deemed unnatural and to be taking away the 'mystery' of life.[30]

Such concerns extend to mattters relating to the disposal of affected embryos and foetuses, and involve broader ethical and moral debates over when life begins and the subsequent question about whether or not an embryo or foetus has mauri. There could therefore be perceptions of negative implications of the disposal of an embryo or foetus, with subsequent impact on mauri, for prospective parents and their whanau.

Barlow[31] conceives of wairua as the spirit within all things – all things have a physical body (tinana) and a spirit (wairua). These physical and spiritual properties are joined together by mauri but "when a person dies, their physical remains are interred in the earth; their spirit lives on and travels the pathway of Tane to the gods that created them".[32]

Tapu has two aspects, the first of which is known as intrinsic tapu and is concerned with the recognition of the inherent worth of each individual and the sacredness of life. This is important as Mikaere states that '[n]o individual stands alone: through the tapu of whakapapa, she or he is linked to other members of the whanau, hapu and iwi, and to other Māori as well. Every person is linked to the generations to come and to those that have been before. Every person has a sacred connection to Rangi and Papa and to the natural world around them.[33] This form of tapu extends to the body, with the head generally considered the most tapu part of a person.[34]

The second aspect of tapu is the spiritual prohibition or protection which can be invoked in a number of different circumstances. The function of tapu in this instance is the maintenance of social control and discipline, and the protection of people and property.[35]

Opinions can vary regionally on which things possess significant tapu over others. For instance a coastal iwi may regard a whale as tapu, while an inland iwi may not. Tapu can also apply to individual things as well as groups of things. For example a particular tree might be seen as tapu, while the class of trees it belongs to may not. When a person or thing is deemed tapu, certain restrictions or sanctions come into effect while its spiritual efficacy is enhanced. Tapu is managed carefully as it is seen as dangerous and matters involving tapu are often reserved for specially gifted and competent tohunga to deal with.[36]

Tapu is frequently invoked in discussions surrounding Māori and genetic testing and genetic modification. According to Satterfield *et. al*,[37] '[t]he general consensus or consistency with which human body parts are said to be subject to tapu has potentially significant implications for genetic modification when human genetic material is used, in that most conceptualise a gene as a body part'. There is limited understanding of the precise way in which to deal with tapu in the context of genetic modification. While some argue that humans are simply too tapu to be subjected to this kind of technology at all, others maintain that the tapu of humans does not constitute a barrier to genetic modification.[38]

Noa is often paired with tapu in that noa refers to restoring a balance. A high level of tapu is seen to be dangerous, and in these instances it is the role of tikanga and tohunga to reduce the level of dangerous tapu until it is noa or safe.[39]

The principle of noa has been used, not necessarily in specific relation to genetic modification, but for example, in categorising organisms. It has been suggested that it might be considered more appropriate for a noa organism to be modified than a tapu organism, and consequently that it may be unacceptable for a noa organism to be transferred into a tapu organism.[40]

Such notions are important in this debate as they may form the basis of anxieties and stress that a Māori patient might feel when being treated or subjected to medical procedures or diagnosis:

> *If I was to go to the doctor, I whakanoa myself - I leave all those things tapu that I practise. I leave them here - why? Because I am going to the doctor who I know is going to help me and I trust that will help me. So he doesn't want all my hang ups to get what he needs to do for me. He wants to just do what he can for me and when I get out then I come back and [can] be tapu again ... So, to whakanoa means to leave all those personals behind and go according to the kaupapa of your need.*'[41]

The protection of some areas of the body thought to be extremely tapu can be temporarily suspended through the practice of whakanoa. This has a number of implications for genetic testing as a Māori patient seeking use of the technology might require counselling or karakia whakanoa (tapu lifting incantations) to alleviate concerns or anxieties about the genetic testing process, or the use or disposal of his/her genetic material.

While this may be the case, some Māori have warned against the simplistic notion that Māori resistance to genetic modification be regarded as a problem easily addressed by the use of karakia whakanoa by tohunga on demand.[42]

4 MANA, KAITIAKITANGA AND TINO RANGATIRATANGA

Mana incorporates notions of power, authority, prestige, uniqueness and the recognition of these qualities.[43] Mana refers to the intrinsic power of the gods or atua and their spiritual authority (mana atua), the power embodied in the individual person drawn from the land (mana whenua) as manifest in the skill and acumen in a particular area (mana tangata), or as reference to the power rooted in links to the land and its potential to provide human sustenance (mana whenua).

Mana is an integral spiritual concept in discussions surrounding pre-birth genetic testing as it defines the relationship between others and influences Māori ability to exercise kaitiakitanga and the right of tino rangatiratanga.

Whilst mana has a range of meanings, the most relevant in this debate is that which defines it as the integrity of a person or group that manifests itself in action.[44] Central to the issue of pre-birth genetic testing is the maintenance of both collective and individual integrity.[45] Relationships therefore, both personal and group, are always mediated and guided by the value placed upon mana. The promotion of the collective good and authentic Māori responses to new technologies requires appropriate structures, institutions and frameworks for the ongoing enhancement of mana. Generative power is linked to mana also. For example, the integrity of women, or mana wahine, is connected to Papatuanuku and her generative and nurturing powers, while the integrity of men, or mana Tane, is connected to Te Waiora a Tane, the source of life. Besides life-giving powers, mana is also about order (thus enabling life to avoid chaos, destruction, imbalance) and contributes to mana Māori and the integrity of all Māori people. Mana therefore is concerned with form and order and the concern for ritual and convention.[46]

The source of all mana is through ancestry and descent derived from the atua or gods. In traditional Māori society, this mana atua or mana wairua (spiritual mana) was essential for survival. Together, mana wairua (spiritual authority), mana tupuna (ancestral authority) and mana whenua (authority based on ahi ka) constitute the taonga tuku iho (natural heritage, or legacy) of Māori. Expression of this total mana was through rangatiratanga or the exercise of chiefly authority in respect of land and all other taonga (valued possession).[47]

Mana is both inherited and bestowed, but is not something that people or groups can claim for themselves (even if it is bestowed on an individual, it is within the context of enhancing the mana of the group). Mana therefore, has little relevance outside of a collective context as it is through the 'words, thoughts and hearts of people that mana is established and maintained'.[48]

In the context of whanau, mana plays an important role also. The whanau as a whole has its own mana that comprises a core of mana tupuna, but is also affected by the behaviour of individual members and the way in which the whanau fulfils its function as a collective. Whanau members have a shared responsibility to work to build up the mana of the group and also to restore it when damaged.[49]

At one level there is concern over whether the technology will adversely impact on the mana of the patient or any others associated with the process. It could be argued, echoing some arguments in the related context of genetic modification of organisms, that meddling in human genetic testing and reproductive activities is contrary to Māori culture and values as humans do not have the mana to take on such technology safely - interventions in the human reproductive cycle through the use of pre-birth genetic testing involves interfering with the integrity of the human body (mana tangata) and the will of atua (mana atua).[50] An innovation such as pre-birth genetic testing could adversely impact on the mana of not only those who use it but also those who are involved with the technology in other ways, if negative consequences occur. For example, if potential parents decide to undertake pre-birth genetic testing and subsequently have an abortion, they may be targeted and denigrated by others and their personal mana and that of their whanau is put at risk.

At another level, there are concerns that arise in a collective sense over who has the mana to make decisions in regard to utilising this technology, especially if it is perceived to have negative effects on the wider whanau, hapu, or iwi. This is of significance as mana, kaitiakitanga, and rangatiratanga are all infused in the maintenance and enhancement of whakapapa. Professor Hirini Moko Mead[51] argues that ideally an event or technology should maintain, enhance or improve mana, and lift everybody who participates in the event. The issue here is about the implementation and exercise of mana through kaitiakitanga, rangatiratanga and consequently in decision-making with regard to this technology:

> *In terms of rangatiratanga under the Treaty, Māori assert that they were guaranteed the right to exercise ownership over their taonga resources and the decision-making rights on use and protection that flow from ownership. Taonga resources, in this sense, include significant species and traditional knowledge that might be used to create new life forms or be the subject of a patent.*[52]

Frequently in discussions relating to genetic modification, Māori ultimately position themselves as kaitiaki (guardians) over all things that pertain to Māori.[53] The term tiaki means 'to guard', but also has other closely related meanings depending on the context. Tiaki can also mean 'to keep', 'to preserve', 'to conserve', 'to foster', 'to protect', 'to shelter' 'to keep watch over'.[54] Kai with a verb denotes the agent of the act. Hence, kaitiaki means a 'guardian', 'keeper', 'preserver', 'conservator', 'foster-parent', or 'protector'. The suffix 'tanga' added to the noun means 'guardianship', 'preservation', 'conservation', 'fostering', 'protecting', 'sheltering'.[55]

Māori have practised Kaitiakitanga for millennia and have protected and cared for their environment and heritage. The purpose behind the principle was to ensure the protection of mauri of all things both animate and inanimate. The following quotes taken from Satterfield *et. al.*[56] illustrate the importance of kaitiakitanga in relation to genetic modification:

> *... kaitiakitanga is about ... the mediation of ... the environmental, [the] spiritual and the human. And it's about [the] management of humans, as much as environmental stuff ... you've got to ... do it with integrity.*
>
> *Kaitiakitanga ... is a really big responsibility in our lifetime, to make sure that we care for this planet, and GMO [i.e. genetically modified organisms] is defiantly a part of that thinking so that we make wise decisions.*[57]

The responsibilities and obligations of kaitiaki are as much an attitude about life as they are about human behaviour. Kaitiakitanga is about decision-making, discussion and debate, and the management and safe-guarding of the physical, human and spiritual worlds.

Māori are careful also to preserve the many forms of mana they hold, particularly in relation to ensuring the mana of kaitiaki is preserved:

> *As minders kaitiaki must ensure that the mauri or life force of their taonga is healthy and strong. A taonga whose life force has been depleted ... presents a major task for the kaitiaki. In order to uphold their mana, the tangata whenua as kaitiaki must do all in their power to restore the mauri of the taonga to its original strength ... should they fail to carry out their kaitiaki duties adequately, not only will mana be removed, but harm will come to members of the whanau and hapu.*[58]

The influence of mana and the ability to exercise kaitiaki are central to discussions surrounding pre-birth genetic testing. If pre-birth genetic testing is undertaken and individual and collective mana is in some way compromised, this will in turn affect Māori ability to exercise kaitiakitanga.

As genetic modification and genetic testing are relatively new and to some extent poorly understood, opinions vary on how kaitiakitanga should be exercised in relation to genetic modification decision-making. The following quote taken from Satterfield *et. al.*[59] indicates a guardianship posture to all genetic material, and while suspending permission to manipulate genetic material at present, leaves open the possibility of genetic modification after significant consultation:

> *... [I ask myself] is there any Māori thought in this area, and there kind of isn't. So, if you went from first principles, Māori would say that all genetic material is taonga. I mean, it's been given to us, it's ours to look after. But it's not actually ours. You actually don't own it, but you're its guardian ... [it's] something to be treated with reverence which automatically means that you can't just go ahead and do ... [anything you please]. There needs to be discussion and consultation and some thought put into it. And I don't think Māori would be different from anyone else in that respect.*[60]

In contrast to this view Satterfield *et. al.*[61] states that kaitiakitanga is opposed outright to the kind of options genetic modification involves:

> *... from the point of view of kaitiakitanga - you know, the preservation of whakapapa within food plants, within natural ecosystems, all of that which I said would say well no. I think that those are silly things to do. And they don't take us anywhere and they in fact undermine our long-term benefit.*[62]

Both of the above views on kaitiakitanga express an inclination for long-term planning. They also show that kaitiakitanga is as much about protecting humans as it is about non-human species and organisms. In this sense it can be associated with the imperative of caring for humans, or with the principles of aroha, manaakitanga, and whanaungatanga. With this, the potential for balancing competing interests (human interests vs. non-human, and human interests vs. other human interests) is also brought to the fore.[63]

It has also been observed that:

> *'Iwi and hapu require the presence of mana and tino rangatiratanga in order to be kaitiaki. Conversely, without kaitiakitanga there is no mana. Without kaitiakitanga, hapu may be unable to manaaki their guests, be unable to appropriately feed or house their guests, resulting in a loss of mana. Kaitiakitanga is an action arising from mana and tino rangatiratanga*'.[64]

Explicit in the recognition of kaitiakitanga and in the right to exercise kaitiakitanga is its relationship to rangatiratanga. Rangatiratanga is an inherent part of the exercise of kaitiakitanga, so without recognition of the latter, the former becomes impossible to exercise. Rangatiratanga invokes the authority to make decisions and take control and responsibility for one's destiny and kaitiakitanga imposes an obligation as tangata whenua to protect the wellbeing of future generations.

Tino rangatiratanga is often translated to mean Māori sovereignty. However, this English translation is contested as some Māori argue that the meaning does not suit Māori worldviews and limits what is meant by the word. According to Durie[65], the concept of tino rangatiratanga can be used to 'describe Māori aspirations for independence and self sufficiency ... iwi [tribal] control over people and assets in a particular region'.

To Barlow[66] however, rangatiratanga does not describe Māori power and status because it was a word coined by Pakeha when the Treaty of Waitangi was signed. Barlow believes that the appropriate word is arikitanga, which describes the concept of supreme mana or power of Māori. Mana motuhake is therefore the preferred term for self-determination or authority among some iwi (for example Ngati Porou).[67]

Tino rangatiratanga is however frequently used in Māori discourse and provides a way for Māori to unite around issues of power and resistance.[68] Smith[69] states that 'the politics of sovereignty and self-determination have been about resisting being thrown in with every other minority group by making claims on the basis of prior rights'. Tino rangatiratanga can therefore be seen as a statement about authority or, as Professor Mead[70] argues, as 'honestly and sensibly as self-government or as home rule'.

Within the genetic modification debate, tino rangatiratanga was a key focus regarding the control over issues pertaining to decision-making at both an individual level and at a collective level. Embedded in the acceptance and recognition of rangatiratanga is mana. Tino rangatiratanga was often raised in discussions surrounding an individual's right to make decisions surrounding genetic modification. The following quote taken from Satterfield *et. al.*[71] outlines a respondent's use of tino rangatiratanga when pursuing medical treatment.

> *... we only need to look at Seventh Day Adventists' use of blood transfusion. The likes of the Holloway case, of parents having the right [to decide] on cancer therapies, and realise that if we are going to be true to our own tino rangatiratanga if you like, it also needs to support others and the rights for them to make decisions.*

From this statement, it could be argued that tino rangatiratanga can be elicited to either accept or reject genetic modification and genetic testing.

5 SUMMARY

There are a number of unique concerns from te ao Māori in relation to genetic modification. These concerns have been outlined in the previous section and will be used as a point of enquiry into pre-birth genetic testing.

Through an understanding of the cultural, ethical and spiritual concepts outlined previously, we seek to gain a better understanding of the potential that pre-birth genetic testing may have on Māori. The themes that have emerged in relation to pre-birth genetic testing are somewhat different from existing debates surrounding genetic modification. The following section reviews responses from research participants and discusses the themes that emerge from those discussions.

PART B: MĀORI AND PRE-BIRTH GENETIC TESTING

There is clearly no single Māori view on the potential risks and benefits of pre-birth genetic testing although strong patterns of opinion and agreement on aspects of those potential risks and benefits emerged during this project.

Key principles and practices from within te ao Māori and traditional Māori approaches to reproduction, abortion and infanticide were used as a point of enquiry for pre-birth genetic testing. The traditional Māori practices and associated values that existed in pre-European society do not provide a definitive response as these examples can only guide discussion and inform opinions on contemporary practices such as pre-birth genetic testing. Alongside these traditional stories were also some more contemporary issues surrounding equity and access to pre-birth genetic testing services. An area of considerable concern to be addressed in the legal section of this report is balancing an individual's right to access genetic testing and their responsibilities to the collective, particularly hapu and iwi.

1 REPRODUCTION, WHAKAPAPA AND PRE-BIRTH GENETIC TESTING

The overarching principle of whakapapa and its pervasive influence in all matters of the Māori world is fundamental in a number of historical (and some may argue contemporary) practices regarding reproduction. Whakapapa traditions are replete with examples of arranged marriages (taumau) and predetermined strategic tribal alliances that had beneficial purposes for collective groups. Strong individual and whanau characteristics were also nurtured and passed down through whakapapa lines. The notion of Māori encouraging, supporting and pre-determining desirable characteristics in society was discussed by a number of participants:

> *That was one of the considerations around arranged marriages, the importance ... . bloodlines. ... There was an awareness of genetics, heriditary traits you mix the right blood and you get come up with a good result.*[72]

While a number of participants outlined notions of 'strong bloodlines' and strengthening whakapapa as an important component of reproduction and Māori society, another participant outlined some of the more spiritual practices surrounding te ao Māori and pre-birth:

> *I wonder from a traditional perspective what the perceptions were of pre-birth ... I mean I've heard bits about the health of the child, the amount of prayers and spiritual involvement as well in terms of...makutu, and the way that makutu had a negative impact or haehae or any of those kind of things negatively impact upon a pregnancy ... one could argue that that's still meddling with pre-birth.*[73]

This 'negotiation' or 'manipulation' surrounding reproduction and whakapapa was also exercised by the atua and selected marriages:

> *So there are pregnancies that are attributed to the gods and there are pregnancies that are made by well selected marriages between He Ariki Wahine na He Ariki Taane, tenei tuu Rangatira ka moe, ka puta ko tenei kawai tuakana, kawai mataamua, kawai tapu nei, so all our history is full of it ... The culture is absolutely full of it.*[74]

The maintenance of bloodlines and the arranged marriages were an attempt also at maintaining mana and strong rangatira lines. They were:

> *...very much part of Māori thinking, and so much so like some things that have been hidden because of our Victorian time, so brother sister, marriages ... because if sister comes out first, well we're not letting any prick in here take our tuakana off there, so you have to marry your brother ... It's certainly there in the Hawaiians. It's not just us. It's in the Pacific, it's in the Polynesian culture, very much. Looking at kawai and thinking about...because it was believed, you see it come from the atua, [it] is where these kawai come from.*[75]

While participants had a number of stories relating to reproduction and bloodlines, either through taumau, spiritual interventions or the atua, they were all bound by a desire to strengthen whakapapa and ensure the continued well-being of collective groups.

Based on traditional Māori approaches to determining bloodlines, and the reproduction or maintenance of desirable characteristics through a number of functions and processes, a perspective emerged through which such practices could be linked to the contemporary technology of pre-birth genetic testing. Whakapapa was outlined as the fundamental principle bound up in reproduction and child-birth. These notions hold similar importance today, and links were drawn with the potential that pre-birth genetic testing had to foster these traditional ideals.

Interestingly, the degradation of whakapapa values has often been illustrated in debates surrounding genetic modification. While we do not deny the negative potential that pre-birth genetic testing may have for whakapapa, the fact that transgenics and genetic testing are considerably different was an influence. There is a view amongst Māori that distinction should be drawn between pre-birth genetic testing and genetic modification *per se*, in terms of the impacts on whakapapa:

> *Yeah, but the messing with whakapapa to me is different from this because this is when life is being conceived, whakapapa has already been created, so the messing with whakapapa is like when you do things like your genetic modification, you're introducing like the sperm donation, where you're ending up with different lines. This is about parents who are having a child ... so the whakapapa mix, the A and B is going to be C, the C is going to be it no matter what because you're not changing A and B. The messing with whakapapa is changing A and B, the parents.*[76]

Consequently, the potential through which links can be made between whakapapa, bloodlines and the determination of future characteristics are of particular relevance in the context of pre-birth genetic testing. The potential for pre-birth genetic testing as a positive influence

on whakapapa was mentioned when outlining the use of technology to alleviate a number of Māori health concerns:

> *I don't know how I feel about this but we've got for instance, huge issues of diabetes, we've got huge negative stats of hepatitis ... all these things in our society. What if through this kind of process we could actually eliminate some of those things that kill our people? Now I don't know what they can do at the moment, but they might find that people of a certain gene are more likely to have or be the carriers of hepatitis or whatever the thing is, would we still be that, if we found that we could wipe out cancer through this, they identified the gene or genes or whatever, this is just hypothetically speaking, and that could wipe out cancer. Would we still be so thing to say ... about "oh will I have a child, what's the ethical decision about having a child that might be disabled all their life", but it could be actually about the future of a whole people.*[77]

Similar notions were outlined in relation to the potential for pre-birth genetic testing to benefit Māori; one participant raised this in relation to Māori youth with sexually transmitted diseases:

> *We've got huge things that are going to be impacting on us in the next 10-20 years that are going to affect our fertility, and we might not be able to just as black and white ... say that we don't get into this any more, and one of the points I made ... was just the huge proportions of Māori that have STD's, that impede fertility like chlamydia and gonorrhoea and outrageous numbers of our youth are falling to these diseases, and 20 years down the track this might have a profound impact on the Māori population, so when then do you start looking at the survival of the collective, or the right of the collective over the individual?*[78]

With increased rates of sexually transmitted diseases, come increased issues surrounding infertility and Māori may increasingly utilise fertility interventions such as in vitro fertilisation, in conjunction with pre-birth genetic diagnosis.

Whakapapa and reproduction are of considerable importance to Māori and pre-determining desirable characterises within future generations was practised in a number of manners such as taumau and spiritual interventions. A view was expressed that pre-birth genetic testing may be a contemporary extension of such cultural practices.

2 TRADITIONAL APPROACHES TO INFANTICIDE AND ABORTION - CAN PARALLELS BE DRAWN?

Another theme for discussion that emerged in relation to traditional Māori practices was that of infanticide and abortion. It was from these discussions that comparisons and contrasts were drawn with pre-birth genetic testing and the potential this technology has for undertaking terminations of foetuses and embryos.

The potential for increased rates of abortions and the destruction of embryos resulting from pre-birth genetic testing raises a number of ethical issues for Māori and non-Māori alike. The reasons behind the termination of embryos and foetuses based on traditional practice

are not easily ethically or morally discernable and application of this notion may not be easily applicable to pre-birth genetic testing. Views on the appropriateness or otherwise of infanticide and abortion were varied.

One view expressed was based on the protection of the sanctity of life (mana tangata), and as such, would oppose a technology that might increase the number of aborted foetuses. This was a strongly held view and stressed that abortion in the modern day context should only be carried out in extreme cases.

> *Regarding abortions ... the kuikuia abhor the idea of [abortion], it stops the genetic whakapapa of that family, although ... for instance if a woman was raped then they would take this rongoa to stop the birth of the child.*[79]

Examples of values and traditions stressing the importance of protecting future generations and nurturing the potential of the unborn children are a common feature amongst Māori society. Many myths, traditional prayers, incantations, songs and rituals within te ao Māori exemplify the importance of the reproduction process as being sacrosanct.

Juxtaposed with this view are also a number of traditional instances outlined by participants in which infanticide and abortion were practised:

> *It's interesting to think about thehe old practices within te ao Māori because there are instances of inducing abortion or, getting rid of babies that were born haua. I think there was the real practical attitude around the decisions that were made in the interests of members of any particular whanau.*[80]

> *Well in the olden days ... what they would have done was that any deformed babies were actually put to death because they knew these babies were going to die anyway, so some of them would try to use the rongoa Māori to help the foetus, otherwise when it was born and something was wrong then it was put to death.*[81]

> *I've also heard anecdotal things of people saying that there were no Down syndrome babies in pre-European society, well there might have been a reason for that, not necessarily just because they didn't exist.*[82]

Whilst there is evidence within the traditional Māori world view of infanticide and abortions, decisions were rarely made lightly and were often undertaken to protect the wellbeing of the collective:

> *If it was going to be detrimental, for instance, to the collective, the collective security, collective economy, the collective ... life, if they were going to be put in danger, then an individual could be sacrificed ... yes the mother might have been upset or what not, but it happened and there were reasons for that. It wasn't just because it was callous, it was about the security of the collective. The same way that we hear stories of the babies being smothered and killed if an enemy party is approaching because they might endanger, with the crying and that, they might endanger [the collective]. Well, there's a number of cases that you hear about, and it's not that there's no pain there, it's not that the mothers aren't absolutely grieving, but it's for the collective because the whole tribe will die. If you're hiding and you do actually not want to be found and your baby starts crying then everyone dies.*[83]

The conditions in which abortion and infanticide occurred, the manner in which the decisions took place, and the reasoning behind the actions themselves, are decidedly different to lead one to undertake such actions today. The individual nature which pre-birth genetic testing decisions are made at present means that broader societal and collective issues are rarely taken into account.

In combination with these debates are notions surrounding the status of the embryo and the foetus. In existing Western debates, understanding when life begins allows the reconciliation of ethical issues when determining when one may terminate an embryo or foetus. Approaches to life are considerably different in te ao Māori from existing debates in Western discourse:

> *Well I guess the Māori creation story [of] cosmology has life beginning at the very beginning, which is the mixing of the elements ... So from a Māori world view that life was created at the absolute mixing of the chemical elements. I think they knew that, but that's different from making a value judgement on how life should be treated at those times. ... Māori believed right from the beginning it's life, if you look at those whakapapa, and in fact any world view that is based on genealogy to the point that it explains the creation story, I think you have to say that whakapapa at all levels is recognised. So I believe it's right at the beginning, right there, the mixing of the elements, the mixing of the fluids to create the body, that's from that whakapapa.*[84]

According to this narrative, life in te ao Māori occurs at the absolute 'mixing of the elements'. The status of the embryo and foetus within te ao Māori is significantly different from existing debates that shape current regulation. Based on highly contested Western understandings of when a foetus can feel pain, or when it is legally 'alive', determines the point at which termination can occur.

In saying this, a number of Māori today still readily utilise abortion and in vitro fertilisation and other medical techniques such as organ transplants. It appears these technologies have escaped the close ethical scrutiny that genetic science has been subjected to and could arguably be said to have been accepted and readily utilised:

> *We already accept a woman's right to terminate life through abortion. . Is a woman's choice to terminate an embryo, or a foetus, through PGD or PND any different than this? If we aren't prepared to judge a woman's right to abort then I think that we run the risk of being a bit precious about the technology rather than the issue.*[85]

While abortion and infanticide took place in traditional Māori society, a simple transferral into contemporary society and application to pre-birth genetic testing may be untenable and inappropriate. The conditions under which such actions took place were usually based on collective notions of well-being. This is not to deny outright the termination of the embryo and foetus through pre-birth genetic testing today.

There was no dominant viewpoint on the appropriateness or otherwise of the termination of embryos and foetuses through pre-birth genetic testing and in relation to traditional practices from research participants. Views were expressed in the context of traditional practice, and parallels were drawn, but significant doubt remained on the contextualised nature under which the act was undertaken.

However, while many do not deny the ethically and morally compromising status of pre-birth genetic testing, especially in relation to many aspects of te ao Māori, they could not deny the influence that practices such as abortion, in vitro fertilisation and surrogacy had on informing their opinions in relation to pre-birth genetic testing.

3 THE POTENTIAL OF PRE-BIRTH GENETIC TESTING TO ALLEVIATE SUFFERING

The discussion here moves to some of the more contemporary themes surrounding pre-birth genetic testing and the potential the technology has, not just for benefiting Māori, but also for exacerbating existing social inequalities.

Notions of protecting the health and well-being of future generations implicit in whakapapa can be seen in the innate human qualities of alleviating suffering. The values of aroha, manaakitanga, and whanaungatanga, while not explicitly mentioned, can be gleaned from a number of discussions from participants. One participant states quite simply:

> *I think this is a good idea this genome research project because when you look at all the mothers that have their babies they don't really know whether there is something wrong with their babies, their foetus , I think the pre-birth genetic testing is a good idea for Māori women.*[86]

As with many existing discussions surrounding genetic modification, our participants outlined the manner in which they felt compassion for those affected by genetic disorders:

> *I've got a perception which is based on my own, you know, if I had a disabled child I would love that, I would care for it, I would do whatever... My current partner, we were having this discussion and the father of my kids said, his approach was those you look after, those most in need, like the disabled kids are the best people in the world.*[87]

Confronted with the ability to alleviate genetic disorder and the suffering of one's own child, this participant questions the notion of allowing such distress to take place:

> *If there is the power to change it, would you? If you knew that your child was going to have a terminal disease that would kill them by the age of two or three and be in absolute pain and agony for that two or three years. If I had had that choice, I wouldn't want to see anybody go through that pain, child or not ... This is an uninformed perspective, you have to appreciate that, in terms of the actual conditions that will affect us and how this might actually help eliminate disease, eliminate dysfunction, eliminate disability.*[88]

Based on alleviating both the suffering of whanau and the potential pain that genetic disorder may inflict upon an individual, the principles of aroha, manaakitanga, and whanaungatanga could be invoked as reason to support pre-birth genetic testing.

4 EQUITY, ACCESS AND PRE-BIRTH GENETIC TESTING

Based on Māori levels of deprivation and socio-economic standing, it can be assumed that Māori utilisation of pre-birth genetic testing will be significantly less than that of non-Māori. This would likely be exacerbated if pre-birth genetic testing is not publicly available.

Resource allocation is inevitably about money and the tensions that abound between those who can pay and those who cannot. Such views and the implications were outlined by one participant:

> *Absolutely, this technology is a part of that, fixing a lifestyle problem. That's the thing about a lot of technology based research now, it is directed towards addressing lifestyle health issues rather than fundamental health issues. And that's what I see as the dilemma around making technology available and resource allocation. PGD is not high on the Māori health priority list and you would question whether or not it should get resources over issues like diabetes and cardiovascular disease. However, there will be Māori that might want to use the service and would likely be disadvantaged if it is only available privately.*

Concerns remain that because Māori do not presently access this technology as readily as non-Māori (and it could be argued that Māori will, based on current health forecasts, continue to exercise the same levels of utilisation in the future), there may be potential for 'eugenic like'[89] discrimination to take place in the future. Current levels of utilisation for technologies such as pre-birth genetic diagnosis are levelled in New Zealand at predominantly Pakeha, and on a global scale at developed nations. The participant below outlines similar fears:

> *Well there's good evidence that even when Māori are at the same level of sickness as everyone else, they've got worse outcomes and what that suggests is that health resources are not evenly distributed and so if there's an inequality in any distribution of these health resources then what does that mean for advanced reproductive technology, which is this area. Because there's a kind of view in the world that the first world people are slower at breeding than third world peoples and I think one of the reasons for reproductive technology is to try and reverse that, and so ... there's a little bit of a feeling that there might be some eugenic stuff there going on ... so we want some nice good white babies, not some brown babies.*[90]

While it may be unfair to subscribe to generalisations of eugenics based on utilisation rates by non-Māori at this early stage, we argue that there is potential in the future for discriminatory behaviour against Māori. Care must be taken, however, for as another participant argues:

> *If you're not in on it will you lose the opportunity to build a super race. You know all the other kids will come out ... any imperfections would have been long since deleted, you'd finish up with a group of people who didn't want any part of it, who have higher levels of deformity and abnormalities.*[91]

A view exists that, potentially, those not utilising the technology may be left with high levels of 'deformity and abnormalities', while other population groups may be building a 'super race' devoid of 'imperfections'. Such notions were outlined as being morally and ethically compromising:

> *If you want to build a stronger Māori race, it would be quite good to eliminate as much of the blemishes in there. I think Hitler was trying to do that. It's probably very unethical and immoral to do it.*[92]

While this participant uses the eugenics argument with Māori as an example, the point is still clear that the elimination of 'blemishes' within ethnic groups is of concern.

Assumptions of eugenic discrimination against Māori are based on the uneven use of pre-birth genetic testing between Māori and non-Māori. At the heart of matters regarding access to this technology are broader arguments surrounding equity and resource allocation:

> *We're not exactly short of people and we have very big problems with the way resources are distributed, both between the first world and the third world - the whole 80% of the world's resources are consumed by less than 20% of the world's population. Now we're part of the developed world except we're an indigenous population, as Māori who appear to be more like third world in a lot of our health status, certainly we are in common ... [in] health status with all other indigenous peoples, within the first world. For instance, we have similar health status to Native Americans, Aboriginal people in Australia, so because of that we have an obligation when looking at these kind of issues to consider the wider context of equity and if these sorts of things end up being accessible only to those who are wealthy, only to those who have resources, only to those who have a large extent personal and political autonomy for themselves and their whanau. Then Māori won't be included, koia teera, there would only be a handful.*[93]

The issue for this participant is the manner in which resources are allocated not just within New Zealand between Māori and non-Māori, but also at a global scale between developed and developing nations. While Māori are part of the developed world they still experience levels of health and well-being similar to that of the third world or other indigenous peoples from developed nations. The point here is that pre-birth genetic testing has the potential to be another example of resource misappropriation based on broader issues related to equity and access. As such, concerns remain about further discrimination stemming from this.

When analysing the potential for Māori uptake in pre-birth genetic testing, it is useful to reflect on broader issues regarding the utilisation of health services in general. The nature and extent of Māori engagement with emerging biotechnologies regarding the human genome can be gleaned from statistics for existing health care service utilisation and Māori birth rate trends. Perceptions of a health system that has failed to address Māori health disparities and continued over-representation in negative health statistics will influence Māori responses to pre-birth genetic testing.

Māori health disparities are linked to a range of factors including lower socio-economic positioning, such as living in deprived areas of New Zealand (56% of Māori live in the most deprived areas of New Zealand).[94] Key Māori health priorities include probable asthma,

diabetes, high blood pressure, obesity, iron deficiency, and injuries, and in negative health behaviours such as smoking, and low levels of physical activity. Suffice to say, key health issues facing Māori do not include the need for reproductive technologies such as pre-birth genetic testing.

However, whilst pre-birth genetic testing may not provide immediate improved health outcomes for Māori the preventative nature of the technology and the potential for genetic 'improvements' for some Māori whanau might prove persuasive in the future.

A theme of interest that emerged from discussions was the preventative potential of pre-birth genetic testing:

> *I think the health thing is a social prevention. If you can prevent a health problem from arising, we've won - prior intervention is the most useful type of prevention if you've got a mechanism to do it, very few mechanisms can do it, this would be one.*[95]

The preventative potential of technologies such as pre-birth genetic testing can lead not only to prevention of genetic disorders but also the prevention of distress by those involved:

> *Well I think, in general terms, prevention is ... the cure, so that ... if you've got any technology that's likely to prevent a disorder and it's gonna work, and I think that's a good approach. So this raises the added complication to prevent the disorder by getting rid of the lot, which is a strange sort of prevention, and so the question is whether it's linked more to the prevention of [the] disease sufferer or the prevention of distress by parents and probably by the child. So that's one area that's prudent I guess is the preventative medicines. It is primary prevention.*[96]

However this preventative potential has to be offset with continued under-utilisation of health care services for Māori. Current trends indicate under-utilisation of and expenditure on primary medical care and related services to Māori.[97] While there are a variety of health services available in New Zealand, from general practitioners to public and private hospitals, the level at which they are utilised varies widely between different population groups.[98] Māori are under-represented in all health service utilisation involving, for example, general practitioners, pharmacists, dentists, accident and emergency and after-hours care, and private hospitals.[99]

The potential for Māori to utilise pre-birth genetic is important as it will influence the potential Māori will benefit from this technology. Based on current trends with private service utilisation and existing data on personal income, it is likely that utilisation of pre-birth genetic testing by Māori will be less than that of non-Māori. This is significant considering the potential for Māori to utilise pre-birth genetic testing due to increased Māori fertility rates, birthing rates and population growth.[100]

Increased population growth and high fertility rates, compared with those for non-Māori increases the potential pool of Māori who might utilise pre-birth genetic testing. However, this uptake is likely to be offset by a number of barriers such as bad past experiences with health services, other health priorities, mistrust of professionals, lack of funds and the lack of confidence amongst Māori that their spiritual and cultural values will be appreciated and accounted for.

Māori values, concepts and perspectives of health and well being, and the importance of reproduction, childbirth and whakapapa within Māori society, are of vital importance when accessing health care services. The spiritual and emotional concerns of parents and whanau also need to be better provided for if Māori are to utilise, and fully benefit from pre-birth genetic testing.

5 INDIVIDUAL RIGHTS IN THE CONTEXT OF COLLECTIVE RESPONSIBILITY

The tensions between the right of the collective and that of the individual are at the centre of the debate for Māori and pre-birth genetic testing. These tensions are derived from an individual's right to make a decision to engage with pre-birth genetic testing, and the broader implications this may have over Māori communities at the level of whanau, hapu and iwi. This tension is fuelled by the collective manner in which many whanau, hapu and iwi groups either make decisions or perceive issues.

Traditional Māori decision-making was made with the collective wellbeing of the tribe the paramount concern. Individual choice and decision-making was not exercised in the interest of one person's well being, but rather, in relation to the outcome most suited to the collective. With the advent of colonisation and the introduction of Western notions of individualism, ideas of collective decision-making and choice have been diluted. However, decision-making at collective levels is still practised by Māori today.

When discussing pre-birth genetic testing, a recurring theme in regard to individual rights, choice, and collective responsibility, was the pervasive importance of the collective over the individual in traditional Māori society. This was outlined on a number of occasions, for example:

> *Traditionally there was a huge community involvement, again depending on your whakapapa and everything, with families, about who you would be with, and what were you to do and all the rest of it. It was something that was more communally, it wasn't individual right and that's again with arranged marriages, all that kind of stuff. The naming of the baby, who the baby was to be ... all that kind of stuff was decided pretty much by those of status within the group.*[101]

Decisions surrounding reproduction, marriage and the naming of babies were often made collectively. This was done not with individual interests in mind, but for the security and well-being of the group as whole:

> *Where the good of the majority is at risk ... there are records of kids who were killed by their parents rather than being taken ... kids who were killed because they were crying and that would attract an enemy and that's the example of prevention to secure the wellbeing of the group. So at some stage ... the child's life is not as highly valued as the ... group.*[102]

> *I know that the way that our, from my understanding of traditional culture, that the way that society had to operate in order to survive was to make sure that the collective right was the paramount right and if you look at the way that it was structured, that's what it was based on. It was the whole idea of everyone goes on that consensus decision-making ... the*

way that our communities operated were based on collectivity, not individualists, whereas opposed to the Pakeha, it's actually the individual, individualisation to land, individual title, individual, you know everything is individual. And now we've got to the point where the right of the individualist is paramount to the right of the collective.[103]

The overriding principle of the collective good over that of the individual led to decion-making processes based on similar notions:

It's difficult ... as soon as you start looking at the pattern individualist approach, it gets difficult because families do things for family reasons and cultures do things for cultural reasons as opposed to, you know we get born and think, what is my individual purpose in life and why was I born and why didn't you do this and why didn't you do that? We are very egocentric in that regard and, although I think that's part of the human nature, I don't necessarily believe that fundamental fixation, obsession with the individual was the leading, was the determining factor, in the way that Māori society made their decisions.[104]

Individual rights, in relation to the good of the collective, are troubling notions to reconcile in contemporary Western society. While it is undeniable that traditional Māori society saw the collective good as paramount over individuals and as such made decisions accordingly, there remain inherent difficulties in maintaining such collective responsibilities today. One participant acknowledges this notion:

I don't know that Māori society is unified enough to be too prescriptive in this regard, in that we do live as individuals. I think that it's a breakdown in our society, I think a more community approach is definitely the way to go if we want to keep our culture alive, but the fact that "what happens in your home, is your business" kind of mentality doesn't help that, and it also means that our power to influence the individual home or the individual as a community, basically they can just turn around and say "hmm nah, we're out of here", you've got no control over that. So when then do you start looking at the survival of the collective, or the right of the collective over the individual?[105]

While our report recognises that notions of collective responsibility by individuals have been degraded, we still argue for the incorporation of culturally aware processes and procedures for those willing to utilise them. This imperative is related to broader issues surrounding Māori ability to exercise kaitiakitanga and tino rangatiratanga.

The implementation and recognition of collective rights and decision-making are ultimately about Māori exercising tino rangatiratanga. Control is a crucial component of indigenous people's role in decision-making regarding pre-birth genetic testing.

These tensions need to be addressed for Māori to exercise their right as kaitiaki. In doing this, recognition must be given to the status of whakapapa and the fact that it is collectively not individually held. Processes and procedures that recognise the influence this technology may have on collective groups, and that recognise Māori decision-making, must be put in place. Whether participants argued for or against pre-birth genetic testing, they all strongly asserted Māori need to exercise kaitiaki and rights to assert rangatiratanga over their cultural practices. The issue is less about ownership of human genetic material and decision- making authority and rights, and more about ensuring that the integrity (mana) of all being impacted is maintained.

Decision-making processes based on individual and collective rights provide a unique challenge when dealing with pre-birth genetic testing. A number of participants outlined the influence this technology may have particularly on whanau. Whanau as a collective group have a number of values and processes upon which they function and organise themselves. The utilisation of technology such as pre-birth genetic testing provides a number of concerns for whanau groups regarding their unique decision-making dynamics not currently catered for under the current Human Assisted Reproductive Technology regulatory regime.

Whanau in its original reference was to refer to a set of siblings (brothers and sisters) born to the same parents. Today, however, whanau generally refers to a 'large family group comprising several generations and parent-child families related by descent from a recent ancestor'.[106] While whanau structures experienced decline and decay under British cultural tradition since 1840, Māori whanau structures are still apparent today. Whanau as a collective group have a number of values and processes upon which they function and organise themselves. The utilisation of technology such as pre-birth genetic testing provides a number of concerns for whanau groups, regarding their unique decision-makingdecision-making dynamics not currently catered for under the current Human Assisted Reproductive Technology regulatory regime.

Mikaere[107] outlines the importance of whanau through the relationship between whakapapa:

> *The strength of the whanau lay in the tapu status of whakapapa that connected whanau members to one another, to past and future generations, to the gods and through them to the environment. The principle of balance was of vital importance, for it ensured the continued integrity of the group. The very survival of the whole was absolutely dependent upon everyone who made it up, and therefore each and every person within the group was important. They were all part of the collective; it was therefore a collective responsibility to see that their respective roles were valued and protected.*

There are a number of roles and functions for individuals within the whanau context. From children to kaumatua, all have a role that is complimentary to the function of the group as a whole. 'Front' roles within whanau such as kai korero (speech makers), kai karanga (callers) and kai-whakahaere (directors of proceedings) are usually filled by the most senior descendants of the whanau most suited to the role. Similarly the whanau group is usually led by kaumatua (either male or female). The eldest sibling of the most senior generation has a special status in the whanau as te kai-pupuri i te mana - 'the one that holds the mana' on behalf of the collective. In many whanau groups several kaumatua form a collective leadership group with the matamua acting as coordinator and spokesperson.[108]

An example of the differing manner in which decisions are made to contemporary Western nuclear families is through child care. Decision-making in the whanau context with regard to child care was not always made by the parents. According to Māori way of thinking, parents do not necessarily have exclusive right to bring up their children or even to choose alternative care-givers. Up until the 1950s, and to a certain degree even today, kaumatua often made decisions about who would raise the children of the whanau. From the 1950s, with the advent of urban migration and economic independence, this practice has decreased. Nevertheless, Māori today generally recognise the rights grandparents have in decision-making regarding mokopuna (grandchildren), and play an important role as advisors, negotiators and the bearers of knowledge regarding parenting.[109]

6 SUMMARY

The emerging themes on Māori and pre-birth genetic testing uncover a number of issues that need to be addressed if the utilisation of pre-birth genetic testing is to take into consideration Māori cultural, ethical and spiritual concerns. Regulation of pre-birth genetic testing needs to consider the broader context of whakapapa, decision-making, and collective responsibility. While there are a number of potentially positive effects for pre-birth genetic testing discussed at the start of this section, there are still concerns surrounding termination of embryos and foetuses, equity and access, but most critically the balancing of individual and collective rights and cultivation of an environment through which this can be achieved.

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PART C: PREIMPLANTATION GENETIC DIAGNOSIS - A MĀORI PERSPECTIVE

Tenei au, tenei au, tenei au te hokai nei i taku tapuwae,
Ko te hokai-nuku, ko te hokai rangi, ko te hokai
A to tupuna a Tanenuiarangi i pikitia ai
Ki te rangi-tu-haha,
Ki Tihi-o-Manono,
I rokohina atu ra
Ko Io-te-matua-kore anake
I riro iho ai nga Kete o te Wananga:
Ko te Kete Tu-a-uri,
Ko te Kete Tu-atea,
Ko te Kete Aronui.
Ka tiritiria ka poupoua ki Papa-tu-a-nuku,
Ka puta te ira tangata
Ki te wheiao
Ki te Aomarama!
Tehei wa mauri ora

1 INTRODUCTION

The tauparapara (chant) of Tāne's journey to the uppermost heavens represents a powerful link for Māori between the spiritual, physical, cultural and the ancestral. All knowledge was brought forth and retrieved by Tāne. It is from the sacred knowledge contained in Ngā Kete o te Wānanga (baskets of knowledge) that Tāne performed the karakia whakatō tamariki (recitation to bring about conception). This knowledge and understanding facilitated the beginning of the ira tāngata, into Te Ao Marama, the world of light and being.

The word ira means 'life principle' and can be used more specifically to mean 'gene',[110] while tāngata means human. Ira tāngata hence refers specifically to a human life that has inherited a collection of genes from the parent(s). The genes are more than biological elements, however. There is a godlike and spiritual quality to all of them because as human beings, ira tāngata descend from ira Atua, the Gods.[111]

2 OVERVIEW

The following draws together material that have been gathered primarily from a literature review undertaken for this project. It is not intended to be definitive, nor is it a representation of all Māori views, but it is an introductory guide to assist in the formulation of policy or guidelines in relation to preimplantation genetic testing (PGD) or, more generally, human assisted reproduction technology. Some of the concepts, beliefs or principles may be mentioned in other parts of this chapter but are included below with additional details.

This part of the chapter raises the question: what are the needs, values and beliefs of Māori? An exploration of this question, which may assist decision-makers in the exercise of powers or functions pursuant to the Human Assisted Reproductive Technology Act 2004 (the HART Act), involves a discussion of Te Ao Māori (Māori world view) and the system of Māori values, needs and beliefs.

The first section of this part attempts to identify values and beliefs that may help provide guidance in giving effect to section 4(f) of the HART Act which states:

> *All persons exercising powers or performing functions under this Act must be guided by each of the following principles that is relevant to the particular power or function:*
> *(f) the needs, values, and beliefs of Māori should be considered and treated with respect.*

The second section, which relates to the HART Act and Preimplantation Genetic Diagnosis Guidelines formulated by NECAHR, looks into responses from a Māori focus group held in November 2004 that raised several issues about PGD.

The third section sets out a tikanga Māori framework that is premised on a model provided by Professor Hirini Moko Mead.

3 TE AO KOHATU (TRADITIONAL SOCIETY)

> *Culture . . . constitutes a resource which we create and on which we draw, consciously and unconsciously, to comprehend our social and physical environments and our place in them. It shapes the ways in which we see and experience our world. Culture defines the way in which we see, understand and respond to physical and social phenomena.*[112]

Any society's beliefs and practices are shaped by that society's culture and can only be usefully analysed in its terms. The values that underpinned traditional Māori society[113] shaped and informed Māori systems and cultural practices, and continue to do so. Concepts derived from traditional society, such as tapu and makutu are still important to Māori in understanding illness, disease or genetic disorders.

In the early nineteenth century Māori encountered new agricultural methods and medical practices via missionaries, whalers and colonial settlers. Ethnographic materials, missionary journals and manuscripts are an invaluable source of information about this period of New Zealand history. Māori interactions, whether of a collaborative nature or otherwise, with Pākehā involved a decisive era of change for the indigenous and settler cultures.

> *...the Māori response to western contact was highly intellectual, flexible and progressive, and also highly selective, aiming largely to draw upon the strengths of the west to preserve the Māori people and their resources from the threat of the west itself, and to enable them to enjoy its material and cultural riches with the Westerners.*[114]

The deeds of Māori ancestors (Ngā mahi a ngā tūpuna) during this time continue to inspire the current generation of Māori thinkers, practitioners and researchers. Māori practices, law and values evolved from the deeds of the ancestors and developed over subsequent generations for Māori society.[115]

If men are unable to perceive critically the themes of their time, and thus intervene actively in reality, they are carried along in the wake of change. They are submerged in that change and so cannot discern the dramatic significance.[116]

The use of human assisted reproductive technology to biopsy embryos and diagnose genetic disorders requires Māori to explore the efficacy and relevance of traditional concepts in an ever-changing contemporary world. The following is an exploration of the concepts of tapu, makutu and karakia (charm, spell, incantation) in relation to preimplantation genetic diagnosis and Māori attitudes to illness.

3.1 MATE MĀORI

Mate Muaori is a term used to describe illness believed to be due to Māori causes and for which there is no remedy other than that which is uniquely Māori, as distinct from diseases introduced by the Pākehā or "Mate Pākehā".[117]

Pre-contact Māori society was described as healthy, virile and relatively unaffected by serious disease.[118] Māori had rational procedures for treating minor, curable conditions, but faced with the serious, they had to resort to the "supernatural" because such disease was thought to be the result of an atua, or spirit.[119] The causes of disease or illness were attributable to a transgression of tapu or makutu.[120] It seemed to Māori that there was a class of illness which was impervious to European medical procedures. Such illness was termed mate Māori, indicating a malady caused by some spiritual disturbance.[121]

The definitions of health (hauora) and illness (mate), the boundaries between the two conditions, and markers which indicate we have moved from one condition to another are provided by culture and learnt experience.

Tapu had a spontaneous origin in the fear of the supernatural, but was moulded by experience or what was believed to be experience; and the belief is fortified by suggestion which produces death or disease when tapu is broken.[122]

The importance of culture is reflected in the ways in which people recognise and articulate symptoms of illness or disease. In relation to a genetic disorder Māori may still view their illness as a transgression or a punishment, or a sign of personal weakness and therefore may not seek treatment. Historically, the violation of tapu or a committed hara may have resulted in an illness which the tohunga or the wider collective may have resolved.

3.2 TAPU

Tapu is a principle which acts as a corrective and coherent power within Māori society. It acts with a system of prohibitory controls, effectively acting as a protective device. Tapu and makutu were applied to control human behaviour.[123]

The laws of tapu affected all areas of life – conception, birth, marriage, sickness, death, burial, exhumation; all industries; and no person in the community was exempt from its stringent rules. Tapu came originally from the gods or the mediums of the gods, who were impregnated with tapu.[124] Examples of infringements of tapu included: used weeds, stones or water from tapu

places for the purposes of cooking; taking tapu objects into cooking houses or any common place, or interfering with them; defecating or spitting on any sacred object or depositing cooked food there; trespassing on any tapu spot, or handling any tapu object and not having the tapu removed from one's person by being made noa or common.[125] Punishment could take any number of forms such as minor skin ailments or serious illness. An example is provided below to illustrate the point of how traditionally a serious illness could have been treated.

Te Moananui, a Ngāti Kahungunu rangatira, was afflicted by an unknown disease. Two tohunga took the chief to a stream before dawn, immersed him in the water and conducted several rituals. The object of the incantations was to absolve the patient from all wrongs and act as an appeal to the gods; at birth, a chief would have certain rites performed and particular gods were given control over him to protect him from the dangers of war, misfortune, ailment or witchcraft.[126] The tohunga then proceeded to recite a healing charm, followed by a ritual to compose, tranquillize and relieve the patient of their fears and to cause him to have faith in the efficacy of the procedure. Finally, the last ritual appealed to the superior beings to bestow health. The chief recovered from his serious illness.[127] A similar procedure would have been utilised to treat a patient affected by makutu albeit with different karakia.

Shortland noted the following:

> *Intimately connected with the superstition respecting things tapu is the belief as to the cause of disease, namely, that a spirit has taken possession of the body of the sufferer. The belief is that any neglect of the law of tapu, either wilful, accidental or even brought about by the act of another person, causes the anger of the Atua of the family who punishes the offender by sending some infant spirit to feed on a part of his body - infant spirits being generally selected for this office on account of their love of mischief and, because not having lived long enough on earth to form attachments to their living relatives, they are less likely to show them mercy. When, therefore, a person falls sick, and cannot remember that he has himself broken any law of the tapu, he has to consult a matakite (seer) or a tohunga to discover the crime and use the proper ceremonies to appease the Atua; for there is in practice a method of making a person offend against the laws of tapu without his being aware of it. This method is a secret one called makutu. It is sufficient for a person who knows this art, if he can obtain a portion of the spittle of his enemy, or some leavings from his food, in order that he may treat it in a manner sure to bring down the resentment of his family Atua. For this reason a person would not dare to spit when in the presence of anyone he feared might be disposed to injure him, if he had a reputation for skill in this evil art. With such a belief as to the cause of all disease it will not be wondered at that the treatment of it was confined to the karakia of a tohunga or wise man.*[128]

Tohunga were the repositories of tribal knowledge, history and esoteric lore. They were perceived as the spiritual head of the community. Tohunga performed a diagnostic role in relation to sickness by formulating a case history and family history via the patient's dreams and activities prior to becoming ill. The tohunga also investigated the role of the family to discover the hara (infringement) which caused the disease. The next step was to propose a treatment plan to remove the offending spirit. This may involve the family with the requisite ritual performed by the tohunga. The treatment plan could conclude with a period of rehabilitation for both the individual and the family.

The role of tohunga in the twentieth century changed dramatically. The Tohunga Supression Act 1907 prohibited tohunga from practising traditional Māori medicine and Māori spirituality by imposing fines on tohunga who practised and maintained traditional knowledge. Tohunga did continue to practise but the Act sufficiently restricted cultural practices. The Act was repealed in 1962.

In 1977, Mason Durie explored contemporary issues of Māori attitudes to sickness, doctors and hospitals.[129] Durie maintained that tapu continued to enable the social life of the community to be upheld – it was the basis of law and order and its respect ensured the survival of the community. The laws of tapu had direct application to matters of health and sickness. The concepts of tapu and the perception of illness as an infringement against tapu are central to much of the anxiety and depression which surround the Māori patient while in hospital. Family involvement at times of illness is likewise a very traditional and culturally necessary attitude which must be recognized in the management of the whole patient and not just his impaired organ.[130] Durie considered that mate atua – sickness – was an infringement of tapu and therefore an interference with the particular atua.

However, the current notions of tapu may have changed. The elders have intimated that it is very difficult for most people of this generation to become tapu because we lack the commitment to maintain conditions by which a person becomes tapu.[131] It is difficult for most Māori today living in suburbia to observe and adhere to tapu. The knowledge of what is prohibited and restricted requires experience and contact with repositories such as kaumatua or tohunga. Historically, everything was regarded as tapu. Individuals and groups continue to have responsibilities and obligations to abide by the norms of behaviour and practices established by the ancestors.[132] In summary, the primary purpose of tapu is to protect – through recognizing the whakapapa between ira atua and ira tāngata, and adhering to tikanga.

3.3 KARAKIA WHAKATŌ TAMARIKI

The following karakia (ritual) whakatō tamariki was recited by Tāne over Hine-titama in order to cause her to conceive.[133] It was used to implant a human embryo. The word whakatō means to be pregnant or to conceive or to plant.

1	Tenei au he awhi nuku, he awhi rangi nau, e hine, ki au
2	Koia takere rangi, koia takere nuku, koia takere wai
3	Takere wai uriuri ki te whai ao, ki te ao marama
4	He wai nui, he wai tinana, he wai kai, he wai oti rangi
5	Ka rukutia, ka tuhikitia, ka tuhapainga he uriuri
6	Ka tipu, ka toro, ka whakaiho tangata
7	Toro te akaaka, toro te iho nui, te iho roa
8	Ka whakaupoko, ka whakaringaringa, ka whakawaewae,
9	Ka whakatinana mai koe
10	Tu takawhaki nuku, tu whakataki rangi
11	E tu whaitiri i paoa
12	Ka puta i tua, ka puta i tawhito ngawariwari
13	E tu takawhaki karihi
14	E paoa ki roto kite pokopoko nui nau, e Rangi . . . e . . . i
15	Tapiki tu, tapiki nuku
16	Ki te whai ao, ki te ao marama, e hine e!
17	He kauru nui, he kauru roa ki au nei, e hine, e!
18	Whai ake, whai ake kit e putahi na karihi
19	Whakahoro ki roto te pu nui, te pu matua
20	Tapi tapae auaha ki taha, auaha ki roto
21	Auaha ki te pae kura, ki te pae kapukapu
22	Ki te pae nau, e Puainuku, e puapua i teke
23	E puapua, e hanahana, e werewere, e katitohe
24	E kamu to hanahana ki karihi ora
25	Ki a karihi auaha nui, auaha puru
26	Heke to pia, heke to ware, heke to nguha
27	Ki tenei aro, e hine, e!

The karakia discusses the drawing forth of a genetic line of descent so a being forms, develops and grows. At line 8 the ritual refers to the forming of the head, limbs and body of the embryo. In pre-contact the karakia whakatō tamariki was performed by the tohunga, by virtue of their mana.[134] The tohunga would instruct a prospective parent (mother) as to reproductive rituals

and procedures that would cause them to conceive. In some cases a mother would insert something into her which would be returned to the tohunga who would then recite the karakia while immersing the object in sacred water. The karakia would be dedicated to Rongo-mā-tāne (if a female was desired) or Tūmatuenga (if a male). There are also examples of sacred places where rites and incantations were performed in the hope that the couple may conceive. Elsdon Best documents several sites of reproductive significance where tohunga would perform rites over the woman while she held a tree or stood in a particular sacred place to conceive.

> *The wairua (spirit) of a child is, according to several of my authorities, implanted by the male parent during coition. "I think," said a worthy friend of mine, "that the wairua is implanted during sexual connection. We do not know where this spirit comes from, but I think the spirit (wairua) of an ancestor may thus be implanted in a child, because see how often a child resembles a grandparent or ancestor.*[135]

However, it is also noted that since the arrival of Pākehā (contemporary) the effectiveness of these rituals may have declined. The place of karakia whakatō tamariki may no longer be relevant, but District Health Boards, for example Waitemata Health and the Otago District Health Board, have policies and practices in place to meet the potential requirements of Māori. The Waitemata Health DHB is an example of how tikanga Māori and the principles of the Treaty can be incorporated into the provision of health services.[136] The "Tikanga Best Practice Policy" models provide the patient or consumer (tūroro) access to new technology and health care in a culturally appropriate way that respects and protect their needs. This accords with the obligations of DHB's under section 4, New Zealand Public Health Disabilities Act 2000.

3.4 KAIHAU WAIŪ - BIRTH RIGHT

The kaihau waiū refers to the rights a child inherits at birth. A child is born into a kinship system which is already in place and has been for many generations. The whakapapa of a child affects access rights to land, resources and establishes their place in society. The mātāmua or first born inherits a tapu in recognition of the law of primogeniture and the associated rights of being born first. Many of a person's prospects in life depend on parents and the legacy they pass on: genes, social standing, economic position, education and within some tribal groups this continues to be the case:

> *... tapu pertained to everything connected with birth. Some first born children were kept strictly tapu from birth, and not allowed to carry food or to perform any labour whatever. This would apply to first born male and female children of a chief's family.*[137]

What are some factors that affect birthright?

~ Moenga Rangatira - a child from a chiefly line may inherit more than others;

~ Mātāmua - first born and the order of birth are important in terms of a child's whakapapa and the associated privileges;

~ Tuakana[138] / Teina[139] - status in relation to another family member and the associated responsibilities (but also consider reciprocity of position - the elder and younger have an obligation to look after each other)

3.5 HISTORICAL PRACTICES RELATING TO PREGNANCY OR GENDER SELECTION

There are several historical examples of how Māori pre-determined the gender of the child. These may involve the way the baby moved in the womb, or a whe (praying mantis) found upon a woman was a sign she had conceived and, depending on the type of mantis, whether it was a boy or girl.

Several customs existed in relation to becoming pregnant or wanting a child of a particular sex. For example, a prospective mother could attend the birth of another member of the community and she would stand over the afterbirth (whenua) and stand (piki) over it in the hope of having a child of the same gender. She could also have a tohunga perform karakia over the placenta of another woman's afterbirth in the hope that she would conceive too.[140] The same custom could be used for infertile women. Tohunga could also prevent conception by reciting a karakia whakapā.[141]

A woman is considered most tapu when she is pregnant. When a woman was closer to giving birth, she was taken to the whare kohanga away from the rest of the hapū. Separating women from the rest of the tribe ensured two things. Firstly, it removed most of the duties a woman would have had to perform, letting her rest and stay strong while carrying the child. Secondly, by remaining separate from the rest of the hapū, the risk of sickness and disease was greatly reduced; hence the mother avoided any unnecessary duress during pregnancy. The tapu of the woman in this context ensured the survival of as many children as possible, to keep the hapū strong.[142]

3.6 WHARE NGARO

The term whare ngaro implies the death of all children of a couple. The term is not applied to lines of descent broken through infertility of women, or by a person not marrying. This affliction of a whare ngaro, is attributable to the dead or ancestors, or caused by witchcraft - makutu.[143] If parents lost their first child, a tohunga would be asked to perform the tu ora rite over the next child so that the whare ngaro (lost house) might be averted, and the child survive.[144]

> *In the Rua-tahuna district, of late, several women, whose children had died in infancy, and hence who feared a whare ngaro, were not allowed to eat of any food which had come from Rua-toki, inasmuch as the infliction is thought to have had its origin at that place. These women were afterwards taken to Rua-toki, where some rite was performed over them, in order that the cause of the children's death might be destroyed (ka tahuna ana mate e te tohunga - the tohunga destroyed those afflictions).*[145]

3.7 WHAKATAHE

> *E ahua tangata ana te pakeke o te wahine. He whakatipu tāngata taua mea. (The pakeke of a woman is a sort of human being, it is a person in embryo).*[146] *Best discusses menstruation and says that the pakeke has no wairua although tapu.*

According to the Lore of the Whare Kohanga, Māori believed that premature birth was caused by some infringement of the laws of tapu. When a woman wanted to abort the fetus herself, she would deliberately infringe tapu, for example, by passing cooked food over the head of an elder; or she may take cooked food to a tapu place and eat it. The aborted fetus is termed an atua kahukahu and has the potential to develop into an unwanted spirit. If an abortion was to take place the fetus needed to be properly buried so that an animal wouldn't unearth and eat it. Karakia would be performed over the fetus when buried to nullify the effects of the spirit.

4 TE AO HURIHURI

4.1 NATIONAL ETHICS COMMITTEE ON ASSISTED HUMAN REPRODUCTION (NECAHR)

In June 2003, the Minister of Health gave approval in principle to the use of PGD in New Zealand, and requested that NECAHR develop guidelines on the use of this technology. NECAHR's draft guidelines on PGD were disseminated to fertility clinics, District Health boards, professional organisations, consumer groups, government agencies and interested individuals in October 2004. The guidelines were subsequently approved by the Minister of Health in March 2005 and are deemed to be guidelines issued by the Advisory Committee on Assisted Reproductive Technology (ACART) pursuant to interim arrangements under the HART Act: see section 83(2)(1). Category 1 of the guidelines has, since then, been declared by Order-in-Council to be established procedures under section 6(1) of the Act. It is worth reiterating that the transitional provisions under the Act ensure that the guidelines which were developed by NECAHR remain effective until such time when ACART issues new guidelines.

4.2 MĀORI FOCUS GROUP DISCUSSION

In November 2004 a Māori Focus Group raised several key issues and concerns about PGD. The purpose of the Māori focus group was to provide a forum to discuss, from a Māori perspective, issues that were of interest and/or concern arising from the proposed guidelines. The following is a discussion of some of these key messages.

4.2.1 CONSULTATION AND TE TIRITI O WAITANGI

> *At the heart of the requirement of informed decision-making is the need to ensure that Māori perspectives are known and understood. But this is a two-way process. It is equally important for Māori to be informed. Proper and adequate consultation is an important part, however, consultation is the end point not the starting point. The starting point is the development of constructive relationships that will lead to a real knowledge and understanding of all of the points of view of all parties.*[147]

The courts and the Waitangi Tribunal have variously outlined the requirements of genuine consultation with Māori, and these have been well tested over the years through a number of legislative avenues. In the case of *Air New Zealand Ltd v Wellington International Airport Ltd* [148], Justice McGechan noted that: "Consulting involves the statement of a proposal not yet finally decided upon, listening to what others have to say, considering their responses and

then deciding what will be done." In addition, the broad principles established by the courts in relation to consultation should be kept in mind.

The focus group was concerned about how Māori are consulted on these issues. Members of the group noted that the Treaty of Waitangi and the principles of the treaty were missing from the Guidelines. Furthermore, the group stipulated that the Crown and Māori, in partnership, should decide on the introduction of new technologies. In short, genuine consultation did not happen. The group asked how could they have input into the Guidelines to protect a Māori view or perspective? The ability of Māori to make informed decisions about PGD is impaired by the Crown. The principle of partnership is a two-way process; in this case, the interests of Māori in PGD have not been adequately protected.

The Te Wanaka O Otautahi Research Team has advocated for legislative amendment to the Act to include the Treaty of Waitangi. The focus group sought to include the Treaty of Waitangi in the PGD guidelines. The inclusion of a Treaty of Waitangi clause would require committees to act reasonably and in good faith, and to make informed decisions that actively protect Māori interests. An example of an appropriate statutory provision is section 8 of the Hazardous Substances and New Organisms Act 1996, which states:

> *All persons exercising powers and functions under this Act shall take into account the principles of the Treaty of Waitangi (Te Tiriti O Waitangi)*

It is also advocated that a statutory Māori advisory committee be established. The committee would be required to provide advice and assistance, as sought by the other committees constituted under the Act, on matters relating to policy, process and applications. This advice would be given from a Māori perspective as described within Terms of Reference set by the committees.

4.2.2 COUNSELLING

Genetic counselling[149] provides information and support to an individual or to a family about genetic disorders.

The Māori focus group highlighted the important role that whānau could play in a couple's decision-making process. In particular, concern was expressed that the whānau may not be aware that the couple is experiencing infertility issues or that they (or future children) may be susceptible to a genetic disorder. It was emphasised that for Māori the process around options for the couple began at home. However, it was also recognised that the individual(s) may be separated from whānau. The group clearly expressed the view that counselling may be achieved by whānau and that genetic counsellors would involve kaumatua or whānau.

A possible solution may be that providers of genetic counselling services in collaboration with Māori develop culturally appropriate qualifications or incorporate mātauranga Māori into existing programmes of study. Alternatively when counselling, kaumatua or appropriate person(s) with relevant skills and expertise could be included or advised at the information stage during counselling.

4.2.3 PGD IS NOT A MAJOR HEALTH ISSUE FOR MĀORI

One of the first points raised by the focus group related to health. There are a number of health priorities for Māori. The bullet points below highlight areas of concern for Māori health and wellbeing:

~ *Te Puawaitanga:* Māori Mental Health National Strategic Framework states that mental health problems are now the number one health concern for Māori.[150]

~ Māori rates of diabetes are over twice the rate of the total population.

~ Health providers such as District Health Boards rationalize health expenditure and prioritise investment. For example the Otago District Health Board in collaboration/ partnership with Kai Tahu have identified health and disability services as its number one priority. Reproductive Technologies do not feature on an extensive list of health priorities set by Ngāi Tahu

~ Relatively recent advances in medical technology may make some genetic changes possible but such developments will only affect a very small section of the population.[151]

~ The direction of Māori health policy and research is generally focused on reducing inequalities and supporting Māori families to achieve maximum health and well-being.[152]

~ In terms of causes of lost healthy life years, and causes of disparity in life expectancy between Māori and non-Māori, the Clinical Research Trials Unit in Auckland has identified tobacco as the single most important risk factor and cardiovascular disease as the most important disease category.[153]

Māori may have greater health concerns and priorities. This does not preclude Māori from engaging in PGD and the associated services offered by assisted reproductive technology or diagnostic testing for genetic disease.

5 CULTURAL DECISION-MAKING FRAMEWORKS

Tikanga are essentially a set of ethics expressed as customs and traditions that have been handed down through many generations and accepted as a reliable and appropriate way of achieving and fulfilling certain objectives and goals.

In 2004, Mere Roberts in collaboration with Lincoln University conducted and completed an extensive survey of Kāi Tahu to collect their views on biotechnology.[154] The project involved 22 interviews and focus groups involving a total of 91 people who affiliated themselves with Kāi Tahu. The interviewees were questioned about xenotransplantation, stem cell research, cloning, genetic modification, and bioprospecting.[155]

The overwhelming feedback was one advocating tino rangatiratanga (self-determination) and kaitiakitanga (guardianship). Participants were concerned at the perceived lack of involvement and control by Māori in the existing risk assessment and decision-making processes. In their view, a Treaty of Waitangi framework should form the basis for Māori involvement in biotechnology. Most participants believed that Article II guaranteed them

their rights and responsibilities to participate as partners in the policy setting and approval processes surrounding research on novel biotechnologies. These rights and responsibilities, inherent in tino rangatira, provide the mandate for kaitiaki and the practice of kaitiakitanga. This concern led to a range of suggestions that a more culturally appropriate process should include a political/pragmatic approach based on Article II rights, and a spiritually-based approach centred on culturally specific values. The concerns raised in the Roberts study are consistent with the concerns raised by the NECAHR Māori focus group.[156] This adds impetus to developing initiatives for cultural decision-making frameworks.

5.1 TIKANGA MĀORI FRAMEWORK

> *Tikanga - as what is ethically correct, right and socially appropriate. An essential part of wise decision-making because it contains cultural integrity – "In all things there are tikanga, principles, process and guidelines [for] preventing and managing that which is desired as good ... Violation [can] come about when [this] does not happen"*[157]

The purpose of looking into a tikanga framework in the context of this report is to provide a prospective mother or family with a means of assessing the risks/benefits of PGD in a culturally appropriate way. The framework discussed is premised on the model provided by Professor Hirini Moko Mead. Professor Mead defines tikanga as:

> *A means of social control – tikanga controls interpersonal relationships, provides ways for groups to meet and interact, and even determines how individuals identify themselves. Tikanga has a place in any social situation. Ceremonies relating to life itself – birth marriage, sickness and death – are firmly embedded in tikanga Māori.*[158]

Professor Mead's reference refers to a tikanga Māori position is sometimes also referred to as a framework of assessment. It provides a method for assessing a situation or event that challenges our thinking and values. The key point is that the framework provides *a* position not *the* position. The following provides a checklist of matters and questions to consider as part of an attempt towards developing a tikanga Māori framework for PGD.

5.2 CHECKLIST OF QUESTIONS AND MATTERS TO CONSIDER

Test 1: *Tapu*

Tapu is a complex concept that acts as a code for social conduct so people can keep safe and avoid risk. The starting point of Professor Mead's framework is to subject the ethically controversial issue to the tapu test. In this case the first question that could be asked is:

~ Does PGD breach tapu?

Māori are inherently tapu by virtue of their whakapapa. The removal of an embryo from the whare tāngata (womb) for diagnostic purposes does breach the tapu of the mother, the embryo and by implication the whakapapa of the wider family. The second test below is linked to the first.

Test 2: *Mauri*

Every living thing has a mauri. The mauri test is essentially a test of the risks to the life of the subjects of PGD. This may involve asking further questions and analysing the risks to the future child, mother, father and family. For example:

~ Has the mauri of the embryo been put at risk?

~ Does an embryo biopsy damage mauri?

~ What is different about the selected embryo?

~ When implanted is the embryo different?

Professor Mead concludes that most of the concerns will probably be focused on the moral and social issues rather than risks to mauri. The concern would be for the life of the new being and for the long term prospects of the future child.

Test 3: *Take - utu - ea*

If a breach of tapu or mauri is established or is an issue, the next step is test 3.

Test 3.1: *Take*

The take issue is necessarily concerned about the breach of tapu or mauri. The take has to be accepted by all parties as a legitimate cause - there has to be recognition that tapu has been breached (or will be) and the reasons are canvassed and debated. The difficulty is reaching a mutual agreement about the breach or wrong committed.

Test 3.2: *Utu*

The next element is utu.[159] Utu raises the question:

~ What is the form of utu most appropriate for this sort of breach?

~ Who is implicated?

~ What is the reason for doing this?

~ Is it to harm or benefit?

~ Have the parties involved assessed the likelihood of damage to the well-being of the people who will use the new technology?

Test 3.3: *Ea*

The final, desired state is that of ea, a state of satisfaction where a sequence has been successfully closed, relationships restored, etc.

Test 4: Precedent

Test 4 involves a search for precedents. In Te Ao Māori, an event or tradition might help people understand the issue or help frame a response to it. The creation of life and the role of atua, tohunga gives a clear indication that whakapapa is inherently tapu. See the examples of traditional reproductive practices and the discussion of Te Ao Māori above.

Test 5: Principles - whanaungatanga, manaakitanga, mana, tika, noa

Test 5.1: *Whanaungatanga*

Whanaungatanga creates an obligation of support and assistance if the person seeking help is a blood relative - irrespective of whether it was supported by tikanga Māori or not. In the context of a couple wanting to use PGD the wider family are obliged to support their decision.

Test 5.2: *Manaakitanga*

Manaakitanga underpins all tikanga Māori - it focuses on positive human behaviour and encourages people to rise above their personal attitudes and feelings towards each other and towards the issues they believe in. The aim is to nurture relationships and respect the mana of other people. The value is often expressed as "acting like a rangatira".

Test 5.3: *Mana*

A decision to use PGD should not damage the mana of a patient, a consumer, nor anyone associated. Ideally, mana should be enhanced. For example: doctors who perform abortions are often targeted or denigrated. The role of the doctor complies with the principle of manaakitanga but their personal mana is put at risk.

Test 5.4: *Noa*

Noa - reaching a state whereby a new idea is accepted, incorporated into the thinking of people and is no longer a controversy - an informed public? People need to know the harms and benefits of PGD.

Test 5.5: *Tika*

The success of tikanga depends on public acceptance. The basic question to ask is whether PGD is tika, that is, ethically, culturally, spiritually or medically right. The answer should be, yes, it is tika and right to participate in new technology.

6 SUMMARY

The tests are proposed to assist those who want a tikanga framework to help them develop and justify what may be called a Māori position on current contentious issues. The discussion is firmly based on mātauranga Māori, on traditions, customs and eventually, on the principles of tikanga Māori. Other principles can and should be added to suit the particular circumstances. The tests identified here could be useful to families confronted by the dilemma of having to decide whether to participate in new technologies, new cures for medical problems, and new ways of doing things.[160] Although adherence to tikanga reduces the risks to both individuals and society from abnormal behaviour or wrongdoing, sometimes it is only through deliberately flouting culturally embedded norms that important and beneficial changes to society are brought about.[161]

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PART D: LEGAL ISSUES AND REGULATORY RESPONSES

1 POSITIONING THE LAW

Regulatory decisions concerning biotechnologies, particularly genetic modification, occur within a landscape of contestation; the moral acceptability, practical risks and benefits, short and long term consequences remain highly disputed. Reprogenetics, and specifically pre-birth genetic testing, is similarly contested, beset with numerous sites of community divergence, concerning for example: the moral status of the embryo, the extent of rights to reproductive autonomy, trepidation at the prospect of 'designer babies', commodification of life and the like. Responding to disparate community perspectives in a regulatory framework is an onerous undertaking.

Endeavouring to provide for Māori perspectives is a further and perhaps greater challenge, as the imperatives which must be accommodated are cultural, ethical and spiritual values, founded in a distinct, contrasting world view (as discussed above). Any regulatory framework adopted must command popular support and be guided by principles of proportionality, certainty, clarity, accountability, efficiency and accessibility. It must also respect and protect the integrity, holism, nuances and institutions of a Māori values system, the intangible and amorphous nature of which is exceptionally difficult to respond to within a legal instrument, often described as 'blunt'.

This section of the chapter considers the nature and form of a suitable regulatory model, capable of meaningfully recognising Māori values, institutions and issues pertaining to pre-birth genetic testing. It does so in three parts; first, the intersection between the various facets of pre-birth genetic testing and Māori values are identified; secondly, the jurisprudential framework informing the nature and extent of a regulatory framework is discussed; and finally, an appropriate regulatory form is considered. The guiding objective is to construct a legally sustainable regulatory regime which ensures Māori have the 'space' to self-determine and perpetuate customary values and institutions as they relate to the multifaceted aspects and implications of pre-birth genetic testing.

2 REGULATORY ISSUES - INTERSECTING VALUES AND TECHNOLOGY

A suitable regulatory regime for pre-birth genetic testing must traverse all aspects of the technology, seeking to provide for Māori values, institutions and issues at each significant juncture. We have identified four critical junctures which we introduce briefly to centre the subsequent analysis; standards and processes for determining acceptable uses of pre-birth genetic testing; clinical processes and accountability; barriers to equitable access; and processes for reproductive decision-making.

Presently, the ambit of pre-birth genetic testing is primarily constrained by scientific knowledge and technical expertise. The processes and standards for determining permissible applications of scientific 'know how' will inevitably reveal further normative disparity within society, ideally to be resolved through deliberative processes. For Māori, the prima facie acceptability of the technology remains disputed; there is no consensus as to whether pre-birth genetic testing in any form is concordant with customary values. Research participants considered the use of pre-

birth genetic testing to threaten maintaining the integrity of whakapapa[162], continued exercise of mana, rangatiratanga and kaitiakitanga,[163]so as to protect and preserve tapu, mauri and wairua[164]. Equally, they considered these values and institutions to be cardinal determinants of acceptability. An appropriate regulatory framework must in some way provide substantively and procedurally for the continued exercise of these values, in the standards and processes for approving current and future uses of pre-birth genetic testing.

Clinical processes relate to laboratory procedures and administrative reporting and monitoring of services provided. Māori values pertaining to whakapapa, tapu, and mauri are directly affected by such processes, and ought to be recognised in regulatory protocols relating to clinical processes, especially, embryo and fluid disposal. As a corollary, it would be necessary to supplement reporting and monitoring requirements with appropriate accountability measures.

The embedded disparities between Māori and non-Māori in every measurable social indicator, especially health, indicates that Māori utilisation of this technology will be less than that of non-Māori, foreshadowing significant social concerns with equitable access to pre-birth genetic testing. It is difficult to directly regulate for equity. However contributing barriers to Māori uptake, such as prohibitive costing, mistrust of health professionals and 'cultural safety' concerns can and should be considered within the regulatory framework.

Reproductive decision-making concerns the processes by which an individual or couple elect to utilise pre-birth genetic testing. Dominant discourses posit the prospective mother as possessing an individual right to reproductive autonomy, and the consequent entitlement to engage with this technology, limited by the 'half rights' of the embryo or foetus to be treated with dignity, and wider societal values.[165] The individualism determining this balancing of rights is juxtaposed against the collectivism within Māori society, which vests mana, rangatiratanga and kaitiakitanga in a collective; whanau, hapū or iwi. Reconciling individual rights to reproductive autonomy and collective rights to enjoy and perpetuate culture, where the full exercise of that right would limit individual enjoyment, is perhaps the most incisive and contentious challenge. It reveals the normative chasm between Māori and non-Māori perspectives, which must somehow be bridged or accommodated in a suitable regulatory framework responding to the current era of Māori cultural revitalisation.

The extent to which an appropriate regulatory regime ought to accommodate Māori values, institutions and issues at each critical juncture is informed by jurisprudence arising from various legal doctrines recognising Māori entitlements as Treaty partners and indigenous people.

3 JURISPRUDENTIAL RECOGNITION OF TE AO MĀORI

Identifying the ambit of ethically and legally legitimate recognition of Māori values, institutions and issues in a regulatory regime is helpfully guided by five legal doctrines; the Treaty of Waitangi, human rights standards, the doctrine of aboriginal title, fiduciary duty imposed on the Crown and status of tikanga Māori as a system of customary law in New Zealand.

3.1 THE TREATY OF WAITANGI

The Treaty of Waitangi (the Treaty) is repeatedly described as New Zealand's founding document, occupying, in the contemporary era, a constitutional status permeating throughout all spheres of government to which it has relevance. Various competing conceptual approaches to interpreting and applying the Treaty exist; however, formulating the 'principles of the Treaty' has become pre-eminent. The 'principles' jurisprudence is premised upon constructing interpretative aids, capable of giving effect to the 'spirit and intent of the Treaty', reconciling the textual differences between the Māori and English versions in which it was executed, and ensuring its continued application in contemporary New Zealand.[166] While the principles approach is vigorously critiqued as both over-stating Māori entitlements,[167] and impermissibly diluting the Treaty terms,[168] the Waitangi Tribunal has justified the 'principles' methodology as follows:

> *As we see it, the 'principles' enlarge the terms, enabling the Treaty to be applied in situations that were not foreseen or discussed at the time. Conversely, a focus on the terms alone would negate the Treaty's spirit and lead to a narrow and technical approach. The Treaty cannot be read as a contract to build a house or buy a car. It was a political agreement to forge a working relationship between two peoples and must be seen in light of the parties' objectives. The principles of the Treaty are ventilated by both the document itself and the surrounding experience.*[169]

We consider the 'principles' methodology to be an entrenched approach, which will almost certainly be favoured in any regulatory regime developed, and so confine our Treaty analysis to applying the principles of the Treaty in their current permutation.

There is no definitive list of Treaty principles, and arguably they are in a state of constant evolution, responding to new and particular issues. Two cardinal principles have evolved: partnership and active protection, respectively obliging the Crown to treat with the Māori Treaty partner(s) co-operatively, honourably and in good faith, and to protect Māori interests, as is reasonable. A further 'equal citizenship' principle is obtaining greater prominence in the contemporary era. In concert, these principles create a template for an appropriate regulatory response to pre-birth genetic testing.

Partnership is the overarching tenet, from which all other principles are derived. It delineates the nature of the relationship between the Crown and Māori, and the means by which that relationship is to be translated into practice. The relationship is premised upon the juxtaposition of tino rangatiratanga retained by Māori, and kāwanatanga obtained by the Crown, which imposes mutual fetters upon the respective rights and responsibilities of both parties:

> *It is clear that cession of sovereignty to the Crown by Māori was conditional. It was qualified by the retention of tino rangatiratanga. It should be noted that rangatiratanga embraced protection not only of Māori land but of much more, including fisheries ... The Crown in obtaining the cession of sovereignty under the Treaty, therefore obtained it subject to important qualifications upon its exercise. In short, the right to govern which it acquired was a qualified right.*[170]

This bargain has been analogised to both marital[171] and fiduciary[172] relationships, the common essence of which is to act honourably, reasonably, co-operatively and in good faith towards one another.

The practical implementation of this relationship is that the Crown undertakes open minded consultation with Māori Treaty partners to inform policy decisions and directions:

> *The responsibility of one Treaty partner to act in good faith fairly and reasonably towards the other puts the onus on a partner, here the Crown, when acting within its sphere to make an informed decision, that is a decision where it is sufficiently informed as to the relevant facts and law to be able to say it had proper regard to the impact of the principles of the Treaty.*[173]

The depth and outcome of engagement required to discharge Treaty obligations will depend on the nature of Māori interests affected. Where policy impacts upon rangatiratanga or other valued taonga, consultation is essential, and ought to consider all reasonable means for recognising and protecting Māori interests.[174]

With reference to pre-birth genetic testing, the principle of partnership therefore, is primarily procedural in nature, informing the means by which an appropriate regulatory regime ought to be designed. As discussed above, the technology potentially impinges upon rangatiratanga, mana, and the sanctity of whakapapa, consequently obliging good faith consideration of Māori values, institutions and issues, through a process of deliberative dialogue exploring various regulatory approaches and models.

Active protection is premised on protecting the cultural presence and integrity of Māori within New Zealand. Positive obligations are imposed upon the Crown to create conditions conducive to the retention or regeneration, and transmission of customary values, relationships and institutions.[175] The essential facets of the principle have been succinctly stated by the Tribunal as:

> The duty of active protection applies to all interests guaranteed to Māori under article 2 of the Treaty. While not confined to natural and cultural resources, these interests are of primary importance. There are several important elements including the need to ensure:
>
> ~ that Māori are not unnecessarily inhibited by legislative or administrative constraint from using their resources according to their cultural preferences;
>
> ~ that Māori are protected from the actions of others which impinge upon their rangatiratanga by adversely affecting the continued use or enjoyment of their resources whether in spiritual or physical terms;
>
> ~ that the degree of protection to be given to Māori resources will depend upon the nature and value of the resources. In the case of a very highly valued rare and irreplaceable taonga of great spiritual and physical importance to Māori, the Crown is under an obligation to ensure its protection (save in very exceptional circumstances) for so long as Māori wish it to be protected ... The value to be attached to such a taonga is a matter for Māori to determine;

~ that the Crown cannot avoid its Treaty duty of active protection by delegation to local authorities or other bodies (whether under legislative provisions or otherwise) of responsibility for the control of natural resources in terms which do not require such authorities or bodies to afford the same degree of protection as is required by the Treaty to be afforded by the Crown. If the Crown chooses to so delegate it must do so in terms which ensure that its Treaty duty of protection is fulfilled.[176]

The two central points of inquiry in this context are: firstly, whether a Treaty protected interest is affected, and secondly, the extent and means of protection the Crown must afford that interest, in light of wider obligations to govern in the national interest, which in this paper is characterised as involving proportionality assessment.

Treaty interests constitute a broad class of things deemed to fall within the Treaty terms. On its face, the class includes property rights to resources listed in Article II, namely lands, forests, fisheries and estates, but has been interpreted as applying to Māori interests generally, including rangatiratanga and an increasingly diverse range of taonga, both tangible and intangible. In context, only the latter two are relevant, as property rights in body parts and in situ genetic resources are clearly prohibited[177].

In context, the retention of rangatiratanga over genetic materials, whakapapa and the originating mātauranga Māori is a protected Treaty interest, directly affected by the approval processes for uses of pre-birth genetic testing, and subsequent clinical processes. We also emphasise that rangatiratanga extends over tikanga Māori, especially as it applies to matters of social and political organisation;[178] however, we consider the recognition of tikanga as a distinct head of inquiry below.

Rangatiratanga is most commonly articulated as the right to retain authority or control as an antecedent to maintaining relationships with customary resources, obliging the Crown to protect maintenance of rangatiratanga over a particular resource. The scope of entitlement has three tiers:

> *The first is that authority or control is crucial because without it the tribal base is threatened socially, culturally, economically, and spiritually. The second is that the exercise of authority must recognise the spiritual source of taonga (and indeed of the authority itself) and the reason for stewardship as being the maintenance of the tribal base for succeeding generations. Thirdly the exercise of authority was not only over property but of persons within the kinship group and their access to tribal resources.*[179]

The regulatory response must be guided by the three dimensions of rangatiratanga which can be understood as empowering Māori to exercise effective control over relationships with resources and between people.

The concept of effective control embraces the ability to be self determining, self governing or self managing of matters affecting Māori interests:

> *Broadly ... we consider 'aboriginal autonomy' to describe the rights of indigenes to constitutional status as first peoples, and their right to manage their own policies, resources, and affairs (within rules necessary for the operation of the State) and to enjoy cooperation and dialogue with the Government.*[180]

With respect to whakapapa, genetic materials and mātauranga Māori, this facet of rangatiratanga necessitates Māori possessing some degree of control over what purposes, and under what conditions pre-birth genetic testing is conducted. The extent of that capacity is discussed below where proportionality assessment is considered.

The third dimension of rangatiratanga, relating to relationships between people, has particular salience to reproductive decision-making, applying to Māori individuals and couples seeking to use pre-birth genetic testing. As discussed, reproductive decision-making according to customary values posits the collective interest as primary, subordinating individual autonomy to the collective good. This collectivist imperative within Māori society is embraced under the rangatiratanga principle, discussed below with reference to tangible resources, but arguably directly transposable to this context:

> *The conferral in the Māori text of "te tino rangatiratanga" of their lands on the Māori people carries with it, given the nature of their ownership and possession of their lands, all the incidents of tribal communalism and paramountcy. These include the holding of land as a community resource and the subordination of individual rights to maintaining tribal unity and cohesion.*[181]

Consequently, there is a strong Treaty basis for recognising the collective interest in reproduction, extending to both collective decision-making processes, and perhaps recognising collective interests as limitations upon individual reproductive autonomy. Māori possess the right to develop socially and politically as a people, enabling appropriate contemporary collective decision-making processes to be created as necessary.[182] Reflecting collective decision-making within a regulatory framework must respect the right of Māori to control their own tikanga, as an incident of rangatiratanga, and therefore, must protect the ability to self determine and self define appropriate decision-making processes, principles and institutions. [183]

Whether the Treaty would be interpreted so as to subject individual reproductive autonomy to collective interests is unclear, as it induces competition between the recognition of collective expressions of rangatiratanga, and the rights of individual Māori protected under Article III, an as yet under-explored area of Treaty jurisprudence. In light of the recognition that Māori society is currently infused with an individualistic ethic, and insufficiently unified on the contemporary role of collectives, we caution against an overly dichotomous juxtaposition of individual and collective rights. Rather, we posit the Treaty as imbuing collectives with a participatory, but not coercive capacity, acknowledging that customary vesting of mana and rangatiratanga was by consent, and the absence of common consent in the contemporary era necessitates the collective assuming a different role, permitting that role to evolve, as Māori cultural revitalization warrants.

Various aspects of pre-birth genetic testing also affect matters falling within the class of Treaty protected taonga. Taonga is literally defined as a 'treasure' or 'prized thing', jurisprudentially; it has been extended to embrace tangible and intangible things of particular cultural significance to Māori, such as te reo Māori,[184] mātauranga Māori,[185] and Māori values such as mauri[186]. The amorphous, subjective identification of what properly constitutes a taonga has frustrated some Treaty commentators.[187] However, the Tribunal has provided clear and appropriate guidance:

> *While the term taonga is not easily defined, a spiritual link with the people and an obligation on them to protect it for future benefit is commonly a critical element, as is conveyed, for example, in the following pepeha: Kia āhia rā anā te mana, te ihi, te wehi, te tapu a te Atua ki runga, kātahi ka waiho ai ki ngā kaitiaki hei manaaki mā ngā whakatupuranga e tupu ake - he taonga kei reira. A property (material or non-material) becomes a taonga when, with divine blessing, it is entrusted for the benefit of future generations.*[188]

This form of kaitiaki relationship protects the values of whakapapa, mauri, wairua and tapu, and the whanau relationships imposed upon by pre-birth genetic testing. As previously discussed, whakapapa is a cardinal element of Māori identity and society, imbued with tapu and mauri, and contained in genetic materials. The current diagnostic use of pre-birth genetic testing was cautiously considered as possessing potential to foster traditional values and ideals pertaining to whakapapa. However, we note that some commentators are likely to consider such acceptance to constitute an impermissible misinterpretation and redefinition of tikanga Māori.[189] Therapeutic or genetic enhancement applications of the technology were perceived to potentially undermine the kaitiaki relationship. Should these applications eventuate, the Treaty endorses Māori rights and capacities to maintain their kaitiaki relationship. Attendant clinical processes to any use, especially embryo and fluid disposal must also respect these values, through implementing processes respecting the tapu and mauri of genetic materials, by meaningfully providing for the expression of kaitiakitanga.

Whanau relationships have been judicially recognised as a taonga protected by the Treaty, informing appropriate regulation of matters affecting the nature and form of whanau in the contemporary era:

> *We also take the view that the familial organisation of one of the peoples as party to the treaty, must be seen as one of the taonga, the preservation of which is contemplated. Accordingly we take the view that all Acts dealing with the status, future and control of children, are to be interpreted as coloured by the principles of the Treaty of Waitangi. Family organisation may be said to be included among those things which the treaty was intended to preserve and protect.*[190]

Pre-birth genetic testing has the potential to transform whanau relationships through reproductive decision-making processes. The paramount status of the collective role of kaumatua and kuia as repositories of both knowledge and mana, and taonga status of the future child do not correspond to the implicit hierarchy of rights within the dominant individualistic approach, which prioritises the reproductive autonomy of the prospective mother. The failure to recognise an alternative normative positioning of the interested persons or entities would equally fail to protect the nature and form of whanau relationships within te ao Māori, contrary to the spirit and intent of the Treaty.

The extent to which the Crown must protect the Treaty interests discussed is dependent upon a proportionality assessment, which seeks to weigh Māori Treaty interests against the Crown's wider obligations to govern in the national interest. The equation is to balance the significance and/or vulnerability of the Treaty interest against all other competing interests, including other stakeholder and sector interests and principles of fiscal responsibility. The inexorable answer is that the Crown is only obligated to do what is reasonable:

> *[I]f as is the case with the Māori language at the present time, a taonga is in a vulnerable state, this has to be taken into account by the Crown in deciding the action it should take to fulfil its obligations. This may well require the Crown to take especially vigorous action for its protection....It is therefore accepted by both parties that the Crown in carrying out its obligations is not required in protecting taonga to go beyond taking such action as is reasonable in the prevailing circumstances.*[191]

Assessing 'reasonableness' is necessarily an imprecise art, considered on a case by case basis. The guiding methodology iincludes the following: the significance and/or vulnerability of the Treaty interest ought to be assessed by Māori, specifically the collective possessing mana over the taonga or thing;[192] the national interest is to be assessed objectively, in a spirit of good faith, and co-operation; and Māori Treaty interests should only be overridden or compromised as a last resort in the national interest.[193] The guiding objective is to ensure that the cultural and spiritual values of both Treaty partners are respected, and that neither attains pre-emptive standing.[194] With respect to pre-birth genetic testing, the equation applies differently to each critical juncture.

The standards and processes for determining permissible uses of the technology clearly affect all persons wishing to access the services. Consequently, the national interest comprises primarily of their rights and interests to do so, notably including those persons at high risk of producing a child affected by genetic or chromosomal disorders. Māori interests, as stated above, are there to maintain rangatiratanga over genetic materials, whakapapa and values systems. All these interests are of the greatest significance to Māori, and are arguably vulnerable due to consistent incursions since colonisation. However, the preventative potential of the technology to lessen human experiences of severe inheritable disorders is ethically and morally compelling, and will inevitably be interpreted so as to offset the exercise of rangatiratanga. It is our opinion that the balance between Māori interests and the national interest ought to result in a minimum of Māori effectively contributing to decision-making processes, enabling due recognition and representation of Māori knowledge, values and ethics. This is inherently a position of compromise, but we note that compromise is implicit to the Treaty itself.

Clinical processes do not possess a comparable national interest; they consist of the day to day operation of laboratories offering pre-birth genetic testing services. Māori interests that enable the exercise of kaitiakitanga involve respecting and providing for the tapu and mauri of persons utilising the service, and the bodily materials tested and disposed of. These values could be accommodated through various processes, including reciting karakia, developing clinical protocols with mana whenua groups regarding disposal of bodily and genetic materials, and creating advisory positions for kaumatua. We also believe that these processes would enhance Māori uptake of the technology as demonstrating respect for Māori culture, going some way to restoring trust in professional health services. This issue is considered further under the principle of equal citizenship.

Reproductive decision-making does not directly possess a national interest element; it is confined to recognising individual rights to access pre-birth genetic testing services. Therefore, the equation in this context is the counterbalancing of individual Māori and collective Māori rights, held by whanau, hapū and iwi, to participate in reproductive decision-making. As

discussed above, we consider it untenable for collectives to exercise coercive or absolute powers in this context, due to value of reciprocity underlying customary practices and the contemporary influence on Māori society. However, recognising collective interests is a vital antecedent to providing for the sanctity of whakapapa and customary repositories of mana and rangatiratanga, and it is therefore imperative that principles of collectivism are in some form accommodated by the regulatory response. We consider these Treaty interests to necessitate an innovative decision-making model which validates the position of collectives, and seeks to respect, and to an extent restore the reciprocity between individuals and collectives. The actual form such a decision-making model could take is discussed below under the head of 'Tikanga'.

The principle of equal citizenship speaks directly to the issues of equitable access to pre-birth genetic testing services. Under Article III, individual Māori were guaranteed equal rights as British subjects; in contemporary society, it transposes into an obligation on the Crown to ensure Māori enjoy the same rights and freedoms as non-Māori. As with human rights standards pertaining to equality, the distinction between equality of opportunity and equality of outcomes remains contested, which is especially significant under the Treaty due to the perpetuation of Māori social and economic disadvantage from colonisation to the present day. The weight of Treaty jurisprudence, however, favours equality of outcome, extending to affirmative action where necessary to redress disadvantage.[195] Pre-birth genetic testing, as a health service, will almost certainly manifest the embedded pattern of lesser Māori access and uptake, necessitating conscientious efforts to achieve equity between Māori and non-Māori.

Effective means for redressing disparity is a subject of continued academic debate. We do not presume to offer a comprehensive remedy, rather we set out principles on which distributive equality might be better achieved and suggest some practical interventions specific to pre-birth genetic testing. Equality in a substantive sense does not follow automatically from equal treatment. Conversely, there is an extensive body of discourse which attributes the perpetuation of Māori disadvantage to homogenous treatment of a multicultural population. It is imperative that Māori cultural and spiritual values are recognised and provided for in a regulatory regime, so as to create conditions conducive to promote Māori uptake and trust in the service. Mechanisms could include: recognising the validity of collective processes, enabling cultural protocols to be practised; creating appropriate cultural support services, such as the availability of kaumatua; and encouraging the presence of Māori staff in clinics. Equally, social and economic barriers such as prohibitive costing, travel and accommodation requirements and whanau dynamics must be recognised in public funding of the service, should pre-birth genetic testing become publicly funded.

In summary, the Treaty protects Māori rights to participate in a deliberative consultation process conducted in the utmost good faith, to develop an appropriate regulatory regime, and to accommodate the following Treaty-protected interests:

~ the exercise of rangatiratanga within the approval process for the application of pre-birth genetic testing technology;

~ the exercise of kaitiakitanga within the clinical processes pertaining to the technology;

- collective decision-making to supplement individual reproductive decision-making in relation to pre-birth genetic testing;
- equitable access to the technology; and
- the creation of cultural, social and economic conditions conducive to equitable Māori access and uptake of pre-birth genetic testing services.

3.2 HUMAN RIGHTS STANDARD

Human rights norms broadly correlate to Treaty jurisprudence, and provide an enriching alternative and supplementary framework to consider the recognition of Māori values, institutions and issues in developing a regulatory response to pre-birth genetic testing. We utilise international human rights discourse that has arisen over the past 20 years and as pertaining to indigenous peoples as this helps inform domestic standards. We note the requirement for our municipal law to give effect to international conventions[196] and that the Cabinet Manual expressly directs law-makers in New Zealand to be mindful of our international obligations.[197]

International law is normative and constantly evolving. The implications for our study is that there are both crystallised and emergent standards relating to the rights of indigenous peoples, both of which can and are variously interpreted dependent upon one's objective. As this report is intended to inform policy reform, we consciously adopt a conservative interpretation of international human rights discourse and also note wider jurisprudential trends.

Crystallised human rights standards embrace indigenous peoples' rights to equal enjoyment of the 'universal' human rights and fundamental freedoms contained in the International Bill of Rights, the Universal Declaration on Human Rights (UDHR), International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR), which are supplemented by a number of hortatory instruments. The two standards of particular relevance to this study are the norm of non-discrimination and the right to culture. Both of these have long been recognised as interdependent, especially with respect to culturally distinct collectives existing with a dominant culture society. The Permanent Court of International Justice commented with respect to the objective of peaceable co-existence of minority populations that two conditions were necessary:

> *The first is ensure that nationals belonging to racial, religious or linguistic minorities shall be placed in every respect on a footing or perfect equality with other nationals of the State.*
>
> *The second is to ensure for the minority elements suitable means for the preservation of their racial peculiarities, their traditions, and their national characteristics.*
>
> *These two requirements are indeed closely interlocked, for there would be no true equality between a majority and minority if the latter were deprived of its own institutions, and were consequently compelled to renounce that which constitutes the very essence of it being as a minority.*[198]

Whilst we note that minority and indigenous issues are distinct, this judgment was delivered prior to indigenous peoples' rights assuming international prominence. Consequently, acknowledging the various possible formulations of indigenous peoples' rights, we frame our arguments in light of the primacy of freedom from discrimination and right to culture.

Arguably, the right to freedom from discrimination has reached an inviolable status, which prohibits prejudicial treatment on specified grounds, notably for our purposes, ethnicity. However, the norm expressly exempts 'special measures', otherwise known as 'affirmative action', as being discriminatory and implicitly recognises that differential treatment may be necessary to realise true equality:

> *Special measures taken for the sole purpose of securing adequate advancement of certain racial or ethnic groups or individuals requiring such protection as may be necessary in order to ensure such groups or individuals equal enjoyment or exercise of human rights and fundamental freedoms shall not be deemed racial discrimination, provided, however, that such measures do not, as a consequence, lead to the maintenance of separate rights for different racial groups and that they shall not be continued after the objectives for which they were taken have been achieved.*[199]

In our domestic law, the implementation of special measures on the basis of 'race' or ethnicity is specifically provided in both the Human Rights Act 1993 (HRA), which applies to the government and other public actors, and the New Zealand Bill of Rights Act 1990 (NZBORA), which applies to both public and private actors. Section 73(1) of the HRA exempts measures undertaken in good faith to promote equality from constituting discrimination.[200] Section 19(2) of the BORA provides that measures taken to assist persons or groups of persons disadvantaged because of, amongst other things, colour, 'race' and ethnic origin do not constitute discrimination.[201]

On this basis, both international and domestic standards correlate to the 'principle of equal treatment' discussed above, thereby augmenting the legitimacy and need for a regulatory response to pre-birth genetic testing capable of ensuring equitable access and uptake, necessarily through differential provision for Māori cultural, social and economic issues.

The right to culture is unique amongst crystallised standards in that it provides for collective as opposed to individual enjoyment of the right. The right is sourced in a number of international instruments, including the ICCPR, ICESCR, CERD and the UDHR.

Since the passage of the International Bill of Rights, UNESCO has been prolific in adopting a raft of non-binding declarations affirming the importance of cultural diversity.Specifically with respect to indigenous peoples, the right is interpreted as upholding the ability of indigenous collectives to maintain their cultural integrity, and freely develop their cultural identities, customs and practices.[202]

An example where distinct cultural values and institutions of indigenous peoples were recognised is the *Hopu & Bessert v France* decision of the Human Rights Committee (HRC). The complaint related to planned construction of a complex on an ancient burial site, which the complainants argued breached their rights to family under Article 17 of the ICCPR.[203] The Committee deemed it necessary to apply the concept of family sourced in the indigenous

community. Customary understandings of 'family' were found to encompass ancestral relationships, and the proposed construction was therefore in breach of the community's right to family. The HRC has similarly affirmed the cultural values and practices of indigenous peoples primarily in the context of relationships with lands and resources.[204] The resultant body of jurisprudence can be summarised as follows; individuals have a right to participate in the life of the indigenous community:[205] that the continued existence of the collective can, in some instances, limit individual rights[206], and that rights to cultural integrity are not absolute when confronted with the interests of society as a whole.[207]

Further support for the recognition of indigenous normative and knowledge systems in regulating the control and access of genetic resources is found in environmental instruments, such as the Convention on Biological Diversity (CBD), the Rio Declaration and Agenda 21. These instruments have pioneered implementation of the right to culture, specifically in relation to land, resource and environmental matters, as these issues have dominated indigenous advocacy to date. Therefore, international instruments regulating access and utilisation of biological diversity provide authoritative precedents for the accepted scope of the right to culture as it pertains to indigenous peoples. For indigenous peoples, people are not separate from the environment, and the values and principles recognising their knowledge and guardianship over genetic resources in nature, apply equally to the use and access of human genetic material. In this respect, we note Article 8(j) of the Biodiversity Convention, whose purpose is to ensure that genetic resources are preserved and benefits arising are shared, clearly obligates nation states to:

> *...respect, preserve and maintain knowledge, innovations and practices of indigenous communities embodying traditional lifestyles relevant for the conservation and sustainable use of biological diversity and promote their wider application with the innovations and practices and encourage the equitable sharing of benefits arising from the utilisation of such knowledge, innovations and practices.*

Authoritative human rights organisations, supported by a wider international movement, have therefore consistently affirmed that indigenous peoples are entitled, as of right, to enjoy in community, conditions which support the maintenance and evolution of customary values, institutions and practices, imposing upon their host nation states, positive substantive and procedural obligations:

> *Culture manifests itself in many forms ... The enjoyment of those rights may require positive legal measures of protection and measures to ensure the effective participation of members of minority communities in decisions which affect them.*[208]

Applying this jurisprudence to the regulatory response to pre-birth genetic testing, the right to culture would require that the framework contains special provisions for Māori, recognising the distinct cultural values and institutions of Māori, providing for the role of Māori collectives, and ensuring the framework itself is developed through a process of deliberative dialogue with Māori. Consequently, we reiterate that the standards and processes for approving the use of pre-birth genetic testing, and clinical procedures and processes pertaining to reproductive decision-making must all provide for the meaningful expression of Māori values and institutions relating to rangatiratanga, kaitiakitanga, whakapapa, tapu, mauri and wairua.

The central tenet contained in relevant material on international law and norms in this area is the articulation of indigenous peoples' right to self determination.[209] Due to the avid assertion by States of the primacy of territorial and political integrity, and the current stalemate encountered in the passage of the Draft Declaration, we do not wish to examine in great detail at this stage the issue of self determination, other than to acknowledge a substantive body of commentary persuasively advocating the reassertion of indigenous rights and ability to determine their own destinies politically, socially, culturally and economically. Actual rights to self determination would necessarily create far greater entitlements in a regulatory response to pre-birth genetic testing than the discrete and segregated rights discussed within this report. We emphasise that should this right attain customary international law status, this area of regulation, and many others, would require substantial reconsideration.

3.3 ABORIGINAL TITLE

Aboriginal title is a common law doctrine derived from 16th century Spanish canon law. It operates to protect the property rights of prior, indigenous inhabitants of a territory on the acquisition or transfer of sovereignty to a colonising power. It is founded on the principle of modified continuity, in that the property rights as constituted under indigenous customary law are recognised by the received law and transmuted into a legal form cognisable by the contemporary modern state. Consequently, the common law does not create the property rights; it merely declares their continued existence. While a novel legal argument could be asserted that Māori, on the basis of aboriginal title, can assert property rights in bodily and genetic materials, such an argument would need to surmount tremendous legal hurdles[210] and is so tenuous that we do not elect to consider it within this study. Rather, we are concerned with the implications for the continuity of collectives within Māoridom, and self governance over customary law.

The continuity of indigenous identity is an implicit objective of aboriginal title. To protect property rights, it is necessary to recognise and protect the rights 'holder'. Therefore, aboriginal title can be interpreted as impliedly supporting the retention of the distinctive cultural identity of indigenous collectives, even if not as its primary objective.[211]

The recognition and preservation of the cultural identity of indigenous peoples would inform suitable regulatory responses involving reproductive decision-making. As discussed, reproductive decision-making affects customary values and beliefs pertaining to the possession and exercise of authority, processes for reaching decisions, and the principles on which decisions ought to be based. Inherently, pre-birth genetic testing possesses the potential to transform customary modes of social and political organisation, and affect how the current path of cultural revitalisation progresses. On the basis of aboriginal title, it is arguable that the regulatory response must provide for the continuity of customary collectives, enabling the continued expression of social and political structures and processes, as is necessary for the retention of a distinct cultural identity. The correspondence with the Treaty-based rangatiratanga principle is clear; the regulatory framework ought to permit Māori to reassert and reinvigorate customary decision-making processes, to be self defined and self perpetuating.

The application of aboriginal title to the customary law is considered below under the head of tikanga Māori.

3.4 FIDUCIARY DUTY

The concept of fiduciary duty in New Zealand is an established aspect of Treaty jurisprudence, interpreted as informing the nature of the Treaty partnership; as an independent source of obligation its scope in New Zealand is latent and untested. International precedent indicates that it is an independent doctrine, evidenced in the Supreme Court of Canada's landmark decision *Guerin v. The Queen*[212] which established the relationship between the Aboriginal peoples and the Crown is fiduciary in character, giving rise to fiduciary obligations in situations where the Crown has discretionary power that can affect their interests. Leading New Zealand scholars such as Brookfield, Boast and Dorsett consider an independent actionable fiduciary duty is capable of recognition in New Zealand. We also note a novel fiduciary duty application has been lodged by a number of iwi relating to historical alienation of Wellington lands.[213] Therefore, despite the doctrine of fiduciary duty being under-explored in New Zealand, it is possible that it could be seen to inform a regulatory response to pre-birth genetic testing. Should it be operative, the discretionary ability of the government to affect Māori reproduction, cultural values, and equitable access to pre-birth genetic testing would be a sufficient base to invoke fiduciary obligations. The consequence would be to reinforce the principles previously discussed, namely, that the government would be obliged to regulate in the best interests of Māori, necessarily inducing provision for customary values, institutions and issues.

3.5 TIKANGA MĀORI

Tikanga Māori is recognised as a system of customary law which remains an operative source of law in New Zealand on the basis of constitutional principles applying to colonisation, and is protected by the doctrine of aboriginal title and the Treaty of Waitangi.[214] Tikanga is thus adducible in our courts, as custom, except to the extent it has been overridden by statute.[215] The relevance of looking to tikanga in this context is that it is the philosophical and normative system in which the values and institutions discussed are sourced. A tikanga framework provides an holistic and integrated methodology to give effect to Māori values and institutions, in contrast to the discrete and compartmentalised solutions discussed above under the various branches of jurisprudence reviewed. Therefore, if tikanga Māori can be considered a valid and operative source of law in New Zealand, the regulatory regime conceivably could, and perhaps should, support its application within the Māori community, and reinvigorate its presence throughout the wider context of pre-birth genetic testing. The result would be to create a truly pluralistic regulatory regime.

Legal pluralism is not a contemporary advent of post modernist discourse. Its origins are in colonisation from the 17th until the 19th centuries, during which many subjugating powers elected to retain local laws operating at the acquisition of sovereignty. Imperial law provided that municipal law operative in the United Kingdom would be received into the colony but it also provided for local laws, institutions, customs, and rights to remain in force until abrogated by the imperial power.[216] Local laws can be recognised as incorporated within the received municipal system or remain intact as a parallel foreign law system. Both models

of recognition provide for local customary law to remain intact and the local community retains self governance abilities necessary to perpetuate and modify the customary norms.[217] Additionally, both models preserve customary law by requiring that any instance of abrogation occur through a positive act which clearly and plainly extinguishes the operation of the local law or custom.[218]

With reference to pre-birth genetic testing, the result is that tikanga Māori is prima facie an operative legal system, quashed only to the extent it has been clearly extinguished by legislation. To date, there has been no blanket abrogation of Māori customary law – the statute governing pre-birth genetic testing (the HART 2004) does not expressly extinguish tikanga – and neither, from research conducted, are there related statutes which would extinguish tikanga in this context. Therefore, there is no legal barrier to the recognition of tikanga Māori as a distinct stream of customary law applying to pre-birth genetic testing. There may be however, practical barriers to effective recognition of Māori custom.

Should one advocate the recognition of tikanga Māori as an operative source of law in New Zealand, a number of questions would arise such as: who would it apply to? how would it be enforced? who would enforce it? how does it intersect with New Zealand common and statute law? and perhaps most piercingly, what is the tikanga that applies in this circumstance? There are no ready answers to these questions, especially with respect to emergent technologies. However, the lack of immediate answers does not impair the legitimacy of tikanga as a source of law; it simply necessitates a constructive and deliberative process to resolve these issues. Pending such a dialogue, it is beyond the scope of this paper to advocate for particular technical or substantive recognition of tikanga. However, we can reiterate founding principles derived from aboriginal title and the Treaty.

Aboriginal title, as discussed above, is premised upon the continuity of customary law, and implicit provision for self perpetuating that custom, which implies some degree of recognition for collective self governance. In the case of *Hineti Rirerire Arani v Public Trustee of New Zealand*, the Privy Council stated in relation to customary Māori adoption:

> *It is based upon the old custom, as it existed before the arrival of Europeans, but it has developed, and become adapted to the changing circumstances of the Māori race today.*
>
> *It may well be that this is a sound view of the law, and that [Māori] as a race may well have some internal power of self-government enabling the tribe or tribes by common consent to modify their customs ...*[219]

The continued existence of self governance capacity permitting the modification of customary law has similarly been recognised in both Canadian and Australian judicial decisions on aboriginal title.[220] The theoretical basis of this ability to modify custom is significant, deriving its legitimacy neither from state sanction, nor from immemorial usage as with English custom, but from the preceding indigenous legal regime.[221] By necessary implication, the result is that indigenous communities retain an inherent, indissoluble right to self define principles and processes of customary law, quite apart from state processes and powers.

The relevance of inherent rights to self govern and so modify customary law is that it requires the regulatory response to pre-birth genetic testing to permit Māori to control and direct the

incorporation of values and institutions in the regulatory regime created. As a preservationist doctrine premised on the continued existence of indigenous peoples, it counsels a non-prescriptive regulatory framework which enables Māori to retain the right and ability to continue the self definition of customary laws as they relate to reproduction in the context of pre-birth genetic testing. It thereby mirrors the implications of the right to development sourced in Treaty jurisprudence, discussed under the rangatiratanga principle above. Specifically, it reiterates the imperative of providing for customary values and institutions at all significant junctures identified above, with particular regard for customary processes and principles to infuse reproductive decision-making, in a form which ensures Māori retain the effective right and ability to define and redefine the applicable values, processes and institutions.

3.6 SUMMARY OF JURISPRUDENCE REVIEWED

The jurisprudence reviewed is all highly consistent, reaffirming the legal and ethical right for Māori values, institutions and issues to be recognised, provided for and addressed in a regulatory response to pre-birth genetic testing. While a tikanga Māori framework would be the most appropriate, as it embraces the epistemological origins of Māori values, and customary law, it would be an unprecedented approach within New Zealand. Therefore, we advocate for a deliberative process to explore how tikanga could be holistically provided for in this context, and at this stage, reiterate the common jurisprudential support for the following specific, albeit imperfect, features in the regulatory framework:

1. The ability for Māori to effectively participate in formulating and administering the standard processes under which permissible uses of pre-birth genetic testing are decided;
2. The provision for Māori values pertaining to whakapapa in clinical processes, and appropriate monitoring of those processes;
3. The issues of equity and access addressed through culturally appropriate clinical processes and social and economic barriers mitigated;
4. The creation of an innovative reproductive decision-making process which recognises the role of collectives within Māori society.
5. The recognition that Māori customary values and institutions are dynamic, thereby enabling Māori to self define and redefine their expression and implications in relation to pre-birth genetic testing.

It is to the actual means for implementing these jurisprudentially supported standards that the paper now turns.

4 NORMATIVE REGULATION

4.1 WHY REGULATE?

Māori perspectives and values ought to be specifically addressed within the regulatory framework so as to recognise that Māori are a distinct people within New Zealand, possessing ethical and legal rights to retain and perpetuate cultural identity and presence within the

wider polity. New Zealand has already recognised the necessity of intervening in pre-birth genetic testing, and passed a regulatory framework under the Human Assisted Reproductive Technologies Act 2004 (HART), which contains limited provision for Māori values.

4.2 CURRENT REGULATORY FRAMEWORK

The critical features in the current regulatory framework providing for Māori values and perspectives comprise the following. Section 4 of the HART Act which stipulates the guiding principles binding all persons acting pursuant to the Act and includes, under subsection (f), the provision that the needs, values, and beliefs of Māori should be considered and treated with respect. Section 34 (f) which requires that ACART must have at least one Māori member with expertise in Māori customary values and practice and the ability to articulate issues from a Māori perspective. We note that the total membership of ACART is not more than 12 persons. As ACART possesses a mandate to advise both the Minister and ECART on matters relating to assisted reproductive technologies, the influence of the Māori member does extend throughout the regulatory framework. Additionally, the ECART Terms of Reference require that the Committee have at least two Māori members, out of a total membership of not more than 10.

Provision for Māori values, institutions and issues relating to acceptable uses of pre-birth genetic testing is not apparent on the face of the Preimplantation Genetic Diagnosis Guidelines begun and prepared by the National Ethics Committee on Assisted Human Reproduction (the NECAHR PGD Guidelines) that was approved by the Minister of Health in March 2005. However, NECAHR did acknowledge that:

> *The pluralistic nature of New Zealand society means that universal agreement on the use of PGD was not a possibility. In revising the guidelines following the public consultation, NECAHR took account of all the submissions and focused on the strength of the arguments with regard to particular clauses in the guidelines, rather than on the number of stakeholders for or against them.*[222]

Nevertheless, we note their use of pluralistic referred to numerous sites of community contestation, not particularly Māori perspectives.

When reviewing the NECAHR PGD Guidelines, ACART has a duty under section 4(f) to consider and treat with respect the needs, values and beliefs of Māori and presumably the presence of two Māori members will inform deliberations. We note there is no apparent substantive recognition of Māori values.

~ The NECAHR PGD Guidelines also set out the reporting and monitoring obligations imposed on clinics. Reproductive decision-making is governed by section 4 of the NECAHR PGD Guidelines which imposes information obligations on clinics conducting PGD and counselling requirements on people seeking to access PGD.

Additionally, providers must ensure those seeking PGD are, prior to consent being obtained, informed about NECAHR's requirement for providers to supply information for the Committee's annual report.

All applicants must undertake psychosocial counselling from qualified counsellors who are trained in genetic counselling. The counselling must be culturally appropriate and include consideration of the following:

~ the nature of the disorder, its likely impact on the offspring and family/whānau and the availability of treatment

~ the family/whānau experience of the genetic disorder

~ the range of alternatives to PGD and subsequent decision-making processes

~ the possible implications of undertaking PGD.

From that, we note the only apparent provision for Māori perspectives is the requirement that counselling is culturally appropriate and the reference to whanau.

The current regulatory regime appears to fall rather short of the reviewed jurisprudential standards at every significant juncture of pre-birth genetic testing. Therefore, we consider substantive reform of the current regulatory framework is warranted in order to give appropriate recognition to Māori ethical, cultural and spiritual interests. In the following section, we consider the principles on which a new model ought to be based, and subsequently, mechanisms drawn from comparative precedents which could enhance the recognition of Māori values, institutions and issues.

4.3 FOUNDING PRINCIPLES

The founding principles of an appropriate regulatory model have been canvassed through the applicable jurisprudence above. However, the essence of their commonality is the establishment of a truly pluralistic regulatory framework. Pluralism is premised upon the recognition of multiple communities with distinct values and normative orders existing within one polity, creating a contemporary nation state which is multi-central and multi-cultural.[223] In its contemporary articulation, legal pluralism is situated within post modern discourse, reviling hegemony and advocating for dialogical engagements between formally equal, but socially and culturally embedded subjects.[224] Legal pluralism, as a theory supporting formal and meaningful recognition of Māori values, is a useful tool to assess the various forms the regulatory framework could assume. Such a framework would exist on a spectrum between weak or classic pluralism and strong or substantive pluralism.

Weak pluralism, also known as juristic or classic pluralism, has been described as a centralist model of law, under which indigenous customary law is only relevant to the extent that it has been incorporated by statute.[225] Regulatory regimes which adopt a weakly pluralistic approach recognise that Māori possess a distinct value system and seek to provide for those differences through either establishing procedural safeguards or incorporating substantive concepts from the Māori value system into state law.

Strong pluralism is a recent doctrinal development, which posits law as existing independent of state sanction, embracing a 'dialectical analysis of the relationship among differing normative orders'.[226] The consequence of a strong pluralistic perspective is a more holistic consideration of the law, more concordant with the approach of legal anthropologists and sociologists,

which posits law as interacting with society, enabling it to change or evolve as required by the people without state intervention or sanction. Under this model, indigenous customary law and indigenous perspectives are valid normative orders, contributing to the wider law of New Zealand, and capable of being changed according to their internal prescripts, without state endorsement. Consequently, recognising tikanga Māori as a stream of law, and over which Māori have some internal power of self government enabling it to coherently evolve without state action or endorsement.

The necessary caveat on all forms of pluralism is that the apparent receptivity toward customary values, laws and institutions can belie the very real effect of perpetuating the ethic of colonisation, by capturing, redefining and reducing the customary law and originating knowledge system.[227] Therefore, it is imperative that any pluralistic undertaking does not seek to codify, or otherwise 'lock up' the customary order, which is dynamic by nature, and over which is an inherent indissoluble right held by indigenous peoples to self define and redefine its form and content.

4.4 COMPARATIVE PRECEDENTS

A number of extant regulatory regimes manifest a pluralistic ethic, providing varying degrees of recognition for Māori values, institutions and social or economic issues. We have identified three classes of pluralism currently in force and review each in turn: weak procedural pluralism; weak substantive pluralism; and strong pluralism, prior to a comparison with HART.

4.4.1 WEAK PROCEDURAL PLURALISM

Procedural pluralism consists of creating mechanisms which facilitate the reconciliation of indigenous custom and state law.[228] In New Zealand, procedural provisions generally amount to granting consultation rights, or other participatory rights to enable Māori perspectives to be represented in decision-making processes. Four alternative formulations will be considered: the New Zealand Public Health and Disability Act (NZPHDA), the Resource Management Act (RMA), the Local Government Act (LGA), the Hazardous Substances and New Organisms Act (HSNO), and the Trade Marks Act.

The NZPHDA governs district health boards. Section 23 (d) – (f) incorporates Māori perspectives into decision-making by requiring health boards to obtain information and perspectives from Māori. Health boards must consider how to facilitate Māori contributions, establish processes to elicit Māori contributions, and provide relevant information to Māori to enable them to contribute. There is also a further requirement under section 29 (4) that Māori membership on district health boards is ideally proportional to the percentage of Māori resident in the district or at least reaches a minimum of two Māori members.

The RMA and LGA intersect to provide two key mechanisms for representing Māori values and interests in local government decision-making processes. The LGA applies to all local government decision-making, and is very similar to the NZPHDA, in terms of both eliciting Māori perspectives, and ensuring Māori representation. Section 81 of the LGA mirrors section 23 (d) – (f) of the NZPHDA. The Local Government Commission, which advises on matters relating to local government must have one member who has knowledge of tikanga Māori and

is appointed by the Minister of Māori Affairs (section 33). The RMA has a narrower ambit, requiring decision-makers to take into account Māori perspectives and values as they relate to decisions over natural resource use and development. The tripartite provisions intersect as follows: section 6 requires decision-makers to recognise the relationship between Māori and their ancestral lands, waters, wahi tapu and other taonga as a matter of national importance; section 7 requires decision-makers to have particular regard to kaitiakitanga, and section 8 requires decision-makers to take into account the principles of the Treaty of Waitangi.

HSNO regulates the use, development or importation of hazardous substances and new organisms, including GMOs, as defined by the Act which are approved for use by the Environmental Risk Management Authority (ERMA). The Act has two mutually reinforcing components which seek to recognise Māori perspectives. First, it contains similar provisions to sections 6 and 8 of the RMA, requiring that ERMA recognise the relationship between Māori and their ancestral lands, waters, wahi tapu, valued flora and fauna and other taonga, and to take into account the principles of the Treaty of Waitangi. The notable points of differences with the RMA, is that the class of resources is greater, including valued flora and fauna, which was inserted as a result of the increased debate around indigenous rights to native flora and fauna which followed the lodging of the WAI262 claim and the passing of the Biodiversity Convention 1992. ERMA has also undertaken to develop a schedule of matters contained under section 6, known to be of particular concern to Māori, and a list of contact persons to facilitate consultation with iwi. Secondly, the Act, supplemented by the Methodology Order-in-Council, provides for Ngā Kaihautā Tikanga Taiao, a Māori advisory committee to ERMA, charged with providing advice and assistance from a Māori perspective, on matters relating to policy, process and applications for approval.

The Trade Marks Act provides for the establishment of a Māori Advisory Committee to the Trade Marks Commissioner, with the mandate to advise the Commissioner whether marks derivative of Māori imagery and/or language are or would be likely to be offensive to Māori.

The common feature of all schemes is that Māori values and perspectives are recognised as being distinct and warranting recognition. Therefore, they are pluralistic in the sense that they recognise more than one value system existing in New Zealand. However, they are weakly pluralistic as they only provide for these values to be represented in the decision-making process and enforced only to the extent that decision-makers must pay them due regard. Māori values and perspectives do not found a power of veto, and in all instances, Māori perspectives are provided by persons in merely an advisory rather than decision-making position. This form of weak pluralism has been criticised on the basis that it provides only nominal protection of customary values and that in most, if not all, instances of a conflict between Māori values and commercial ventures, Māori values will be dismissed as 'metaphysical' and less significant than the other interests to be balanced.[229]

4.4.2 WEAK SUBSTANTIVE PLURALISM

Substantive pluralism involves incorporating rules from indigenous custom into state law.[230] Historically, New Zealand sought to incorporate elements of Māori customary law into New Zealand law, albeit primarily for the purpose of gradually replacing custom with general laws, and that temporary incorporation followed by assimilation was the most expeditious means to do so.[231] The clearest example is the Native Exemption Ordinance 1844, followed by the Resident Magistrates Courts Ordinance 1846, and the Resident Magistrates Act 1867, which all sought to incorporate norms derived from Māori customary law into the criminal law of New Zealand, and involve Māori leaders in the judicial process. The customary practice of muru (redress) was incorporated into sentencing for theft and assault. These provisions were repealed in 1893. Additionally, section 71 Constitution Act 1852 provided for Māori districts to be set apart, where Māori laws and customs would govern relations between Māori, and that those laws and customs would only be quashed if repugnant to the principles of humanity. However, no such districts were ever established despite the strident efforts of a number of Māori groups, including the Kingitanga.[232]

In the present day, the clearest example of substantive incorporation is under Te Ture Whenua Māori Act, which directs the Māori Land Court (MLC) to apply tikanga Māori in a number of instances, including customary land status orders, succession rights to Māori land, and kin group issues including mandate and representation. Principles and prescripts of tikanga Māori are not defined in the Act and so the MLC is charged with both discerning the applicable tikanga, and subsequently applying it as a body of law to the facts presented before it. The MLC has developed a sizeable body of precedent concerning tikanga Māori.[233]

The RMA incorporates narrow elements of tikanga Māori, namely in relation to the concept of kaitiakitanga and determining what sites are properly wahi tapu. Kaitakitanga is defined in the Act as exercise of guardianship by the tangata whenua of an area in accordance with tikanga Māori, and wahi tapu sites are defined as sites of significance, with such status determined according to tikanga Māori.[234] As no statutory guidance for applying tikanga Māori in this context is provided, decision-makers, including the courts, have had to identify and apply the applicable tikanga.

Tikanga Māori has also been applied by the courts in family law matters, primarily in respect of adoption, custody disputes and succession under the Testamentary Promises Act and family protection proceedings. Tikanga has also been considered in the context of criminal sentencing.[235]

The common feature of these regimes is that they direct or permit decision-makers to apply tikanga Māori, but provide limited guidance as to the content of the applicable tikanga. As the tikanga is unknown to decision-makers, they are required to discover, interpret and finally, apply it. This has led to forceful criticism that by allowing tikanga Māori concepts and values to be interpreted and enforced by state entities, tikanga Māori is misinterpreted, misapplied, and in effect extinguished by assimilation.[236] Additionally, as discussed above, where decision-makers are required to balance principles and values of tikanga Māori against the interests of third parties, Māori values are most commonly sacrificed to other interests on the grounds that they are intangible or metaphysical. Where, as with Te Ture Whenua Māori, there are no analogous third party interests, tikanga Māori is less likely to be compromised.

4.4.3 STRONG PLURALISM

An example of strong pluralism in a modern context, is currently manifest in the Customary Fisheries Regulations.[237] These regulations apply to all salt water non-commercial customary fishing conducted by tangata whenua. The regulations institute a process for obtaining consent to conduct customary fishing according to tikanga Māori, from a tangata tiaki/ kaitiaki, who has obtained their authority from a process premised on tikanga Māori. The Regulations are based on the tikanga of mana whenua mana moana, meaning that persons should only be able to conduct customary fishing in a particular area if they have obtained the consent to do so from the mana whenua (the group holding customary authority over the area) and that persons exercising that authority on behalf of the mana whenua should be duly authorised according to tikanga Māori. Additionally, they empower the tangata tiaki to exercise kaitiakitanga, through enabling their participation in the creation of Mataitai (reserves). The Regulations create an entire regime based on the values of tikanga Māori and seek to recognise the rights and relationships prescribed by tikanga Māori. However, they are codified in a form which has been less than successful, and so have not been widely implemented largely due to difficulties in appointing tangata tiaki and to the lack of resources, and dispute resolution and enforcement procedures.

4.4.4 COMPARISON WITH THE HART ACT

The HART Act clearly adopts a weakly pluralistic approach, providing limited procedural incorporation of Māori values, through sections 4 and 34, defining the guiding principles and providing for Māori membership on ACART respectively. Therefore, it is similar to the procedurally pluralistic regimes reviewed, in that it contains a statutory direction for persons acting pursuant to the Act to take into account Māori ethical, cultural and spiritual perspectives, and membership rights to an advisory body, one step removed from the decision-making table. However, it is weaker than any of the procedurally pluralistic frameworks reviewed on the grounds that the statutory direction to take Māori values and perspectives into account is less explicit than other Acts with analogous clauses, and that membership on ACART is a lesser form of advisory role than the separate Māori advisory committees under HSNO and the Trade Marks Act, albeit, the provision on ACART membership is directly comparable to that under the NZPHDA and the LGA.

As discussed, pre-birth genetic testing poses significant cultural, ethical, spiritual and social risks to Māori as a people. We consider it is inconsistent, and inadequate as the current regulatory regime is one of the weakest pluralistic forms currently operating in New Zealand, and strongly recommend reform.

5 RECOMMENDATIONS FOR REFORM

Reforming the HART Act ought to be guided by jurisprudential standards and constructive models from comparative precedents. We reiterate the ethical and legal legitimacy of recognising Māori cultural values and institutions, and social or economic issues, as consistently affirmed in the jurisprudence reviewed. Equally, we emphasise the significant impact this technology could have on cardinal customary values, patterns of social organisation, and equal ability to participate in the wider polity should this technology have increased application. Consequently, we recommend that the current framework should be substantially reformed at each significant juncture of pre-birth genetic testing. The actual content of reform could be usefully guided by the comparative precedents reviewed, specifically, their balancing of Māori and wider interests.

The weakly pluralistic regimes all govern matters which affect a wide range of parties, and necessitate the balancing of Māori interests against those of third parties. In order not to afford Māori the ability to control or constrain the actions of third parties, Māori are only granted the right to have their perspectives represented in the decision-making process. The stronger forms of pluralism found in Te Ture Whenua Māori Act and the Customary Fishing Regulations in contrast, applies to intra-Māori issues, where there is no comparable third party interest to balance.

Standards and processes for approving uses of pre-birth genetic testing are currently the subject of a great deal of community contestation, and involve compelling moral rights of persons at risk of transmitting serious genetic or chromosomal disorders. Therefore, we respect the propriety of the current standard for approving uses of pre-birth genetic testing; namely a cautiously permissive approach, but recommend increased procedural provision for Māori in the decision-making process. Specifically, we recommend that a Treaty clause be inserted into the HART Act, operating throughout the scheme of the Act, requiring all persons under the Act to 'give effect' to the principles of the Treaty.

We also consider the presence of Ngā Kahautu Tikanga Taiao in the ERMA process to be a more meaningful provision for membership and advisory capacities, and an analogous body ought to be created within the HART framework, applying to all assisted reproductive technology, and perhaps other emerging genomic biotechnologies, including pre-birth genetic testing. Drawing upon the current responsibilities of Ngā Kahautu Tikanga Taiao, ACART could be responsible for providing input in the following areas:

~ Application of the principles of the Treaty of Waitangi;

~ The approach of Māori to reproduction;

~ Specific reproductive and cultural issues of concern to Māori;

~ Appropriate consultative mechanisms with Māori;

~ Ensuring adequate consultation and dialogue occurs with Māori organisations and affected individuals.

We also emphasise that ACART and a supporting secretariat must be adequately resourced to fulfil these functions.

With respect to clinical processes, we recommend that there should be statutory or regulatory provision for cultural protocols, including the availability of kaumatua to advise clinic staff on cultural protocols, provision for karakia and related protocols to be conducted at appropriate times; and the creation of appropriate embryo and fluid disposal protocols developed with mana whenua under the supervision of ACART. Additionally, we consider that ACART ought to be responsible for monitoring these clinical processes, providing assistance in the area of professional and resource development and supporting kaumatua.

Issues of equity and access are notoriously difficult to cure through aspirational statements and standards. We consider that social and cultural access barriers should initially be addressed through the creation of a 'culturally safe' environment. The clinical processes discussed above, and augmentation of information and counselling requirements discussed below, are a partial solution, but we note that embedded patterns of Māori disadvantage require a far more comprehensive and penetrating solution that is yet to be agreed upon by academics and politicians alike. We also recommend that should the service be publicly funded, the particular economic issues and barriers experienced by Māori are targeted as areas needing to be addressed.

The issue of reproductive decision-making is the most challenging aspect of the regulatory regime which is not amenable to a ready transplant of a pre-existing precedent. We recommend that the current framework be amended in two critical respects: firstly that the provision for culturally appropriate information and counselling be enhanced, and secondly that specific provision be made for collective decision-making processes.

The current information and counselling requirements are quite bare, and appear to emphasise consideration of the health risks, benefits and limitations according to the current state of the scientific understanding. We recommend that counselling also enable applicants to discuss matters of tikanga Māori, including potential spiritual harm and offence and related cultural concerns, with persons possessing appropriate expertise.

We consider this is especially important in light of the current era of cultural revitalisation, so that some Māori have a sense, but not comprehensive understanding of tikanga, resulting in anxiety as to the cultural acceptability of their decisions. Additionally, the counselling services can only be conducted by qualified counsellors trained in genetic counselling; while we have not been able to obtain statistics on the number of Māori qualified to provide these services, we estimate there to be few. We recommend that persons providing 'tikanga counselling' be exempted from these formal qualifications requirements, and that they be appointed according to culturally relevant indices. For the purposes of clarity, we recommend that 'tikanga counselling' be an additional counselling service which augments, rather than supplants the current framework.

Provision for collective reproductive decision-making processes is an important, although challenging component of an appropriate reform package. An appropriate response must reconcile a number of founding principles including the inherent reciprocity between individuals and collectives under customary principles, contemporary and customary patterns of social organisation and relationships such as tuakana- teina relationships, kai pupuri i te mana – 'the one that holds the mana' on behalf of the collective, ahi kaa – maintenance of whakapapa rights, and the imperative to respect the right and ability of Māori to self define and redefine these customary principles. Additionally, it must grapple with the contemporary reality that Māori society is tribally diverse and multifaceted and gaining consensus for any prescribed and universally applied response is challenging. We consider the composite of these issues to constitute significant, complex philosophical, judicial and political challenges, for which there is no contemporary precedent or adequate guide. Further, the most appropriate means to address these issues is through a process of deliberative dialogue within Māoridom, considering implications beyond the narrow application of pre-birth genetic testing. As we have not been able to conduct extensive dialogue with the Māori community, the solutions we set out are merely preliminary comments, and we do not presume that they are other than an initial starting point.

Actual provision for collective decision-making must be premised in an affirmation of both individual and collective rights, recognising that Māori collectives are the kaitiaki of future generations and whakapapa, and that individuals are also kaitiaki possessing rights to reproductive autonomy. Implementation should proceed through a voluntary collective decision-making process. It should be voluntary so as to recognise that some or many Māori may not wish to involve the whanau and/or hapū in their personal affairs. Equally it ought to be statutorily recognised so as to validate the presence of the collective to the wider polity. We emphasise that the legitimacy of the collective, and collective processes is sourced in tikanga Māori, therefore, the statutory basis does not have a legitimating effect; it is intended entirely to create 'space' for collectives by entrenching their visibility to wider New Zealand. The actual provision endorsing collective processes should be a bare recognition of collective processes and not extend into any description of the applicable principles or processes of tikanga Māori. We reiterate that Māori autonomy over tikanga is an inherent right, and codifying it in this context, as with all others, poses the unacceptable risk of its redefinition and reduction. Therefore, the provision should read some analogous variant of: "Providers must inform person(s) seeking PGD for any purpose, of their ability to engage in a tikanga Māori collective reproductive decision-making processes". To support applicants to elect a collective decision-making process, ACART should be empowered and resourced to assist applicants with practical matters, such as contacting and notifying members of the collective, assisting with hosting a hui, including a marae or whare if the hui is to be away from the applicants' turangawaewae, travel costs and so forth. Consequently, the actual process and principles on which the collective decision-making proceeds are matters of kawa, entirely under the control of the responsible collective, as is appropriate under tikanga Māori. Necessarily, this would result in the definition of the collective, rights to participate, and dispute resolution processes being determined by the responsible collective.

In summary, our recommendations for substantive reform of the current regulatory framework are as follows:

a. Inclusion of a Treaty clause, framed in the words "to give effect to the principles of the Treaty of Waitangi";

b. Creation of a stand-alone Māori Advisory Body, responsible for advising ACART, setting and monitoring clinical protocols and standards, and supporting collective decision-making and other cultural support services, including 'tikanga counsellors' and kaumatua;

c. Provision for 'tikanga counsellors' who possess expertise in tikanga Māori and are exempted from formal qualifications requirements; and

d. Statutory recognition of a voluntary collective decision-making process, the principles and process of which are defined by the responsible collective.

We acknowledge that these regulatory remedies are largely drawn from existing precedents, all of which have been criticised as inadequate in principle and ineffective in practice[238]. However, pending the crystallisation of indigenous rights to self determination, the constitutional entrenchment of the Treaty of Waitangi, and/or the re-unification of Māori society under a tikanga Māori system of law, means for greater recognition of Māori cultural values and institutions are difficult to identify.

These recommendations at least will begin to constitute a practical and jurisprudentially grounded framework which endeavours to respect and protect the integrity, holism, nuances and institutions of a Māori values system.

CONCLUSION

Reproduction is the physical means of perpetuating the divine genealogy of the gods and ensuring the political and economic survival of the collective. Historical reproductive practices within te Ao Māori were premised on the tapu of whakapapa and collective exercise of kaitiakitanga manifest in complex, interrelated practices imbued with spiritual understanding and directed to strengthening bloodlines. Contemporary reprogenetics may offer an additional means of protecting whakapapa by alleviating the experience of whare ngaro (infertility) and the prevalence of genetic disorders within the Māori population. Whether engaging with pre-birth genetic testing is a sustainable extension of tikanga Māori must be treated cautiously as opinions and interpretations of customary values differ. Negotiating if and/or how Māori could comfortably engage with pre-birth genetic testing would be an exciting aspect of cultural revitalisation in the contemporary era. Legal principles can meaningfully guide and assist in navigating through the complexities and challenges that would beset recognition of Māori values in an appropriate regulatory regime. Their essence encourages processes of deliberative dialogue enabling Māori to self define and self determine the process and substance of tikanga Māori as it applies to pre-birth genetic testing. The role of the regulatory regime is therefore to support the expression of tikanga Māori in the modern world, enabling the present generation of Māori to reproduce according to the spiritual and philosophical understandings of our ancestors.

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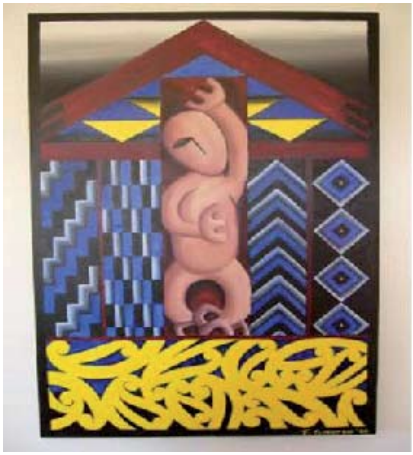

Te Meake Nei-The Future
Ko tatou nga kanohi me nga waha korero o ratou ma kua ngaro ki te po'
We are but the seeing eyes and speaking mouths of those who have passed on
(All artwork is gratefully reproduced with the consent of the artist Tania Clouston)

GLOSSARY

Ahi-Ka	Burning fire, rights to land by occupation
Ariki	High chief
Aroha	Love, respect, compassion
Atua	God, spirit, supernatural being
Haua	Disabled, crippled, lame, anti-social, mental handicap
Hapu	Sub-tribe, pregnant
Ihi	Power, authority, essential force
Kai-Karanga	Callers
Kai Korero	Speech makers
Kaitiaki	To guard
Kaitiakitanga	The act of guardianship

Kai-Whakahaere	Director of proceedings
Kaumatua	Elder or elders
Kawai	Lineage, pedigree
Kuikuia	Female elder or elders
Makutu	Sorcery, witchcraft
Mana	Prestige
Manaaki	Caring person helpful to others
Manaakitanaga	Hospitality
Mana Atua	Gods of the Māori world, spiritual authority
Mana Tangata	Human authority
Mana Tupuna	Prestige and power drawn from the ancestors
Marae	Ceremonial courtyard, village plaza
Matamua	Coordinator, spokesperson, first born
Matauranga Māori	Māori knowledge
Mokopuna	Grandchild
Noa	Balance, neutrality
Rangatiratanga	Political sovereignty, chieftainship, leadership, self-determination, self-management; individual qualities of leadership and chieftainship over a social group, a hapu or iwi.
Ranginui	Sky father
Taonga	Valued, treasured possession
Tangata whenua	First people of the land
Tapu	Restricted, sacred
Taonga tuku iho	Natural legacy or heritage, treasures directly inherited
Te Ao Marama	The full light of day, the cosmological realm of being
Te Kore	The void; the cosmological realm of potential being
Te Po	The night realm; the cosmological realm of becoming
Tikanga	Customary practices
Tino Rangatiratanga	Self-determination

Tohunga	Priest, skilled spiritual leader, expert
Tuakana	Older brother (of male), older sister (of female)
Tupuna	Ancestor, also grandparents, male or female
Wairua	Soul, spirit
Whakapapa	Genealogy
Whanau	Family, extended family
Whanaunga	Relative
Whanaungatanga	Relationships

RESEARCH PROCESS AND QUESTIONS

A. DATA COLLECTION

There is limited, if any, literature available in relation to the Māori ethical, spiritual, cultural and social issues pertaining to pre-birth genetic testing. Consequently, eight Māori with a range of expertise were asked to participate and contribute.

We would like to acknowledge the research participants Professor Mason Durie, Professor Piri Sciascia, Dr Jessica Hutchings, Del Wihongi, Hana Oregan, Maui Hudson and Tim Rochford who were all interviewed and peer review assistance was sought from Moana Jackson.

We would also like to thank the Constructive Conversations: Korero Whakaaetanga research team lead by Rosemary Du Plessis at Canterbury University. Much of the information and literature from the Constructive Conversations Team provided valuable insights for our research.

A genetic testing focus group was also run in Wellington which provided valuable insights for this research project and helped to supplement our interview data.

The qualitative data for this report was taken primarily from these interviews and the genetic testing focus group. As *Tolich & Davidson*[239] stated, interviews are one of the most effective qualitative methods for generating information. The interviews were conducted between October and November 2005, in a number of locations throughout New Zealand, by three members of Te Wanaka Research Team Christchurch Polytechnic Institute of Technology.

Participants were recruited from existing links and networks from within Te Wanaka's Māori Research Team. Contact was made initially via email and over the telephone. Interviews were conducted using Cram's guiding principles, with a particular emphasis on *he kanoho kitea* (refer to table 1), or meeting face to face. Subsequently interviews took place in Christchurch, Wellington, Palmerston North and Auckland.

Table 3.3 Cram's[240] *suggested guidelines for undertaking Māori research*

I. Guideline	II. Description
A respect for all people	Allowing people to define their own space and to meet their own terms.
He kanohi kitea	The importance of meeting with people face to face.
Titiro, whakaronga korero	The importance of looking and listening so that one develops understandings and finds a place from which to speak.
Manaaki ki te tangata	Collaborative approach to research, research training and reciprocity.
Kia tupato	Politically astute, culturally safe and reflective about our insider/outsider status.

Kaua e takahia te mana o te tangata	Not trampling on the mana of the people. It is about sounding out ideas with people, about disseminating research findings, about community feedback that keeps people informed about the research process and the findings.
Kaua e mahaki	Not flaunting your knowledge and it is about sharing your knowledge and using your qualifications to benefit your community.

B. DATA ANALYSIS

Interviews were recorded and then transcribed by a Māori typist familiar with Te Reo.

Participants were given copies of their interviews to check over once the interviews were complete. Not all the participants, however, were interested in reading their transcripts due to time constraints, and work and family commitments.

Analysis of the transcribed information involved understanding the data in a systematic way by sorting and shifting the data, identifying themes, and developing categories and codes[241]. The coding of information involved the identification of themes and determination of meanings within the text.[242]

Through this open coding and close reading, a number of dominant themes and discourses were identified and comprised the primary data used to understand the Māori ethical, spiritual, cultural, and social issues pertaining to pre-birth genetic testing.

Ethical approval or this research was obtained from the University of Otago Ethics Committee and the Christchurch Polytechnic Institute of Technology. Cram's[243] ethical guidelines for research with Māori were used as the guiding principle within these applications, and in general practice.

Research Questions posed to participants were as follows:

The following list of the research questions was compiled and used to guide discussion and analysis by the Te Wanaka. The overarching question posed was:

Whether, from a Māori perspective, pre-birth genetic testing ought to be regulated in New Zealand, and if so, how a regulatory regime can be designed so as to provide for Māori perspectives and/or rights.

This research question was addressed on the basis of the following assumptions:

~ That pre-birth genetic testing enables new types of reproductive decisions, which may or may not be permitted and/or protected by human rights standards; and

~ That the availability of pre-birth genetic testing potentially allows reproductive decisions concerning whether or not to engage in:
  ~ Embryo selection
  ~ Embryo enhancement
  ~ Saviour siblings
  ~ Sex selection
  ~ Genetic determinism - designer babies;

~ That pre-birth genetic testing may increase standards of health and well-being.

Therefore, the focus for this segment of the research (year one) was on the reproductive and health aspects of pre-birth genetic testing. Broader issues applicable to any and all genetic testing, such as ownership, use and storage of genetic information, will be addressed in later stages of the project.

OBJECTIVE 3B: WHAT ETHICAL, CULTURAL, SOCIAL AND LEGAL ISSUES DOES PRE-BIRTH GENETIC TESTING RAISE FROM MĀORI PERSPECTIVES?

Ethical:

The two overarching ethical issues were as follows:

~ Whether, from a Māori perspective, pre-birth genetic testing is a permissible and appropriate undertaking;

~ Whether, and if so to what extent, the reproductive decisions available to potential parents are acceptable:
  ~ Embryo selection
  ~ Embryo enhancement
  ~ Saviour siblings
  ~ Sex selection
  ~ Genetic determinism - designer babies.

Research questions were premised upon a deep exploration of the following ethical concepts within te Ao Māori:

  ~ Tapu
  ~ Noa
  ~ Whakapapa
  ~ Mauri
  ~ Ihi

- ~ Kaitiakitanga
- ~ Manaakitanga
- ~ Whanaungatanga
- ~ Aroha

~ Is pre-birth genetic testing as a process an acceptable and appropriate undertaking?

~ If it is not generally considered acceptable, what are the circumstances in which it becomes acceptable?

~ Are there conditions under which it becomes more or less acceptable?

~ Are the reproductive decisions made available by pre-birth genetic testing acceptable and appropriate?

~ If not, are there circumstances in which these decisions do become acceptable?

~ Are there conditions under which these decisions become more or less acceptable?

Research questions were based on a deep exploration of the following cultural concepts and processes:

~ Matauranga Māori- Māori knowledge and ways of being – the Māori world view – Māori cosmogony, Te Ao turoa, taonga tuku iho;

~ Māori perspectives on health – Whare tapa wha, taha whanau, taha tinana, taha wairua, taha hinengaro;

~ Māori perspectives on the body and body parts – tapu, noa;

~ Māori processes and institutions – whakatapu and whakanoa processes, decision-making processes and institutions regulating conduct, eg muru (redress), principles of leadership and decision-making rangatiratanga/mana motuhake/arikitanga.

The research questions included:

~ How is the embryo conceived of within te Ao Māori?

~ Within traditional Māori society, what reproductive decisions were permissible or impermissible?

~ How were reproductive decisions made? Who was involved? On what grounds were decisions made?

~ How has tradition-based decision-making responded to recent innovations in reproductive technologies, eg IVF?

~ How should decisions to undertake pre-birth genetic testing be made?

~ Who should be involved in those decisions?

~ What conditions should be placed on electing to undertake pre-birth genetic testing?

~ How should pre-birth genetic testing be conducted?

~ How should the genetic information obtained through pre-birth genetic testing be treated?

~ Who should be permitted access to it? When, on what grounds and under what conditions?

~ How does pre-birth genetic testing sit within a Māori model of health?

~ Is pre-birth genetic testing as a process an acceptable and appropriate undertaking?

~ If it is not generally considered acceptable, what are the circumstances in which it becomes acceptable?

~ Are there conditions under which it becomes more or less acceptable?

~ Are the reproductive decisions made available by pre-birth genetic testing acceptable and appropriate?

~ If not, are there circumstances in which these decisions do become acceptable?

~ Are there conditions under which these decisions become more or less acceptable?

Standards of Health and Well-Being:

~ How is pre-birth genetic testing likely to affect Māori standards of health and well being?

~ How will the availability of this technology intersect with current barriers to Māori health and well being?

~ What strategies and/or mechanisms can be created to enable this technology to enhance Māori standards of health and well being?

~ Will Māori be able to avail themselves of this technology? Are there likely to be any particular barriers experienced by Māori in doing so?

~ What strategies and mechanisms can be created to mitigate against any barriers experienced?

Whanau Structures

~ How is this technology, and the reproductive decisions made available, likely to affect Māori whanau structures and relationships?

Discriminatory Use:

~ What are the risks of this technology being used in a discriminatory manner against Māori?

~ What are the risks that Māori will engage in discriminatory practices through this technology?

~ What strategies and/or mechanisms can be created to minimise the risk of discriminatory use of this technology?

Legal Analysis:

Two overarching questions:

Does the law, in some way, recognise and/or provide for Māori ethical, cultural and social issues with respect to pre-birth genetic testing?

If so, to what extent and in what form?

These two questions can be posed as:

1. Do Māori have a legal right to:

(a) Participate in the development of a regulatory regime pertaining to pre-birth genetic testing;

(b) Participate in the ongoing monitoring/regulation of pre-birth genetic testing (procedural protection);

(c) Prevent/ limit/ impose conditions upon the conduct of pre-birth genetic testing – are Māori entitled to have their ethical and cultural priorities recognised? (substantive protection); and

(d) Are those rights limited by any other legal rule or standard?

2. If Māori are not legally entitled to any of the above, are there corresponding moral obligations, and how persuasive might they be?

The particular research questions explored four legal doctrines:

A. The Treaty of Waitangi;

B. The Crown's Fiduciary Duty to Māori;

C. Aboriginal Title; and

D. Domestic Human Rights Standards.

With respect to each doctrine, the following research issues were considered:

A. How does the Treaty of Waitangi inform the regulation of pre-birth genetic testing?

i. Does the Treaty found rights to procedural and/or substantive protection of Māori interests?

ii. What is the nature and extent of such protection?

iii. What is the rationale for any protection?

iv. How should the Treaty be interpreted to this effect?

v. Who, within Māoridom, does the Treaty protect?

vi. How can Treaty obligations be reflected in a regulatory regime?

vii. What precedents are available? (eg ERMA, RMA, Trade Marks Act)

viii. What are their strengths and failings?

ix. What elements can, should or should not be transposed onto a pre-birth genetic testing framework?

x. What limits are imposed on Treaty-based protection and recognition?

B. How does the Crown's fiduciary duty to Māori inform regulation of pre-birth genetic testing?

i. Does the fiduciary duty found rights to procedural and/or substantive protection of Māori interests?

ii. What is the nature and extent of such protection?

iii. What is the rationale for any protection?

iv. Who, within Māoridom, does it protect?

v. How can obligations derived from the Crown's fiduciary duty be reflected in a regulatory regime?

C. How does the doctrine of Aboriginal Title inform regulation of pre-birth genetic testing?

i. Does the doctrine of aboriginal title extend beyond land-based rights to found rights procedural and/or substantive protection of Māori interests with respect to pre-birth genetic testing?

ii. What is the nature and extent of such protection?

iii. What is the rationale for any protection?

iv. Who, within Māoridom, does it protect?

v. How can such rights be reflected in a regulatory regime?

D. Does New Zealand's human rights framework, both codified and uncodified, protect Māori ethical, cultural and spiritual values?

i. Does our human rights framework, specifically with respect to rights protecting culture, found procedural and/or substantive protection of Māori interests with respect to pre-birth genetic testing?

ii. What is the nature and extent of such protection?

iii. What is the rationale for any protection?

iv. Who, within Māoridom, does it protect?

v. How can such rights be reflected in a regulatory regime?

E. Is tikanga Māori, as a system of customary law, relevant to regulating pre-birth genetic testing?

i. Is tikanga Māori part of the law of New Zealand, so that it should properly be considered as a source of law regulating pre-birth genetic testing? (In its own right, or as protected by the Treaty of Waitangi, Fiduciary Duty or Aboriginal Title);

ii. What norms and standards does tikanga Māori provide with respect to pre-birth genetic testing?

iii. Can and/or should tikanga Māori be incorporated by statute to regulate pre-birth genetic testing?

iv. Who would tikanga Māori apply to?

v. How could and/or should tikanga Māori be enforced?

vi. How would the principles of tikanga Māori concerning pre-birth genetic testing be proved/established?

vii. What limits could or should be imposed on tikanga based regulation?

OBJECTIVE 3C: WHAT ETHICAL, CULTURAL, SOCIAL AND LEGAL ISSUES DOES PRE-BIRTH GENETIC TESTING RAISE FROM INDIGENOUS PEOPLES' PERSPECTIVES (IE THE INTERNATIONAL DIMENSION)?

This component of the research was intended to amount to a comparative analysis between Māori perspectives and perspectives held by indigenous peoples globally, therefore, the questions are essentially the same as those posed with respect to Māori perspectives. We will consider indigenous perspectives from the South Pacific, Australia, United States of America and Canada.

It is intended to pick up in years two and three the many issues and questions we were unable to address in year one.

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