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HE URUPOUNAMU E WHAKAHAERENGIA ANA E TE WHĀNAU

WHĀNAU DECISION PROCESSES

Hope Ngā Taare Harawira Tūpara

A thesis submitted for the degree of Doctor of Philosophy in Public Health (Māori) Massey University

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He Mihi[1]

Karanga mai, karanga mai.

I te pō ki te rā, i te rā ki te pō, e mīmiti ana i te tai, e pupuhi ana i te hau, kei whea mai. Ka heke tonu ngā roimata me te hupe ma rātau kua whetūrangitia. Koia rātau e noho pūmau ana ki te puku o te whenua i te kōpū o te wahi ngaro, hoki wairua mai.

Huri noa ki te hunga ora. Ko koutou ērā ngā mata whānui e whai ana i ngā tapuwae o ngā mātua tīpuna, koutou hoki ngā puna mātauranga mo ā tātau kōhungahunga, ā tātau whakatipuranga kare ano kia tae mai, me koutou hoki ngā ahorangi i Te Kūnenga ki Pūrehuroa me te hunga wānanga i aki, tēnā tātau. Kua whakarangatira ahau i te aroha i a koutou.

Kāre aku mihi.

[1] A mihi is a greeting. The mihi contained in the examined copy of the thesis details my whakapapa (ancestry) from the beginning of the universe, according to the tribal traditions of Ngāi Tāmanuhiri. It describes my ancestral relationship to the people of each waka (Māori sailing vessel) that arrived to Aotearoa (New Zealand), as a tribute to key people who assisted me in the completion of this work. I did not provide an English translation of the mihi for examination because it is made up of the names of ancestors. I have deliberately removed my whakapapa for the purpose of public viewing of the thesis and a different mihi has been inserted on this page.

Abstract

A whānau is a social construct of Māori society in Aotearoa/New Zealand that is likened to an extended family. This thesis describes principles and practice that whānau utilise in decision processes from the findings of a retrospective qualitative case study of three whānau, who decided to participate in genetic research into a medical condition affecting their health.

Four elements of whānau decision processes emerged from the data. Hui, rangatiratanga, manaakitanga and kotahitanga are Māori constructs that emphasise the collective nature of whānau decision making, and substantiate philosophical, theoretical and anecdotal evidence that Māori have distinctive ways of reaching decisions, underpinned by unique philosophical conventions.

The results of this research place greater significance on the process of decision making than actual decisions, an incidental finding that has not been articulated by previous studies of Māori health and whānau.

Contrary to western theoretical knowledge of decision making, whānau decision processes are collective activities. Individual decision making is closely linked to and depends on the collective, because individual identity manifests from the collective, and individual wellbeing is closely linked to that of the collective.

When decision processes are familiar to members of a whānau, they are more likely to engage in decision making because they have a greater sense of knowledge and thus control of the processes, and they feel more able to contribute meaningfully to achieving aspirations for their own health.

This thesis provides evidence that the New Zealand health sector, health legislation and policies are largely unfavourable for guaranteeing whānau engagement in decision processes. Yet, whānau decision making is an overall objective of the Government's Māori Health Strategy: *He Korowai Oranga,* to address inequalities in health between Māori and other New Zealanders that have unacceptably become the norm.

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Glossary[2]

ahi kā	literally translated as 'burning fire' as a metaphor for home place, primary settlement or one's land.
ako	learn
Aotearoa	translated as 'land of the long white cloud' and attributed to the sighting of a cloud by the canoe party captained by Kupe, which led to the discovery of land called New Zealand.
hapū	extended whānau, pregnant
hāruru	handshake
hau	wind, breathe
hauora	literally translated as 'breath of life' - hau meaning wind or breath and ora meaning life. Hauora is a metaphorical reference to wellbeing according to Māori philosophy, whereby hau implies the winds or components of wellbeing.
hōhā	frustrated, impatient, tired of.
hongi	act of two people gently resting their foreheads together momentarily to press their noses together as to exchange breaths.
Io	a reference to the beginning of Māori cosmology
iwi	tribal grouping
kaitiakitanga/kaitiekitanga	guardianship denoting custodial relationship
kaikaranga	caller
kainga	home
karakia	expression of gratitude, sometimes likened to a Christian prayer
karanga	invitation expressed as a wail
kawa	customs, practice, etiquette
kotahitanga	unity, collectivity, togetherness
kuia	elder woman/women
makutu	spiritual mark
marae	traditional settlement

[2] All translations are my own.

Mauao	tribal name for a location in the Bay of Plenty, most commonly known as Mount Maunganui
mauri	essence of being
mihi	greeting, salutation
mihi whakatau	informal greeting to visitors
mokopuna	grandchild
Ngāi Tāmanuhiri	tribal group whose tribal area is located on the East Coast of New Zealand
Ngāi Te Rangihouhiri	tribal group located in the Bay of Plenty region of New Zealand named after their eponymous ancestor, Te Rangihouhiri I
noa	risk free
ora	life, alive, wellness
paepae tapu	place for formal oratory most attributed to traditional settings such as a marae.
pā harakeke	flax plantation sometimes used metaphorically to describe the interconnectedness of a social system
pākehā	non-Māori
papa kainga	traditional settlement
pakeke	elder
piki	climb, raise, ascend
pōwhiri	formal welcome ceremony
raru	concern or problem
Rongowhakaata	tribal group so named after their eponymous ancestor
take	topic, issue
take-utu-ea	refers to an issue that requires resolution
tangata whenua	indigenous people or people of the land
taonga tuku iho	heirloom,
tapu	restriction, condition
tauparapara	recitation of ancestral lines and events
te ao Māori	Māori world, Maori worldview
te reo Māori	Māori Language
te tūnga ki te tomokanga	waiting or to wait at the entrance
tikanga	etiquette, norm, tradition

tohu	sign, symbolic
tohunga	skilled person
Tūranganui-a-Kiwa	a tribal area located on the east coast of the north island of New Zealand
wairua	spirituality
wairuatanga	of spiritual being
waka	sailing vessel
whaikōrero	oratory
whakaeke	ascend
whakapapa	ancestry, genealogy
whāngai	to take care of
whare	house structure
whakataukī	proverb
whakawātea	closure to an event or ceremony
whānau	social unit likened to a family
whānau ora	collective wellbeing
whanaunga	a relative, not necessarily a blood relative, but may have a common connection e.g. pacific or indigenous whanaunga
whanaungatanga	relationship, process of strengthening relationship/s
whenua	land, placenta

CHAPTER ONE: INTRODUCTION

Ko Te Pū[3]

Introduction to the Thesis

Facilitating whānau participation in decision making is a key objective of the Government's Māori Health Strategy: *He Korowai Oranga* (Ministry of Health, 2002). The Strategy aims to integrate the concept of whānau into health policy and to promote responsibility for health decisions at the level of whānau first and foremost (Ministry of Health, 2002). There has been no contemporary study that describes the way the health sector interfaces with whānau in decision processes, to advance government health objectives let alone aspirations for whānau. Shared decision making is critical to ensure that health planning at the level of whānau is culturally and therefore ethically oriented toward improving their health.

This thesis explores whānau decision practice in the context of health research ethics. It describes characteristics of decision processes unique to whānau, from an examination of the experience of members of three whānau who made a decision to participate in genetic research. The research question is: what are the principles and practices that whānau utilise to guide decision making about their health?

The study has two aims. The first is to illuminate some understanding of whānau decision processes from which can be developed a framework for application to health research policy and practice, to improve Māori health outcomes.

Secondly, the thesis aims to demonstrate the depth and breadth of a Māori research tradition that arises from a Māori intellectual system, thus broadening the scope of what is conventionally understood to constitute health research in Aotearoa.

Why is the research question important?

Smith suggests that "research is about satisfying a need to know" (Smith, 2005, p. 170). Jackson (2006) says the need to know should be preceded by the question: why do we need to know?

[3] Te Pū – the seed. A metaphor about beginnings, such is the justification for this research.

Inequalities in health between Māori and other New Zealanders are well documented (Ministry of Health, 2002). The Health and Disability sector is required to work in partnership with whānau so that decision making leads to whānau ora improvements, and supports the achievement of Māori health aspirations (Ministry of Health, 2002).

One of the fundamental purposes of health research is to improve the nature of people's lives so they are self-sufficient, maintain wellness, have a sense of their distinctive identity and their cultural systems, and they prosper in whatever setting they find themselves (Durie M, 1998). *He Korowai Oranga* will only be fully realised when whānau and health providers, including health researchers, discuss their common goals and make shared decisions how best to achieve the goals. A collaborative approach to decision making is more likely to lead to the identification and removal of barriers to access to health services, and thus facilitate better utilisation of health services in preventing illness, and promoting health practices that will contribute to a reduction in health gaps (Ministry of Health, 2002). The way the groups come together is critical. At the heart of collaboration, is the need for the health sector to better understand whānau as recipients of health services, including mechanisms that will ensure whānau participation in health services, through their engagement in decision processes.

At the time this study began, debate about human genetic research in New Zealand was fuelled by a news report of a New Zealand genetic scientist, who at an International Congress of Human Genetics in Brisbane, claimed Māori carry a warrior gene that makes them more prone to violence, criminal acts and risky behaviour (Australian Associated Press, 2006). The group the scientist represented was and continues to be, engaged in genetic research with a specific Māori community, to investigate serious medical diseases and conditions that are common in their tribal group. Although the scientist's claim at the conference was dismissed by the science fraternity, his behaviour raised questions about the ethical standards expected of researchers and their overall responsibilities to research participants. The apparent moral dissidence of the research organisation that the scientist represented compounded public concerns about the ethics of human genetic research (Wensley & King, 2008). Consequently, genetic research was identified as the context within which whānau decision processes could be examined, because much human genetic research is also health research.

For the reasons outlined, it is important to identify the characteristics of whānau decision processes that must be accommodated by the health sector, and in this study, decision processes are explored within the context of genetic research.

Thesis Parameters

This thesis describes a Māori conceptual framework developed for this study, based on Māori philosophical principles that were applied to the analysis and methods.

The thesis describes characteristics of whānau decision processes that emerged from interviews with 17 members of three whānau, who reflected on their decision making to engage in genetic research.

An attempt has been made to ensure the widest possible audience in the health research sector has access to the ideas in this thesis. Readers however, should be mindful that any application of English terms to Māori concepts is problematic, and it was a constant tension in this thesis.

Evidence to support the findings of the thesis is gathered from three sources: literature, my direct participatory observations, and interviews.

Thesis Organisation

The thesis is organised into seven chapters.

Chapter Two, *Literature Review,* canvasses knowledge of ethics and decision making according to western and Māori theoretical traditions, in order to understand the context of whānau decision processes at the interface of these traditions. The chapter describes the decision making framework for health research in New Zealand that is facilitated within the constitutional, legal and ethical system including the Treaty of Waitangi, relevant to the constitutional relationship between Māori and the Crown. The chapter also discusses the implications of colonisation on Māori health, drawing on comparisons with other indigenous societies, and it discusses the limitations of the major controlling forces upon whānau participation in decision processes in health, drawn from the literature.

Chapter Three, *Methodology,* describes the conceptual principles that informed the conduct and analysis of this research. It discusses qualitative inquiry and the distinct

features of Māori and western research traditions, noting the commonalities or point of interface, as a useful way to acknowledge the unique qualities that the traditions bring to research. The chapter also describes research frameworks that are articulated in various contexts to argue the existence of a Māori worldview underpinning a Māori research tradition. The implication of using a Māori worldview is discussed, including a framework designed to develop my competence as a researcher to work with Māori participants in this study.

Chapter Four, *Methods,* outlines the steps taken in the research by drawing on the methodical tradition of a pōwhiri to frame the research process. The chapter describes the conceptual principles embedded in kawa (etiquette), intrinsic to Maori inquiry, which guide the research process and assist the application of western research tools such as Case Study theory, a reality for contemporary Māori health research.

Chapter Five, *Initial Findings,* discusses the initial analysis of interviews conducted for the study and describes the medical circumstances of each whānau, information about the nature of interviews, and demographic information about the participants. The chapter then describes the findings of the interviews with reference to the interview guide that comprised five main areas of interest. Under each of the interest areas, quotes are used to highlight the ideas that emerged, which are grouped by whānau.

Chapter Six, *Cross Case Analysis,* is divided into two sections. The first analyses and synthesises the findings from all three whānau or cases. It begins by arguing that the cases are comparable and describes similarities and differences between the cases. The second section articulates the principles and practice of whānau decision processes which have been extrapolated from the data using the conceptual framework described in the methodology chapter. The findings were validated or affirmed by the cases as representative of the ideas embedded in their interviews.

Chapter Seven, *Discussion,* explores how the findings change what is known about decision processes and the implications of the findings for whānau wellbeing, as well as the implications for the health sector in enabling whānau decision processes to occur. The chapter also considers the contribution of the study to health policy, research and education, and the strengths and limitations of the thesis, and concludes by reviewing the aims of the thesis.

CHAPTER TWO: LITERATURE REVIEW

Ko Te Weu[4]

Introduction

This chapter canvasses the scope of literature relevant to understanding decision processes accessible to whānau as participants of health research in New Zealand. The chapter focuses on literature at the interface of western and Māori discourses, and thus recognises that whānau decision processes in the context of this thesis, occur at the interface of scientific and Māori knowledge systems.

Part A: Māori Society and Kawa describes the socio-political context for this research including an overview of Māori health. It describes the social construct that is a whānau and the importance of Māori social processes for Māori moral development. Part A also discusses the Treaty of Waitangi, significant to the constitutional relationship between Māori and the Crown, and the impact of colonisation upon Māori health. It then discusses philosophical and intellectual conventions that underpin Māori ethical decision practice, drawing on commonalities with other indigenous peoples.

Part B: Law and Origins of Health Research Ethics describes the legal and ethical review system that provides the framework for decision practice in the context of health research in New Zealand. The development of western ethical discourse is traced from its philosophical roots, including an overview of the intellectual traditions that have contributed to the development of western knowledge systems and decision theory which dominate modern ethical decision discourse.

Part C: Practice of Health Research Ethics synthesises the literature and discusses the limitations of the New Zealand health and ethical review system to accommodate whānau decision processes, and thus the justification for this research. Part C argues that the existing framework for ethical review is a site for the perpetuation of colonisation, making an important link between the ethical system within which decision practice is facilitated and ongoing inequalities in health between Māori and other New Zealanders.

[4] Te Weu – a shoot depicting the beginning of a life form, used metaphorically to represent the background for this research.

Part A: Māori Society and Kawa

Tangata Whenua (Indigenous People)

Māori are the indigenous people of Aotearoa/New Zealand. Like other indigenous societies, Māori form a non-dominant sector of their lands but they are determined to preserve, develop and transmit their unique identity to future generations as the basis of their continued existence as peoples, and in accordance with their own cultural patterns, social and legal institutions (General Assembly of the United Nations, 2008; Martínez Cobo, 1987; Smith, 2005; Wilmer, 1993).

According to the 2006 Census Māori make up approximately 14.6 per cent of New Zealand's population. Europeans, the largest group, were 67.6 percent of the population (Statistics New Zealand: Tatauranga Aotearoa, 2007). The Māori population has a higher proportion of young people than that for the total population with 35.4 percent of Māori aged less than 15 years compared to 21.5 percent for the total population. Of those aged 65 years and over, Māori have 4.1 percent, which compares to 12.3 percent of the total population that is aged 65 years and over. For the total population, the median age of usual residents according to the 2006 Census was 35.9 years. The median age for Māori women in 2006 was 24.1 years and for Māori men 21.3 years. The median age for females of the total population was 36.7 years and for males 35.1 years (Statistics New Zealand: Tatauranga Aotearoa, 2007a, 2007b).

Whānau

A whānau is a social construct unique to Māori, commonly applied in two distinct ways - a descent-based order (whakapapa whānau) and a metaphoric model (whānau-a-kaupapa) (Durie M., 1997; Walker, 2006). The former classic definition is determined by common ancestry, intrinsically linked to other social constructs such as an iwi (tribe) and a hapū (extended whānau collective). The metaphoric model or kaupapa whānau defines a collective with a common purpose rather than a common ancestry, but it attempts to form relationships and practices based on similar principles to those of a whakapapa whānau (Bishop, 1996; Durie M., 1997).

Mason Durie (2008) describes the whakapapa whānau as distinct from a tribal order because a whānau comprises descendants of about six generations. The oldest living members of a whānau are likely to have a memory of their grandparents. In a hapū (extended whānau) or iwi (tribal order), the founding ancestor does not form part of the

memory of living members, however members remain loyal to their eponymous ancestor.

The role and function of a whānau as a distinctive social unit is increasingly important for kinship and identity because it has assumed roles that might have formerly been conducted by the tribal structure (Durie M., 1997). Mason Durie (2008) proposes that contemporary whānau are carriers of their culture, they provide a model for lifestyle choices, they are portals to their community including access to local health services, they are guardians of the landscape and they are economic units. Access to a supportive and reliable whānau is a fundamental gateway to Te Ao Māori (the Māori world) because whānau have the potential to connect their members to their marae (traditional settlements), hapū, iwi, tribal resources and Māori networks or organisations (Durie, M., 2008).

Conceptualisation of Māori identity is thus strongly linked to kinship systems out of which emerge the values and beliefs of those networks (Borrell, 2005; Durie A., 1997; Durie M., 1995; Liu & Temara, 1998; O'Regan, 2001; Roa & Tuaupiki, 2005; Wirihana, n.d.; Walker, 1990, 2006).

Whānau and wellbeing

The whānau structure is therefore critical to the retention of a Māori cultural identity (Penitito, 2005) and a secure cultural identity is a pre-requisite to optimal Māori health and wellbeing (Durie, M., 2006). Investment in tribal development rather than whānau was the focus of the government from 1980. Most often the benefits of government initiatives were not felt at whānau levels where the greatest influence on children and adolescents comes from, and where the adoption of positive lifestyles and a strong sense of identity is shaped (Durie, M., 2000).

Interest and application of the concept of whānau by government agencies grew with the implementation of programmes such as Matua Whāngai, implemented by the Departments of Māori Affairs, Social Welfare and Justice (Walker, 2006). The original intention of Matua Whāngai was the return of young Māori back to the care of their whānau so they could be deinstitutionalised from welfare homes and prison (Turia, 2007). The programme had the government funded Unsupported Children's Benefit attached to the Orphan's Benefit, as an administrative mechanism for a payment to

whānau that followed the child. Another pool of funding was available from Justice, the Iwi Transition Agency and the Department of Social Welfare. Such funds were used as a koha, an emergency fund for grandparents caring for their mokopuna (grandchildren) (Turia, 2007).

The principle of the Matua Whāngai programme represents the kind of potential that whānau have by being able to convert risk and threat into safety, security, and the realisation of human potential. Conversely a "dysfunctional whānau may impede entry into Te Ao Māori and it can create health risks for their members, contributing to poor health rather than to positive wellbeing" (Durie, M., 2000, pp. 8-9).

The whānau must therefore function in a way to operationalise their responsibilities and obligations. Accordingly the whānau has the potential to point its members towards outcomes in both generic and Māori senses and therefore, the function or performance of whānau warrants attention and resources (Durie M. , 1997; Jackson, 1988)**.**

Whanaungatanga is a process by which whānau bond and strengthen their kinship ties. The concept is premised on the idea that whānau have the capacity to function positively for the benefit of the collective, and whānau members acknowledge and are committed to their ancestral links and practices that enhance the links (Boulton, 2005; Durie M., 1997; Durie, Black, Cunningham, Durie, Palmer, & Hawkins, 2005; Pere, 1984). Consequently decision making is an important mechanism for whanaungatanga because it contributes to the maintenance of social practices that are culturally oriented.

The whānau is an important social construct in modern Maori society, but the health and wellbeing of whānau is partially dependent on the ability of society to cater to their needs. The next part of this chapter considers the socio-political context that has impacted on the health of Maori society in general and subsequently on whānau.

The Treaty of Waitangi and the Politics of Māori Health

The Treaty of Waitangi is a constitutional document that was signed by Māori representatives, and Captain William Hobson on behalf of the British government in 1840 (Appendix 1). The Declaration of Independence authored by British Crown agents, was signed in 1835, but the Crown realised that the Declaration was an impediment to their annexation of New Zealand by emphasising Māori autonomy (Appendix 2). As a result, a revised agreement was prepared in the form of the Treaty,

and the Declaration was revoked to allow full transmission of sovereignty to the Crown (Te Puni Kōkiri, 2001).

For Māori, the Treaty gave added weight to the Declaration rather than being a replacement for it. The Crown, on the other hand, was motivated toward protecting its claim to New Zealand that was perceived to be under growing threat from French interest (Te Puni Kōkiri, 2001). Contrary to suggestions that Maori ceded sovereignty over their land, they did not agree to the unqualified transfer of their authority to the British government. Māori saw the Treaty as ensuring their right to self-determination and self-governance, protection of their lands, lives and possessions, at least how it was written and understood in their language (Appendix 1).

In reality, the Treaty was the primary instrument by which the Crown justified its right to make key decisions about New Zealand's future (Walker, 1989). Through the adoption of an English system of a society the Crown:

> constituted itself as a government with single, undivided sovereignty used its unilateral power to introduce policy and legislation that facilitated the dispossession of whānau (collective) and hapū (extended collective) of their resources and their authority in the land, and enshrined its own authority and capitalist social relations instead. (Healy, 2006, p. ii)

The Treaty recognises Māori as tangata whenua (Sykes, 2007) and at the time it was signed Māori outnumbered the settlers by approximately 40 to 1 (Te Puni Kokiri, 2001). The signing of the Treaty marks the augmentation of colonisation, or the cumulative effect of domination and governance by British society, and the impact of imposed structures upon Māori practices and systems (Smith, 2005; Wilmer, 1993; Martínez Cobo, 1987; General Assembly of the United Nations, 2008).

The Politics of Maori Health

"Māori health status is demonstrably poorer than other New Zealanders" (Ministry of Health, New Zealand Government, 2002, p. vii). Inequalities in health are a commonality that Māori share with other indigenous peoples. Colonisation is another common experience of indigenous societies, a factor attributed with creating the platform from which inequalities in health between Māori and other New Zealanders

emerged (Robson & Harris, 2007). The reasons for differences in health status between Maori and other sectors of New Zealand society are complex. A range of factors described throughout this chapter are critical to explaining Māori health status. By understanding contributors to Maori health, it is possible to then identify the basis upon which health research of Maori was founded.

Three major classes of determinants of health and wellbeing have been described: macro-political, ecological, and indigenous determinants (Durie et al, 2005). Macro-political determinants constitute legislative and policy frameworks across a range of portfolios. Ecological determinants are the social, economic, cultural and environmental factors that impact on health and wellbeing from day to day, including access to education and health services. Indigenous determinants recognise that wellbeing is closely linked to access to cultural identity. Markers of identity, such as proficiency in Māori language and access to marae (traditional ancestral settlements), provide some security of capacity to participate in Te Ao Māori (Durie et al, 2005). The range of health determinants provide a framework for understanding the implications of introduced conventions by way of colonisation, and the ways such conventions become relevant to health.

Traditionally the land was a source of sustenance that provided Māori with a means of survival and an economic base. The personification of landmarks, typical of iwi knowledge systems, is symbolic of their relationship to, and intimate knowledge of the land, within which Māori identity has always been imbued. Once the Treaty was signed, land loss occurred insidiously through a range of mechanisms. The Māori population declined dramatically while the total population increased (mainly attributed to a combination of disease, musket warfare and starvation corresponding to patterns of land loss) (Durie M., 1997). Within 20 years of the Treaty, Māori land ownership reduced from some 64 million acres to 24 million acres. The Native Lands Act 1862, the New Zealand Settlements Act and the Suppression of Rebellion Act, both passed in 1863, the 1953 Māori Affairs Act and a 1967 Amendment, gave the Crown powers to confiscate traditional lands from Māori, to imprison them without trial and without compensation, and to compulsorily acquire and sell Māori land, all because of efforts by the Crown to ensure substantive British sovereignty over Māori (Belich, 1988; Belich, 1998).

Prior to World War I Māori mostly lived in rural areas and upon their papa kainga or traditional settlements. Many young Māori, whose whānau had been dispossessed of their lands, moved to towns and cities in search of employment, accelerated by work opportunities that were created through wartime industries. The number of Māori living in urban areas doubled following World War II, adding to the further dislocation of many Māori from their traditional social and support systems, their cultural norms, practices and ethics (Te Ropu Wahine Maori Toko i Te Ora, 1993).

Gaps between Māori and non-Māori with respect to housing, university study, vocational apprenticeships, death rates and crime from about 1929 to 1959, were identified in the *Hunn Report* commissioned by the Minister of Māori Affairs (Hunn, 1961). Whilst outside his brief to report on the Department of Māori Affairs, Hunn made significant recommendations for social reform. He expressed disapproval of Māori tribal social structure that he saw as detrimental to their adaptation of the dominant system of society, and accordingly he questioned Māori philosophical concepts including concepts of land ownership and customary title. Hunn recommended the first education scholarship specifically for Māori, but he also proposed the concept of assimilation of Māori society into an English system of society, that he saw as the most important objective ahead of the country, and a solution to bridging the gaps between Māori and non-Māori (Hunn, 1961).

Prior to the arrival of British colonists, Māori were fluent speakers of their own language. The Education Act 1877 made provision for central government to take control of education for Māori children that was modelled on a British system of education. For almost a century the government did not assume any responsibility for the preservation and maintenance of Māori language and practices through the education system. By the 1970s the number of Māori who could speak their language declined to 18-20% and most of those people were over the age of 65 years (Te Taura Whiri i Te Reo Maori: The Maori Language Commission, 1988). In 1972 a Māori language petition signed by 30,000 people was the impetus for Northern Māori Member of Parliament, Matiu Rata, to convince the Kirk-led Government to accept the idea of a tribunal to hear Māori Treaty claims. The result was the Treaty of Waitangi Act 1975, establishing the Waitangi Tribunal, to make recommendations to the Crown on claims relating to the practical application of the Treaty, and to determine whether certain

matters were inconsistent with the principles of the Treaty. The Act was later amended by the Lange Government to allow claims to be heard dating back to 1840. By 2006, 42% of Māori said they could speak Te Reo (Māori language) down from 45% in 2001[5]. The language did not become constitutionally recognised until the Māori Language Act 1987 (New Zealand Government, 1987).

The era of modern Maori protest that began in the late 1960s was precipitated by events that highlighted incidents of racism and an ongoing failure by the government to address Māori concerns manifest from the consequences of colonisation (Harris, 2004). Ngā Tamatoa (Young Warriors) emerged in the 1970s dovetailing with the rise of social and civil rights movements internationally, and the group became a catalyst for the politicisation of Māori about the Treaty of Waitangi, and threats to Māori culture and injustices perpetuated by the New Zealand Government, that were articulated as having a basis in Crown breaches of the Treaty (Harris, 2004).

Legislation that had facilitated land loss was the first of a series of instruments which contributed to the overall decline of Māori health. The full effects of colonisation upon the broader social fabric of Māori society emerged from the findings of work into the capacity of the Department of Social Welfare, to achieve its goal of meeting the needs of Māori. The ministerial report, *Puao-Te-Ata-Tū* (Ministerial Advisory Committee on A Maori Perspective for the Department of Social Welfare, 1988), highlighted deficiencies in the welfare system structure and practices, and associated government agencies. The report found for example that the Justice Department was dealing with a disproportionately higher number of young Māori than non-Māori. Concerns were raised by the report about the Social Welfare Act, the Social Security Act, and the Children and Young Persons Act that did not promote or encourage any involvement by the whānau (social network) of young people (Ministerial Advisory Committee on A Maori Perspective for the Department of Social Welfare, 1988).

Further evidence of ongoing concerns came by way of the first quantitative research of Māori by Maori, conducted by the Māori Women's Welfare League[6] (Te Ropu Wahine Maori Toko i te Ora, 1984). Among other issues, the League's research reported that violence in the home was a significant issue. Obesity, smoking and alcohol were

[5] Statistics New Zealand, Census 2006 data, www.stats.govt.nz
[6] The Maori Women's Welfare League had its inaugural conference in 1951 with the primary objectives of preserving Maori culture and supporting the welfare of whānau.

identified as common concerns for Māori women, predisposing to preventable illnesses (Te Ropu Wahine Maori Toko i te Ora, 1984).

The same predisposing issues to preventable illnesses identified by the Māori Women's Welfare League were later reinforced by Pomare and de Boer (1988), who highlighted health disparities between Māori and non-Māori. In the same year, the Royal Commission on Social Policy (1988) emphasised differences in health, justice, employment, and education between Māori and non-Māori. The Commission stressed the importance of three principles arising from the Treaty of Waitangi – partnership, participation and protection, underpinning reasons for diminishing health status and wellbeing amongst Māori and attributed to breaches of the Treaty (Royal Commission on Social Policy, 1988).

Ongoing discriminatory practices that occur at a political level contribute to the perpetuation of disparities between Māori and non-Māori, and such challenges persist today. An example is the International Declaration on the Rights of Indigenous Peoples adopted by the General Assembly of the United Nations in September 2007. Over the past 20 odd years, New Zealand has played a key role in the culmination of the Declaration (Mead, 2009). Under a Labour-led government and within a United Nations forum, New Zealand voted against adopting the Declaration alongside the United States of America, Canada and Australia, while there were 143 votes in favour and 11 abstentions. Australia reversed its decision in 2009 (Macklin, 2009) but New Zealand's position at the time of writing this thesis remained unchanged, on the basis of four provisions of the Declaration that were cited as being incompatible with New Zealand's constitutional and legal arrangements including the Treaty of Waitangi (Banks, 2008). Those provisions were Article 26 to do with the right of indigenous peoples to own, use and develop land they traditionally owned, a provision perceived by the government to grant Māori rights that other members of New Zealand society do not have (Banks, 2008). Article 28 of the Declaration has to do with providing indigenous peoples with the right of redress and compensation, a provision described as being "unworkable" by the New Zealand government because it was perceived that the article could be applied to all society (Banks, 2008, p. 51). Articles 19 and 32 (2) pertaining to indigenous rights of veto over a democratic legislature and national resource

management, were perceived by the New Zealand government to give Māori rights that other groups do not have (Banks, 2008).

Regardless of whether the New Zealand government voted against the Declaration in full or in part, its opposition to the rights of all indigenous peoples across the world must surely bring into question New Zealand's overall commitment to international social justice. It would appear from the government's reasons for opposing certain parts of the Declaration, that it fears being unable to reconcile its commitment to indigenous issues internally, and thus the obligations embedded in the Declaration. In actuality, the obligations articulated in the Declaration are already entrenched in the Treaty of Waitangi. To a large extent, the realities of cultural and economic deprivation, that are effects of colonisation, have come to shape the state of Māori society in general and responses by the Crown in addressing its responsibilities to Māori health (Jackson, 1988).

The next section highlights the range of ways that disparities manifest in Māori health and as this study considers decision processes by whānau in a health context, it is important to understand the broader context of health and thus whānau health decisions.

An Overview of Māori health

Inequalities in health between Māori and non-Māori have consistently but unacceptably become the norm in New Zealand (Robson & Harris, 2007).

- Māori have lower levels of educational achievement than non-Māori. They are more likely to be suspended from school and less likely to leave school with a university qualification compared to their non-Māori peers (Te Tāhuhu o te Mātauranga: Ministry of Education, 2007). The Ministry of Education also reported that Māori students who attend Māori language education schools are less likely to truant, and more likely to achieve academically than their Māori peers attending English language schools, although biases in the population assessed, such as socio-economic variation, are not identified in the Ministry report (Te Tāhuhu o te Mātauranga, 2007).

- Māori unemployment is higher than any other ethnic group and living standards of Māori on average, are lower than other New Zealanders (Centre for Social Research and Evaluation, Ministry of Social Development, 2006).

- Māori who are employed have comparable living standards to other people who are employed (Centre for Social Research and Evaluation, Ministry of Social Development, 2006). However, the income of Māori overall is lower than non-Māori with similar qualifications (Te Tāhuhu o te Mātauranga, 2007).

Evidence suggests that Māori face discrimination in the labour market by consistently being segregated into lower paid occupation classes even after taking into account age and qualification differentials between Māori and non-Māori (Sutherland & Alexander, 2002).

- Maori offenders, as a group, tend on average to be younger than Europeans. Māori have the highest rates of re-imprisonment compared to other groups and re-imprisonment contributes to the disproportionate number of Māori in prison, which masks the true unemployment rate for Māori men (Nadesu, 2008).

- Māori youth are more likely to come to the attention of the youth justice system and, although they present on average with less severe offences, they are more frequently referred by the police to the Youth Court for minor offences where outcomes are generally more severe than the alternative approach of a family group conference. Such outcomes have a corresponding impact on the rates of conviction, imprisonment, and employment or education opportunities (Maxwell, Robertson, Kingi, Morris, & Cunningham, 2004)**,** further compounded by discriminatory processes including bias in police arrest practise and cultural biases within the justice system when Māori offenders appear before the courts (Fergusson, Horwood, & Swain-Campbell, 2003).

- Māori are also at the greatest risk of being a victim of a crime than any other group, because of risk factors that predispose them to victimisation such as being a sole parent, unemployed, receiving a government benefit, those living in rented property and/or in the most deprived areas (Mayhew & Reilly, 2007).

There is direct evidence from New Zealand that links self-reported experience of interpersonal racial discrimination to poorer health outcomes (Harris, Tobias, Jeffreys, Waldegrave, Karlsen, & Nazroo, 2006b).

- Māori are more likely to experience being treated unfairly because of their ethnicity by a health professional, and they are also more likely than non-Māori to be

the victim of an ethnically motivated physical or verbal attack (Harris, Tobias, Jeffreys, Waldegrave, Karlsen, & Nazroo, 2006a).

- Māori are more likely to experience mood disorders, substance use and eating disorders than other ethnic groups (Baxter, Kingi, Tapsell, & Durie, 2006). The prevalence of bipolar disorder remains higher for Māori than for other groups, and evidence shows that Māori, and Pacific people, have a greater burden due to mental health problems. Much of the burden appears related to the youthfulness of the Māori and Pacific populations and their relative socioeconomic disadvantage (Oakley Brown, Wells, & Scott, 2006). Māori report higher rates of suicidal behaviour and they are also less likely to access mental health treatment than any other ethnic group (Ministry of Health, 2006).

- Māori women have the highest rates of lung cancer in the world. Twice as many Māori than non-Māori women smoke cigarettes and many Māori continue to smoke during pregnancy (Public Health Intelligence, 2008; McLeod, Pullon, & Cookson, 2003).

- Mortality rates increase with increasing socioeconomic deprivation and Māori are disproportionately represented in the most deprived areas and are therefore at higher risk of premature death overall compared to non-Māori (Robson & Harris, 2007). The gap in life expectancy between Māori and non-Māori at birth has narrowed slightly, but disparities still exist (Robson & Harris, 2007).

Even with improvements in access to health care services, reducing inequalities remains an important challenge for both the health system and wider society in New Zealand (Public Health Intelligence, 2008).

Health practices and processes founded on Māori philosophical and intellectual systems, can contribute to improvements in Māori health. To do so, requires a commitment to the development of Māori knowledge systems and methodologies that can be translated to a modern health context. Whānau, as carriers of their culture, have an important role to play in the application of Māori methodologies for improving their health, especially by the way their health decisions will be underpinned by Māori ethical systems.

Kawa

It is inconceivable that Māori society could exist without an ethical system as this would imply the absence of a moral system (Durie E., 1999). According to Hudson (2004) "Māori, as an organised society, have always had their own moral framework" (p. 67) informed by Māori philosophy, ethics and values.

Kawa[7] is the regulatory mechanism for maintaining wellbeing according to Māori philosophy. It constitutes norms and practices out of which morality arises. As a risk management system, kawa determines rules of behaviour and thus it is an important construct in the context of health decisions (Durie E. , 1999). Variation in kawa is consistent with diversity in the nature of traditional Māori social systems, classically based along iwi (tribal) organisation. The philosophical and intellectual origins of Māori ethical systems begin cosmologically from a place in time, illustrated and preserved through whakapapa (genealogy), and described by a range of conventions including oral traditions. The following example of whakapapa from cosmology is an excerpt from a tauparapara (recitation):

Matua Kore	the nothingness
Ko Te Pū	the seed
Ko Te Weu	the shoot
Ko Te More	the vine
Ko Te Aka	the root
Ko Te Ao Hunga	behold the capacity for life
Ko Te Ao Punga[8]	behold the proliferation of life

The tauparapara makes reference to the growth of a life form as a metaphor for the genesis of the natural world. As such, it is the characterisation of the origins of Māori society including its intellectual and ethical beginnings.

Māori philosophy draws on the natural world to explain phenomena (Marsden, 1989). Maintaining the integrity or wholeness of the natural world is a key objective of Māori philosophy, and associated concepts are thus motivated toward ideas of holism and collectivity, consistent with the philosophies of other indigenous peoples (Ellerby,

[7] The word tikanga may be used instead of kawa to denote specific norms or practices.
[8] Excerpt from evidence of Warren Pōhatū on behalf of Ngāi Tāmanuhiri, as part of the Tūranga Tangata Treaty of Waitangi claim by Ngāi Tāmanuhiri, Rongowhakaata and Te Pou a Hao Kai. The translation is my own.

McKenzie, McKay, Gariepy, & Kaufert, 2000; Barnhardt & Kawagley, 2005; Kawagley, 2006; Marsden, 1989).

A basic assumption of Māori philosophy, in common with other indigenous peoples, is that the world is viewed as a whole (Ellerby, McKenzie, McKay, Gariepy, & Kaufert, 2000; Barnhardt & Kawagley, 2005; Kawagley, 2006). Māori knowledge arising from such a basic assumption, insists on the observation of, and adaptation to, the natural world, of which the human ecosystem is a key component. The rules of observation and practice applied to the natural environment also apply to human relationships (Marsden, 1989). Māori moral standards are therefore both representative of, and oriented towards preserving the integrity of relationships between humans, and the relationship between humans and the world we live in.

Manuka Henare (1998) articulated a framework for describing and analysing traditional Māori cosmology encompassing ethics titled the *Koru of Māori Ethics.* Using the image of a koru (fern frond), he likened its curled shape to an embryo and the coiled ropes of the original waka (canoes) that arrived to New Zealand, both symbolising new life. At the centre of the spiral-shaped koru are core beliefs or values – Io, tapu, mana, mauri and hau. Io denotes the origin of all phenomena. Tapu refers to a sacred quality. Mana refers to spiritual power and authority imbued on all things. Mauri refers to a life force and hau is the vital essence embodied in a person that is transmitted to their possessions. Four concepts that surround the koru and manifest from the core beliefs are – wairuatanga (spirituality), kotahitanga (unity), whanaungatanga (kinship) and kaitiekitanga (guardianship).

Henare (1998) suggests that the koru framework comprises rules for human conduct. For example, kaitiekitanga or guardianship denotes acts like caring and safeguarding another. By applying the concept of kaitiekitanga to children, pakeke (elders) or the sick, it implies a set of responsibilities and obligations. Mana, a core value, bestows power and authority upon all phenomena including people. Kaitiekitanga is a process by which mana is enhanced and preserved.

Māori philosophy, ethics and values, have inherent assumptions relevant to health or more accurately, hauora (Wenn, 2006). Hauora is the culmination of a balance of interrelated factors or a state of harmony between different elements which include

tinana (physical health), wairua, (divinity), manawa (psychological), tapu (sacred), and whakapapa (social and cosmological connection) (Jackson, 1987).

Inter-related elements of health (a framework for health) according to Maori philosophy, are represented through the use of Maori symbolism, commonly described by reference to Te Whare Tapa Whā[9] (the image of a four-sided house structure); Te Wheke[10] (the image of an octopus); Te Pae Mahutonga (the constellation of stars known as the Southern Cross); tāniko (weaving patterns); pā harakeke (a flax plantation); and whakataukī (proverbs) (Durie, M., 1984, 1985; Pere, 1984; Murchie, 1984; Williams, 2004). The wellbeing of the group, such as a whānau, is dependent on the collective wellbeing of all members, and optimal collective wellbeing equates to collective resilience, necessary to weather adverse crises.

The idea of collective strength is illustrated by the symbolism of the pā harakeke. From a pragmatic perspective, the young inner shoots of the pā harakeke represent new life, or metaphorically, the children or youth of a community. If the young shoots are inadvertently stripped away from the pā harakeke through adversity, then the integrity of the collective is compromised, because the potential future of the harakeke is jeopardised. Modern day examples of adversity affecting younger members of a social group could include sexual or physical abuse, alcohol or drug addiction, suicide and obesity.

All individuals require nurturing and affirmation, most often from their kin group, to sustain their independent endeavours. While they also need a level of independence to be able to explore the boundaries of collective experience, it should not be at the expense of the group. Hence the rationale for the concept of kaitiekitanga (guardianship), that aims to mitigate the possibility of internal friction within collective relationships. Such an example illustrates the way Māori standards of conduct encompass certain behaviours.

E. Durie (1998) reminds us that "values may represent ideals" (p. 65). At any given time an individual may not seem to be living according to the values they hold true, but a breach of their values "does not invalidate the values themselves" (Durie E., 1998;

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[9] Te Whare Tapa Whā is described more fully in chapter three.
[10] Te Wheke is also described in chapter three.

2004, p. 49; Patterson, 1992). In addition, the criteria or values that are relevant at any one time may vary according to the context (Durie E., 1998).

Māori ethical practice and decision making

Decision processes concerning the health of the group are naturally oriented toward being the business of the collective. Collective decision making is a phenomenon that has always existed in Māori society (Bishop, 1996; Royal, 2003; Jackson, 1988)**,** and it is a characteristic of decision processes common with other indigenous peoples (Castillo, 2008).

The collective and communal nature of indigenous communities that includes decision making and tribal consent is emphasised by a Canadian review of Aboriginal Health Research Ethics literature (Ermine, Sinclair & Jeffrey, 2004). One recommendation contained in the Canadian report is the need for steps to ameliorate inherent conflicts between Research Ethics Board policies and indigenous ethical requirements. The primary example being, barriers to decision making about community research by community participants, prior to formal approval for research from institutional research ethics boards.

International research reinforces that collective social structures akin to whānau have a significant influence on individual health decisions (Hoddinot & Roison, 1999). Port (2007) referred to the notion of collective decision making in her doctoral thesis. She recommended the need for research into whānau decision processes because of an incidental finding from her research, that whānau are at the heart of decision making and members work "together towards a common purpose for the good of all" (Port, 2007, p. 245).

Bishop (1996) describes the dynamic of the collective that emerged from his work on whanaungatanga. He states:

> The group will operate to avoid singling out particular individuals for comment and attention and to avoid embarrassing individuals who are not yet succeeding within the group. Group products and achievement frequently take the form of group performances, not individual performances. (p. 218)

According to Bishop's view whānau decision making acknowledges the multi-generational compositioning of a whānau with its associated hierarchically determined rights, responsibilities and obligations. Bishop asserts the collective will always make major decisions as a group and then refer those decisions to pakeke (elders) for approval, and will seek to operate with the support and encouragement of pakeke (Bishop, 1996).

The application of collective decision making such as that described by Bishop, in a modern health context, is a challenge for the health research sector according to Hudson (2004) and Powick (2002). Both described the need for an ethical framework for health decisions in New Zealand that sufficiently meets the moral standards of Māori society. Their views are based on expressed concerns that emerged in their work, about inadequacies within the current ethical review system. Hudson argues, for example, that the western ethical principle of justice[11] is determined by the dominant paradigm of what constitutes justice, based on notions of objectivity, equality and impartiality. While the notion of justice is important to Māori members of society, his research found that it is rarely applied to ethical review in a way that represents Māori philosophy, citing application of the Treaty of Waitangi as a fundamental pre-requisite to ethical review processes (Hudson, 2004).

In addition to Hudson's view, Māori have different experiences of being Māori, which is relevant to ethical decision processes, where it can be assumed that having one Māori involved in the process is sufficient to identify potential ethical issues for all Maori. To illustrate the danger of making such assumptions, the concept of Io described in Henare's framework, is sometimes interpreted as referring to a higher order, a Supreme Being such as God according to Christian doctrine. Though deities referred to as gods exist in whakapapa (Robinson, 2005), they are not the same notion of a god as that followed by Christian order. God of Christ is not a feature of Māori cosmology, though people who live according to Māori philosophical ideas may also have a belief in the principles held to be true by Christian doctrine.

Christianity is one of the major instruments of colonisation and colonisation has contributed to the suppression of Māori intellectual development, contributing to the merging, and in some cases, confusion, about quite distinct philosophical systems

[11] Justice as a principle of western ethics is discussed later in this chapter.

(Reed, 1974; Easdale, 1991). Conversely, Māori expressions have been applied to western constructs. The concept of a "European Tohunga" (Gluckman, 1976, p. 253) as a way of describing a pākehā medical practitioner is a case in point. A tohunga in a traditional Māori sense is one who is fluent in the observation of tohu or Māori signs and symbols. Tohu form the basis of the discipline of tohunga, a title normally attributed to a specialist of a particular skill or knowledge in things Māori. A tohunga is not a specialist of a particular field according to western constructs. Whether a Māori medical practitioner can be called a tohunga, is a debate for another thesis. The point is that the application of Māori philosophical constructs to modern society and modern processes is complex, and one of the major challenges in identifying ethical issues for Māori, is in understanding theoretical frameworks underpinned by Māori philosophy, and how these might apply in the case of this thesis, to whānau decision processes. In any event, an important variable has to do with access to Māori knowledge and philosophy, and the embedded values that guide thinking, actions and attitudes of relevance to decision processes (Durie M., 1985).

Decision Theory and Māori Philosophy

There is no formal construct called Māori decision theory, or at least one that is written down. From a canvas of available literature, a number of frameworks for decision making, based on Māori values or experience, have been described by Maori authors. Hirini Mead (2000; 2003) describes a risk approach to decision making that focuses on risk identification and aversion. He sets out five cultural risk assessment and evaluation tests from which to assess a Māori stance on an issue. The tests involve tapu, mauri, take-utu-ea, precedent and principles. Each test poses different challenges and questions to be explored. To demonstrate how Mead's model works, tapu, a concept mentioned previously, is defined as "the state of being set apart" (Mead, H., 2003b, p. 367) and is used in the following illustration of pregnancy.

Customarily a pregnant woman is afforded the status of being tapu which sets her apart from her non-pregnant state. By being pregnant her health may at the least, become altered physically and psychologically as she adjusts to the demands of her unborn baby. This means that additional measures may be necessary to ensure a balance of her wellbeing, thus protecting her health and that of her baby. Measures might include additional supplements of iron-rich foods or assistance with child care for other

children. The symbolism of a pā harakeke is applicable to pregnancy because the unborn baby is the growth or future of the whānau. Maintaining the wellbeing of the woman constitutes preserving the integrity of the whānau through the protection of her unborn child.

Mead proposes that an evaluation test against the concept of tapu involves deciding whether there is a breach of tapu. The challenge is to identify the nature of tapu and the nature of the breach (Mead, H., 2000; 2003). Using the scenario of a pregnant woman again, a breach of tapu would constitute any action, behaviour or environmental factor that adversely affects her and/or her baby's wellbeing. Such factors include poor nutrition, inadequate access to maternity services, drug taking, damp living conditions, alcohol intake or exposure to domestic violence. The pregnancy scenario attempts to illustrate how traditional concepts still have relevance for modern day experience and especially the way health decisions can be considered.

Mason Durie (2004a) describes a different decision model which promotes the need to move to a potential paradigm that focuses on benefits. Durie draws on the common underpinnings expressed in Mead's evaluation model, but his potential framework consists of three domains: the natural environment, the human condition and procedural confidence. Values (mauri, whanaungatanga, kaitiekitanga, wairua, and hau) are assigned to each domain and arising from each value is a set of research outcomes. The aim of Durie's potential approach is to consider possible outcomes that will advance Māori aspirations, and whether the outcomes are consistent with the values.

Another decision development model also described by M. Durie (1993) draws on past experience of relationships between Māori and the Crown in a specific iwi context. The notion of consensus is at the heart of the decision framework and Durie describes five principles for negotiation (time, active commitment, common goals, respect for differences, and mutual advantage). Unlike the previous models the consensus model is based on characteristics of autonomy informed by principles of the Treaty of Waitangi (Durie, M., 1993).

The three decision frameworks described have some common and distinct features that are summarised in Table 1. The following section discusses decision making in a genetic research context.

Table 1: Maori Decision Frameworks

Theory	Basic Assumption	Basic Features
Risk Paradigm (Mead, H., 2000, 2003)	Holism, collectivity.	Tapu and Noa
Potential Paradigm (Durie, M., 2004a)	Holism, collectivity	Mauri, whanaungatanga, kaitiekitanga, wairua, hau
Consensus Paradigm (Durie, M., 1993)	Tino Rangatiratanga	Partnership, participation and protection are inherent

Decision making in the context of genetic research

The importance of trust between genetic scientists and lay communities is a consistent theme of international research (Petersen, 2006). A breach of trust is a fundamental issue that underpins an assertion by A. Mead (2005) that 'indigenous people's experience of genetics globally, has not been affirming for our identity'. That is, while indigenous peoples might be subjects of genetic research, they are often not in receipt of the benefits that arise from such research.

Decision making about genetic research cannot be considered in isolation from the context, and in the case of this thesis, the context is genetic health research in the face of an adverse health issue.

New Zealand studies of public perceptions of genetic biotechnologies including the views of Māori, have shown that most people are not averse to scientific advancement (Cook, Fairweather, Satterfield, & Hunt, 2004; Hunt, Fairweather, & Coyle, 2003; Roberts & Fairweather, 2004). Many people however, are either not well informed or they are misinformed about debates and discussions. Distinguishing between genetic research and research into genetic biotechnologies is an example of how understanding about the nature of genetic research can be blurred (Hunt 2003; Cook 2004; Roberts 2004). To illustrate the point, identifying genetic predisposition to Type 2 diabetes requires identification of a predisposing gene through an examination of blood or tissue samples. Biotechnology research that explores treatment of Type 2 diabetes genetically is only possible from an understanding of the gene that predisposes certain people. Consequently, there are different kinds of genetic research and therefore different types of discussion and debate needed, and each one has moral, ethical, political, economic,

and social consequences, which are all separate but interrelated considerations (Cook, Fairweather, Satterfield, & Hunt, 2004; Hunt, Fairweather, & Coyle, 2003; Roberts & Fairweather, 2004).

Māori have been found to have a range of views about genetic biotechnologies consistent with studies of the general population, but a distinct Māori view also exists, often explained by reference to Māori philosophical constructs (Cunningham, Holdaway & Tūpara, 2005, 2006; Du Plessis, Scott, Phillips, Cram, Tipene-Matua, Parsons, & Taupo, 2004; Port, 2007; Roberts & Fairweather, 2004; Tāwhara, 2006).

Roberts and Fairweather's (2004) study of South Island Māori (the majority of whom claimed affiliation to the iwi, Ngāi Tahu) concentrated on participants' perceptions of risks and benefits of various forms of biotechnology, including factors influencing those perceptions. Of 44 people they interviewed either individually or in groups participants were asked to rank their acceptability of five specific biotechnologies: Xenotransplantation, Stem Cell Research, Cloning, Genetically Modified Organisms (GMO) and Bio-prospecting. Their study found a general lack of acceptance of most forms of biotechnology. Whilst participants respected the rights of an individual to make a choice, technologies that affected only the individual and not the population at large or the environment were more accepted. Technologies that would save human lives were an exception to the general rule. Roberts and Fairweather (2004) found culturally-based and derived attitudes to biotechnologies fell into two broad categories that were either politically or spiritually grounded. The latter found expression in culturally derived values and beliefs, and thus Māori who expressed culturally-based reasoning for their views demonstrated a distinctive approach to biotechnology issues.

Du Plessis et al's (2004) study, part of a larger project, *Construction Conversations: Kōrero Whakaaetanga*, was convened to talk to community participants about genetic profiling, direct to consumer genetic testing and bio banking. Of 162 community participants in 25 contact groups, Māori made up about one third of all participants. Nine of the 25 groups were solely Māori participants and some Māori were in other groups, from various locations in the country. The Māori research team, *Te Kōpere*, that formed part of Du Plessis et al's study, developed an analytical framework to guide the analysis of transcripts for the Māori contact group meetings. Five concepts formed the basis of their analysis – whakapapa, mauri, kaitiakitanga, tino rangatiratanga and

mana. Du Plessis et al’s preliminary conclusions were that participants locate their understanding of genetic biotechnologies within their lived realities, and for Māori participants, their reality included the politics of Māori sovereignty.

Tawhara’s (2006) research titled: *Attitudes of Māori towards genetic research*, showed findings consistent with other New Zealand studies. Her work with 33 participants in five focus groups, from within the Māori community in Canterbury, drew out three main groups of findings: criteria for genetic research; the informed consent process; the application of appropriate research processes. All participants in Tawhara’s study agreed that in determining criteria for genetic research, there has to be clear value for Māori, actual outcomes that would be beneficial and accessible to whānau and Māori, and by far the biggest criteria, more Māori involved in the research process. Tawhara’s study concluded that informed consent requires the establishment of a trusting relationship with researchers built on integrity and mutual respect, which is not achieved by a one-off process.

A study by Port (2007) elicited opinion on predictive/pre-symptomatic genetic testing for familial cancer. One of the recommendations of her study was the need for work into decision making to improve whānau experiences of genetic testing.

So far the chapter has given an overview of socio-political and philosophical discourses relevant to Māori health including the concept of a whānau and the basis of ethical practice according to a Māori intellectual system. The next part of the chapter focuses on the New Zealand legal and ethical review systems relevant to health, and western philosophical discourse that informs those systems, including health policies and dominant decision practice in New Zealand.

Part B: Law and Ethics

The New Zealand Ethical Review System

The system of ethical review for health research in New Zealand is framed by law. Each piece of legislation provides for a different set of concerns.

The New Zealand Bill of Rights Act 1990 makes provision for civil and political rights of individuals by placing limits on the actions of the government that interfere with their rights. The Bill of Rights is especially important for minority groups to protect them from discrimination on the grounds of their ethical beliefs that are culturally mediated.

The Human Rights Act 1993 makes provision for the protection of rights in New Zealand in accord with United Nations covenants and conventions. Accordingly, the International Declaration on the Rights of Indigenous Peoples has relevance to Māori and therefore New Zealand.

The Health and Disability Commissioner Act 1994 makes provision for *The Code of Health and Disability Services Consumers' Rights.* The Code establishes ten rights for recipients of health and disability services and establishes the duties and obligations of providers of the same services. Under the Act, participants of health research have the same rights as those who are receiving health and disability services (Health & Disabilities Commissioner (HDC), 1996). The right to be treated with respect and the right to be fully informed are examples of rights observed by The Code (ibid).

The Public Health and Disability Services Act 2000 makes provision for publicly funded health services and a structure for ethical review of research. Operationalising the provisions embedded in legislation gives rise to entities such as the Health and Disability Commissioner and ethics committees. The primary purpose of ethics committees is to provide advice to the Crown on 'ethical issues of national significance in respect of any health and disability matters (including research and health services)' (Ministry of Health, 2000, p. 22). Ethics committees also have a function to protect participants of health research by providing advice to researchers through ethics review processes (New Zealand Health and Disability Ethics Committees, 2009). Through a statutory process provided for in the Public Health and Disability Services Act 2000, members of ethics committees are appointed for a period of up to three years. The process of selection is open to applicants who wish to self-apply or those who are

nominated by an organisation. Western ethical principles are the standard norm that governs the ethical review system, and ethics committee members largely conduct review processes against western ethical standards (Cunningham, 2003).

To demonstrate the important link between legislation and policy, the Ethics Committee on Assisted Reproductive Technology (ECART) is established under the Human Assisted Reproductive Technology (HART) Act 2004. The HART Act was the result of two bills that contained similar subject matter: the Human Assisted Reproductive Technology Bill, a Member's bill introduced in 1996 in the name of Diane Yates, and the Assisted Human Reproductive Bill, a Government bill introduced in 1998. Both bills contained proposals for regulating the use of assisted human reproductive technology. In addition, a Supplementary Order Paper 80 (the SOP) was introduced in April 2003 in the name of David Benson-Pope, which contained substantial recommended amendments to the HART Bill. During the submission process relevant to the HART Act, there were a total of 79 written submissions and 25 form submissions[12]. There were no submissions from a Māori organisation or submissions that identified as representing a Māori perspective, although there was some debate about the HART Act by Māori members of Parliament.[13]

When Māori participation in constructing the law is little or non-existent, there are flow-on effects for health and ethics policies. Policy decisions by ethics committees for example, are determined on the assumption that the policies are underpinned by the weight of law, and the strength of the law lies in it being relevant for all members of society. Regardless of whether Māori are substantially contributing to the development of law or not, the functions that flow the law, grounded in the dominant methodology, apply to Māori (Jackson, 1988; Mulholland, 2001; McDowell & Webb, 2006).

Apart from provisions of law, independent authorities are also established by government policy. For example *Toi Te Taiao: Bioethics Council*, was a ministerial advisory committee, set up in 2002 to provide advice to government through the Minister for the Environment, on cultural, ethical and spiritual aspects of biotechnology. The Bioethics Council was a government response to the recommendations of the Royal

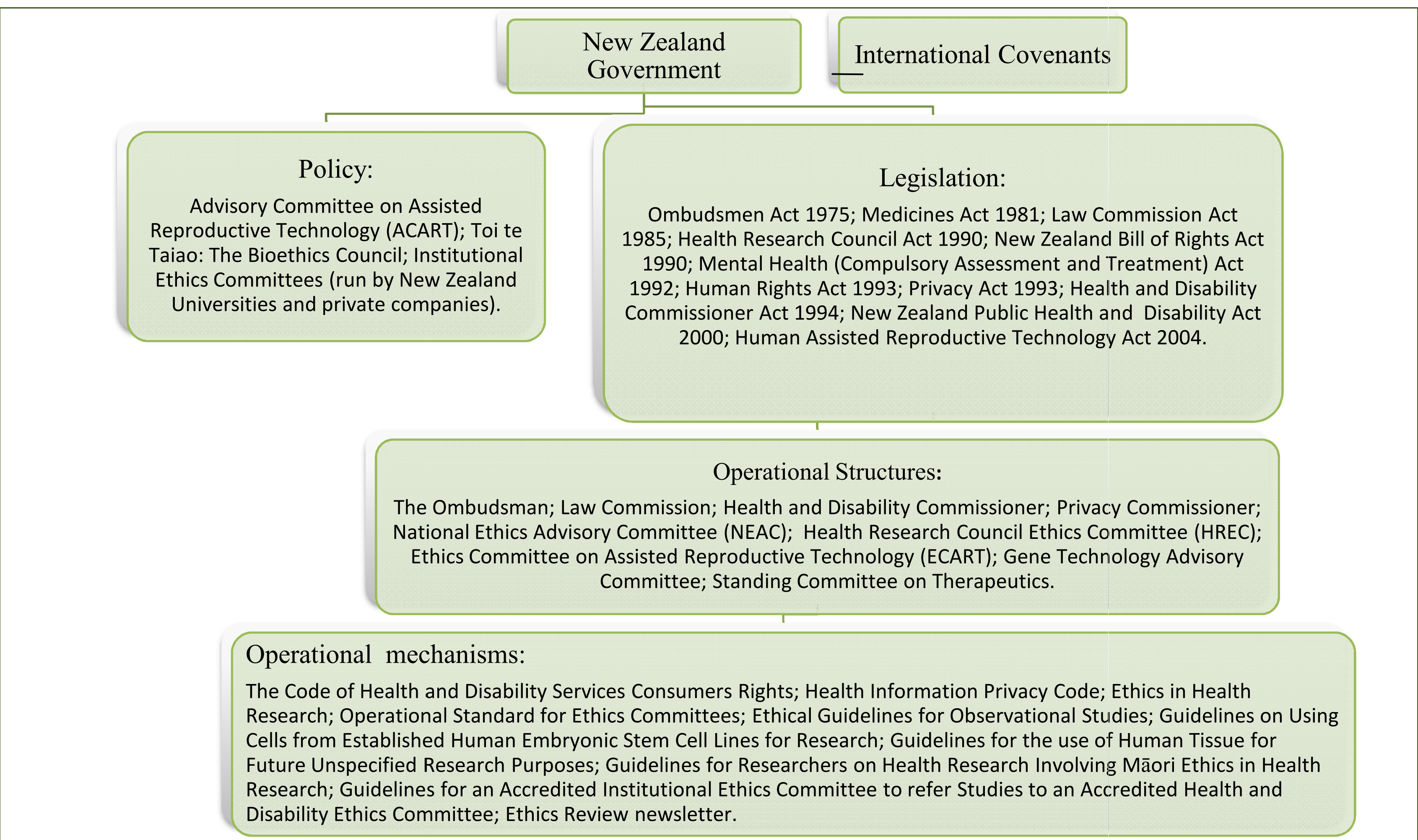
[12] A 'form submission' is a generic form provided for submitters.
[13] Written submissions were cited by me at the Parliamentary library in Wellington, as were various other parliamentary documents that track the development of the HART Act.

Commission Inquiry on Genetic Modification (Royal Commission on Genetic Modification, 2001). While not set up to explore issues in health specifically, the nature of research programmes initiated by the Bioethics Council have relevance across a range of sectors including health, such as a pre-birth testing project (Toi te Taiao: The Bioethics Council, 2008). In 2009 the Ministry for the Environment announced the disestablishment of the Bioethics Council, as a result of government restructuring (New Zealand Press Association, 2009). The implication for Māori is that the Bioethics Council had an important role, not necessarily carried out by other institutions, to promote public dialogue on cultural, ethical and spiritual aspects of genetic biotechnology.[14]

Figure.1 provides an overview of the major elements of the ethical review system. The next section discusses the history of research ethics and the application of ethics to New Zealand research practice. Following on is a discussion about the New Zealand legal system that frames the ethical review system for health research.

[14] http://www.bioethics.org.nz/dialogue/index.html

Figure 1: Summary of New Zealand Ethical Review System



History of Research Ethics

Ethics was first applied to health research following the establishment of the Nuremberg Code in 1948, a response to the Nuremberg Judgment on war crimes, namely inhuman medical experiments committed against prisoners of World War II who were held captive by the German Nazi regime. The Nuremberg Code was the first internationally recognised document that advocated voluntary participation and informed consent in research. Previously ethical standards were generally considered only in terms of the conduct of medical physicians. The Oath of Hippocrates is the first recorded statement of medical conduct in Greek History from about the 5th century BC. The next most significant contribution was from Thomas Percival, an English physician, who published the first modern code of Medical Ethics (Percival, 1849).

The Declaration of Helsinki and the Geneva Convention had the next major influences on international ethical standards for research (World Medical Association, 1964; General Assembly of the United Nations, 1948). As a result, principles grounded in ethical precedents such as autonomy, beneficence, non-maleficence and justice, evolved as the key ethical principles, that represent the dominant standard for conduct in human research (General Assembly of the United Nations, 1948; World Medical Association, 1964).

The autonomy principle emphasises the rights of the individual. It is based on the assumption that all people have a natural desire to control themselves and make decisions for themselves (General Assembly of the United Nations, 1948; World Medical Association, 1964).

Beneficence, a principle embedded in the Declaration of Helsinki, emphasises that 'research is only justified if there is reasonable likelihood that the populations stand to benefit from the results of the research' (World Medical Association, 1964). The definition of benefit is not articulated in the Declaration, but traditionally beneficence refers to "the obligation to provide benefits and balance benefits against risks" (Seedhouse, 2009, p. 96), which means interpretation of beneficence is dependent on definitions of benefit and risk.

Non-maleficence, derived from the Latin words *Primum non nocere,* is commonly translated as 'first do no harm' a fundamental medical precept of Hippocrates, often

considered a corollary to the principle of beneficence. Non-maleficence is not simply a reference to ensuring benefit, but it also involves "the obligation to avoid the causation of harm" (Seedhouse, 2009, p. 96).

Justice is informed by notions of fairness and equality, equity and impartiality (Beauchamp & Childress, 1994). The principle of justice assumes that society itself is equal. In reality, the justice system is designed by the society for whom justice is practised, and in all countries, justice is constructed according to the dominant standard of a judicial system, underpinned by a utilitarian ethic that favours majority populations (Seedhouse, 2009).

Despite the existence of international ethical covenants, the ethics of health research has been fraught with controversy. In the late 1950s Thalidomide was prescribed in the United States (US) to pregnant women to control nausea in pregnancy. Approximately 1,000 medical physicians prescribed Thalidomide for research purposes. Though not illegal, the pharmaceutical company distributing the drug to doctors, was awaiting approval for a distribution license from the regulatory authority, the Food and Drug Administration (FDA), to be able to sell Thalidomide in the U.S. market. Thalidomide has been tested in animals and humans in West Germany, and since it was already in use in the U.S., the FDA considered the application to be routine. However, Thalidomide was withdrawn from the German market because of reports of congenital abnormalities in children born to mothers who had used it, and the drug was never approved for use in the U.S. by the FDA. An FDA survey showed more than 2,500,000 tablets had been distributed to over 20,000 patients of whom 624 were reported to have been pregnant. Of those, 10 documented cases were found where women who had received thalidomide in the U.S. during pregnancy delivered seriously deformed babies (Seidman and Warren, 2001; United States FDA, 2006a).

Another US research project from 1932 until 1972, involved 600 low-income African-American males, 400 of whom were infected with syphilis. The men were given free medical examinations but they were not told about their disease even though a proven cure, Penicillin, became available in the 1950s (United States FDA, 2006b).

In the early 1990s research funded by the US into the prevention of mother-to-baby transmission of HIV in Thailand, was criticised because participants in the control

group were given a placebo, rather than a long course of anti-viral treatment, which had been demonstrated to be effective in developed countries (Bull, 2002; Connor, 1994; Lurie & Wolfe, 1997; 1998; Sperling, 1996; United States Government, 1994). Sadly, the existence of ethical guidelines has not been sufficient to deter or prevent unethical conduct in research in especially developed countries, and such is the case in New Zealand.

Emergence of Health Research Ethics in New Zealand

Ethical guidelines for human research were first formally adopted in New Zealand in 1968, and were later revised to include factors relating to informed consent, vulnerable participants, and health service research (Ministry of Health, n.d.).

New Zealand followed international trends by applying ethical principles to health research under the guidance of the Medical Research Council, set up in 1937 as a committee of the Health Department. The Council sponsored various research programmes looking into nutrition, goitre, tuberculosis, hydatid disease and dental caries (Ministry of Health, n.d.). Medical research constituted the only health research being conducted at the time, mostly at Otago Medical School, and the Council encouraged the establishment of university or hospital ethics committees to examine and agree to the ethics of research proposals.

Other research occurred variously in the early part of the 1900s. The Department of Health sponsored research on such subjects as poliomyelitis, still births and aspects of epidemiology in the 1920s, and in 1928 a New Zealand branch of the British Empire Cancer Campaign Society began to conduct research into the causes of cancer (McLintock, 1966). In 1940 the Travis trustees of Christchurch contributed funds towards fundamental research into tuberculosis. The Medical Research Council was instrumental in getting passed the Medical Research Council Act 1950 that immediately gave the Council powers independent of the Health Department. In 1984 the Medical Council set up its own ethics body, the Committee on Ethics in Research.

One issue arising from a self-governance model of ethical review, a feature of early ethics approaches, was the integrity of informed consent. The Cartwright Inquiry into research at National Women's Hospital in Auckland highlighted the disregard that was shown for individual human rights with respect to freedom of choice (Committee of

Inquiry into Allegations Concerning the Treatment of Cervical Cancer at National Women's Hospital and into Other Related Matters, 1988)**.** The findings of the Inquiry emphasised the limitations of a self-governing system of ethical review. The current system of independent review, developed largely as a response to the Cartwright Inquiry, with further changes recommended after the findings of a different inquiry into cervical screening protocols (Duffy, Barrett, & Duggan, n.d.).

Following the Cartwright Report, Area Health Boards became responsible for establishing ethics committees to scrutinize research projects occurring within their own jurisdiction, and the Health Research Council replaced the former Medical Research Council under the Health Research Council Act 1990.

An important outcome of the Cartwright inquiry was the *Code of Health and Disability Services Consumers' Rights* mentioned earlier in the chapter. The Code emphasises the rights of those who receive health and disability services, which includes participants in health research (Paterson & Manning, 2008). Informed consent is a complex process embedded within the Code, which requires researchers to comply with a range of criteria.

Woods (2007) describes how informed consent in New Zealand, as a decision construct, needs to satisfy a range of standards. He cites examples such as institutional policies and procedures. Cultural practices, legal standards, professional practice standards, reasonable person standards and rational person standards are additional examples. A reasonable person for instance, might be based upon the subjective judgment of a physician. Identifying whether a person is rational however, involves a test of a person's capacity to make decisions.

There are also two challenges to obtaining of informed consent according to Williams (2004). Firstly, obtaining consent is not an objective process although it is intended to be. The nature of information that is deemed to count or be relevant to research participants will be determined subjectively by researchers. Information communicated to participants is open to subjective differences in emphasis and interpretation, and the risks and benefits might be explained differently depending on who is communicating the information. Secondly, informed consent can appear to confer ethical acceptability of a research study. The process of informed consent is often described within the

methods section of research papers, endowed with scientific objectivity, but communicated subjectively (Williams, 2004). While obtaining consent is crucial, it is not sufficient alone to justify research. This begs the question about what criteria is sufficient to determine the ethics of research, and whether it should be the same criteria people use in deciding whether they will participate in such research (Williams, 2004)

Wood's (2007) cites limitations upon decision making laid out in the Crimes Act 1961 with respect to accepting or not, the benefits of medical treatment, an issue relevant to participation in health research, where health research underlies the science upon which medical treatment is developed. Woods also discusses decision making texts that reflect a theorized body of knowledge. He says such texts are largely peer reviewed by those who possess the disciplinary status and prestige of the respective peer group, and thus those who have an understanding of the rules of engagement within the field. According to Woods (2007) ethical practices are often self-legitimised, privileging scientific and rational discourses that may be used to control or suppress the response of others. He also explains the way decision theory is applied to situations in an almost "calculated and mathematical fashion" where there is perceived to be an element of risk, no risk, or an unclear risk (Woods, 2007, p. 73). When the rules, according to dominant discourse, are applied to medical and legal decision making, the results are consistent, but when applied to other kinds of decision making, the rules appear to vary depending on who determines the text of the decision, and the ways in which decision makers are assimilated or otherwise within the rules.

Woods (2007) also refers to common law where an adult is deemed to have full capacity to make decisions, unless it is shown that he or she cannot do so, and he cites distinctions between legal and medical concepts of capacity or incapacity to make decisions. In addition, there are instances where the two concepts of capacity may clash and one is challenged by another (ibid). The idea of conflicting concepts or paradigms in decision making is relevant to this thesis, because a person's capacity to choose on the basis of their own cultural values and intellectual system can be completely ignored in favour of prevailing and dominant knowledge.

Woods (2007 identifies a number of medical decision making models: paternalistic model, the partnership model, the participation-involvement model and the shared decision making model. He says legislation that surrounds informed consent is

constructed around those frameworks, and therefore the societies for whom the models were constructed, that fit into a predominantly mainstream environment. Informed consent is thus a phenomenon of those who are capable of fully responding to the ramifications of rationally focused consent according to the dominant environment. In Wood's view, "anyone that troubles the state and its relationship with individuals in society by refusing science that is normally considered to be both rational and desirable, are therefore challenging not only the scientists, but the state itself" (Woods, 2007, p. 87). Accordingly, anyone who challenges the status quo does not go unrecognised, and the media, as a recorder of state actions, and the law, as the standard setter and enforcer of state control, are set in action (Woods, 2007).

Wood's point about individual relationships with the state or government is significant, because the government has been the most important patron of science in New Zealand (Hoare, 1976). The historical alliance between science advocates and the government, suggests that they share the same philosophical ideas and aspirations, which manifests within the law as a result of the relationship. In order for Māori to have their needs recognised within the relationship, they must be a party to the relationship and subscribe to the same rules.

Contribution by Māori to the ethical review system

Notwithstanding wider political efforts, the first major contribution by Māori to the ethical review system for health research occurred during the health reforms under the National Government in 1993. The Ministry of Health set up an Interim Task Group on Health and Disability Service Ethics, charged with providing recommendations on the health and disability ethics structure. Te Puni Kōkiri (Ministry of Māori Development) established a Māori Working Group to assist the Interim Task Group, focussing on the development of an ethics committee structure for Māori and Māori aspects of the Standard for Ethics Committees (Ministry of Health, n.d.).

The Health Research Council (HRC) Act 1990 had already replaced the Medical Council Act, which had the effect of widening the scope of health research and in particular, health research that could be funded by the Crown. The Health Research Council Ethics Committee, established by the HRC Act, developed *Guidelines on Ethics in Health Research,* cognisant of human rights, biomedical advancements and legislation in place at the time (Health Research Council of New Zealand, 2002). The

guidelines were then supplemented in 1998 with the *Guidelines For Research Involving Māori* by the Māori Health Committee of the Health Research Council, which were revised in 2008 (Health Research Council of New Zealand, 2008).

A major difference between the generic guidelines and those for research involving Māori is the latter has a large educative function, to assist health researchers understand Māori social structures and practices, and ways to consult with Māori, so they may conduct their research ethically. Similar guidelines for indigenous peoples exist in Australia and Canada (National Health & Medical Research Council, 2003; Canadian Institutes of Health Research, 2007). Although a set of guidelines specific to Māori is a fairly recent addition to the New Zealand health research sector, Māori society has a long held tradition of ethical practice to address a range of health matters and health decisions. Underpinning the tradition is a set of moral and ethical principles developed from unique indigenous philosophies and practices that have already been outlined.

The New Zealand Legal System

The legal system is set within the constitution. Parliament (General Assembly) is the supreme law maker and dominant entity within the constitution. The Courts are contributors to the constitutional framework (McDowell & Webb, 2006; Mulholland, 2001). There are no formal limits to Parliament's law making power and 'the role of Courts is to interpret and apply statutes in accordance with Parliament's intent, and to develop case law where there is no applicable statutory rule' (Te Puni Kokiri, 2001, p. 17; Mulholland, 2001).

Unlike the United States of America, New Zealand's constitution is not contained in one written document and therefore fixed. Instead it is made up of different elements, consistent with the Westminster parliamentary system inherited from Britain, and it has the ability to be flexible and evolve according to the context of the time (McDowell & Webb, 2006; Mulholland, 2001).

The legal framework underpinning the ethical review system has evolved from its British origins and the law is informed by two major sources, common law and statute law. Common law is a body of law built up from decisions made in the United Kingdom (UK or Britain), that began from recording local norms and practices seen as common in English society, 'a compilation of the values of that society as shown in practice'

(Durie E., 1999). Developments of common law by New Zealand courts mean that it now differs from the UK on some aspects (Ministry of Justice, n.d.).

Statute law is passed by Parliament and is set out in written published statutes or legislation that may override the common law (Mulholland, 2001). The law is a means of social control (McDowell & Webb, 2006). Criminal law, for example, seeks to control anti-social behaviour. Commercial law provides a structure of rules for business transactions. Constitutional law provides for and determines functions of various bodies of government (McDowell & Webb, 2006).

As a whole, the law is intended to represent the value system of New Zealand society, determined by the beliefs and ideas that arise from the society. Much law "presupposes a certain moral framework within which we conduct our lives" (McDowell & Webb, 2006, p. 4). While prescribing moral or value-based behaviour is purported not to be the function of the law, the law has the effect of being able to enforce widely-held moral beliefs, and the society from which morals and the law emerge are one and the same (McDowell & Webb, 2006; Mulholland, 2001). Morality, it is contested in this thesis, is embedded in the law. Although it is disputed by legal texts that morality and law do not coincide (Mulholland, 2001; McDowell & Webb, 2006), legislation is the primary instrument of coercive power of the government that symbolises and articulates the government's will in exercising its power (Palmer, 2001). Fundamentally a western legal system is the dominant tradition in New Zealand. The formulation of meaning of concepts of law privileges the philosophical origins of western intellectual traditions. The ethical review system underpinned by western moral standards has emerged from western intellectual discourse, the foundations of which will be discussed in the next section.

Western Philosophical Origins

The New Zealand system of ethical review has its roots in western[15] intellectual systems, and European influences upon English philosophy and knowledge that were inherited as a consequence of British colonisation. Ethics is by no means universal

[15] The notion of western philosophy is borrowed from terminology, *the Western front,* used during World War 1, to refer to the battle line separating Germany from other European countries stretching from France to England. The term *western* tends to be applied to all countries that are home to the major philosophers of the European continent and their descendants, who have influenced the nature of societal and legal systems, ethical values, customs and beliefs of those countries, and countries colonised by them. Retrieved 30 June, 2009 from http://uk.encarta.msn.com/dictionary_1861769491/western_front.html

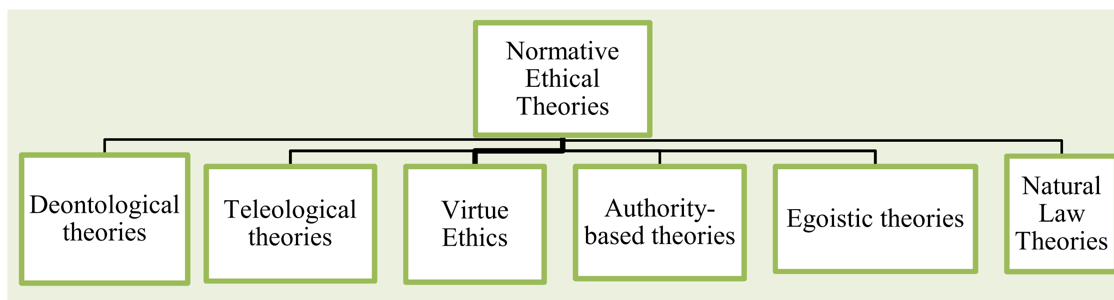
because societies are not uniform and as a field of inquiry ethics is biased towards its dominant origins (Beauchamp & Childress, 1994).

The beginnings of western ethical discourse owe much to the intellectual debates of philosophers who theorised about the nature of the world, and the relationship between humans and the universe. As a body of knowledge ethics is concerned with the study of reasoning about how we ought to act, and ethics is a means by which morals are rehearsed, and moral issues permeate our lives all the time (Beauchamp & Childress, 1994; Mautner, 2000; MacDonald C. , 2002).

Four major areas of ethical inquiry are meta ethics, religious or social, descriptive and normative (Morrison, 2009; Mautner, 2000). Meta ethics is the study of ethical concepts and thus questions about semantics like: what is the meaning of 'good' in moral terms. Religious ethics derives from a distinct body of doctrine such as Confucian ethics and Christian ethics. Descriptive or positive ethics refers to the study of morality of a particular group or society. Normative or rational ethical inquiry holds that people behave morally by conducting themselves according to a prescribed set of norms (Morrison, 2009). Figure 2 shows a range of normative theoretical approaches and three major approaches – deontological, teleological and virtue ethics are discussed further.

Figure 2: Normative Ethical Theories

(Morrison, 2009, p. 4)



The basis of deontological ethical theories is that the motive or intent of an action is important and not the consequences of the action (Beauchamp, 1994). Kantian theory is deontological in nature, where an action possesses moral worth only if it is carried out with good will and therefore a morally valid reason justifies the action (Kant, 1959).

A teleological approach sees the end as justifying the means. Utilitarianism is a teleological or consequence-based approach that originated in the writings of Jeremy

Bentham and John Stuart Mills (Heydt, 2006; Mautner, 2000; Sweet, 2005). Utilitarians share the conviction that the right act in any circumstance is the one that maximizes the overall result or the best outcomes for the most people. The health system in New Zealand operates according to utilitarian philosophy (Woods, 2007).

Virtue ethics has the longest tenure and much subsequent theory can be traced back to Greek philosophers like Socrates, Aristotle and Plato, and Italian theologian, Thomas Aquinas (Morrison, 2009). Socrates did not write anything down. Instead he engaged in a practice of philosophical dialogue dedicated to investigating the development of moral character, largely recorded through the work of his student, Plato (Mautner, 2000). Socrates saw recognition of one's own ignorance as the first step toward the acquisition of knowledge. His prominent definition of knowledge is that of justified true belief. For something to count as knowledge it must be true and believed. A belief on its own is insufficient because people can believe things that are proven to be untrue. Similarly a person cannot be said to know something just because they believe it and it subsequently turns out to be true. His view was later challenged by Edmund Gettier who demonstrated that even a justified belief can prove to be untrue. Regardless, truth, belief and justification have persisted as the three fundamental conditions of western knowledge (Mautner, 2000; Gettier, 1963).

Aristotle's philosophical system known as Scholasticism was fused and reconciled with Christian doctrine. An important feature of Scholasticism was the prevalence of learned disputes which Aristotle applied to much of his work on a range of problems from biology and physics to morals and politics (Mautner, 2000). Aristotle was disposed toward reasoned analysis. He sought a theory that would allow for moral values and scientific truths, and his most basic philosophical commitment was to common sense. Within his work he identified ultimate realities or primary substances and secondary substances (Mautner, 2000).

Based on his theory, Socrates considered that concrete phenomena such as he, constitute ultimate realities, because without such realities nothing else would exist (Mautner, 2000). Secondary substances he proposed, refer to the characteristics of himself, such as being a man, and pale in colour, because such phenomena are reliant on other objects for their existence (Mautner, 2000). Aristotle was therefore the first to deduce that every primary substance falls under a secondary substance. By using logic with science, he

conceived of a class and a genus of species, a system that he applied to the fields of science, knowledge, society and politics (Mautner, 2000). Aristotle saw political theory as continuous with ethics, and he described moral excellence as the acquired rational capacity to choose the mean between extremes (Mautner, 2000).

Thomas Aquinas drew on Aristotle's ideas about reason by advancing two principles underpinned by a relationship between faith and reason, according to his own philosophical Christian bias. Firstly, Aquinas proposed that reason will never discover anything contrary to faith, since both grasp the truth. Secondly, the position held by faith is beyond explanation by rational argument. For example, God's trinity (the father, the son, and the Holy Ghost) is a truth that cannot be explained by unaided human reason (Mautner, 2000).

The work of early philosophers set down the foundations for western ethical theory well into the Renaissance and Enlightenment periods, attributed to European history. The Renaissance period, from about the 15th Century, is characterised by a rediscovery of ancient classical texts and their applications in arts and sciences. An explosion of the dissemination of knowledge occurred through the development of new techniques in the creative arts and architecture (Christians, 2000).

The Enlightenment period of the 18th Century saw nature as an arena of limitless possibilities. Sovereignty of human personality was demonstrated by its mastery over the natural order, and mathematical explanations for the laws of nature and the material world. Intellectual discussion from the Enlightenment centred on the dichotomies of subject/object, fact/value and material/spiritual dualisms arising from interpretations of cosmology inherited from Galileo, Descartes and Isaac Newtown (Christians, 2000).

The prestige of natural science played a key role in the development of western knowledge. Science provided unmistakable evidence that by applying reason to nature and human beings, people could live progressively happier lives. Insanity for example, no longer needed theological repression because it could be explained empirically (Christians, 2000).

Knowledge constitutes an ethical moral stance and western morality is linked to Christian standards of behavior (Christians, 2000). Ethical theory is dominated by

western foundations, attempting to apply the field of analytical philosophy to the empiricism of science, thereby approaching two extremes of thought (Nagel, 1987).

Western Decision Theory

Western decision theory has emerged from distinct philosophical and intellectual foundations. Three broad categories constitute the range of approaches concerned with decision analysis summarised in Table 2 (Bekker, et al., 1999) and each decision approach has originated from a different disciplinary background (Bell, Raiffa, & Tversky, 1988).

Table 2: Western Decision Approaches
(Bekker et al, 1999)

Theory	Basic Assumption	Characteristics
Normative	Rational decision making is quantifiable and measurable	Formalised and rationalised procedures e.g. Probability theory. Decision making reflects true preference or 'expected value' e.g. rational normative theory Choice is a maximisation process[16]
Descriptive	All decision makers are rational, fully informed and able to comprehend information with perfect accuracy.	Describes how humans process information in order to make rational decisions.
Prescriptive	Humans make poor decisions.	Describes ways to facilitate rational and objective decision making

Normative theory has its origins in statistics, mathematics and economics, and describes what people ought to do if they want to be rational decision makers. Two approaches dominate normative theory – scientific or empirical and reasoned inquiry. The scientific method illustrates how rational thinking is achieved by relying on mathematical and statistical standards of proof (Bekker, et al., 1999), while the other major approach emphasises the authority of human reason and conscience (Mautner, 2000). In other words, human beings are motivated by their own desires and goals, and their decisions are influenced by social phenomena and institutions (Mautner, 2000).

[16] (Tversky & Kahneman, 1988)

The descriptive approach to decision theory has emerged from psychology and the behavioural sciences, and is concerned with cognitive phenomena, and how humans actually think and process information. Descriptive theory assumes that each decision-maker is fully informed, able to compute with perfect accuracy, and follow rational processes. However, known features of human information processing are that humans have limited span of the working memory, they have limited exactness in quantitative measurement, and a tendency for human errors and contradictions (Larichev, 1999; Hansson, 2005). Decision making using the descriptive approach is understood to be a sophisticated cognitive activity, sensitive to how complex a task is, the pressure of time, how the task is framed and what reference points are used in order to make a decision (Lichtenstein & Slovic, 2006).

Prescriptive decision theory that originated from operative research and management science, assumes that human beings make poor decisions. Decision aids are necessary to assist decision making to achieve a more objective and quantifiable practice. Information leaflets, language and communication mediums are examples of decision aids.

Cognitive theories of decision making are relevant to health decisions, as is moral development that has been found to contribute significantly to the process of decision making.

Moral Development

Decision making involves deliberation on moral grounds because, to a large extent, morality is concerned with relationships and our rights and obligations that arise from relationships with people and institutions (MacDonald, 2002). As discussed previously, decision making implies an ethical/moral stance, and morality of society is learned through a process of socialisation which occurs predominantly in the home and the education system.

Lawrence Kohlberg and Jean Piaget's cognitive theories locate the beginning of moral development at infancy. Both theorists draw a close association between moral development, learning and a child's environment. Kohlberg (1981, 1984) proposed that moral development involves three levels that become more complex as children move into adolescence and adulthood, and each level is characterized by particular behaviours. Piaget believed that a child's moral reasoning develops out of learning and

it is largely a biological process. His work found that children go through a series of changes or stages from birth. Younger children regard rules as fixed and absolute and older children recognise that rules are not sacred and they are mechanisms to help people get along with each other (Piaget, 1965).

A major opponent to Piaget's ideas was Russian psychologist, Lev Vygotsky, who stressed the importance of a child's cultural background as an effect to the stages of development. Vygotsky claimed that different cultures stress different social interactions, challenging Piaget's theory that was based on a hierarchy of learning development (Vygotsky, 1978).

Vygotsky's key premise is that moral development is culturally mediated. He observed how higher mental functions develop historically within particular cultural groups through social interactions with significant people in a child's life like parents and other adults. Through social interactions children learn the habits of the mind of their culture, including the language and other symbolic knowledge. The specific understanding they gain through these interactions also represents the shared knowledge of a culture and they internalise the ideas and beliefs that constitute the values of the society they live in and the values are perpetuated (Vygotsky, 1978).

The work of Vygotsky is relevant to this thesis because it emphasises the way culture informs moral development and social interactions when people make moral decisions and therefore, their ethical behaviour.

Against the backdrop of information already provided, the next part of the chapter synthesises the principal understandings drawn from the literature review. It also discusses the limitations of the New Zealand health and ethical review systems to accommodate whānau decision processes, and the implications for improving Māori health in particular.

Part C: Practice of Health Research Ethics

Key Issues

There are five key issues that emerge from the literature of decision theory, health research, Maori society and whānau. The first issue has to do with the relevance of one's own cultural norms upon health. In the past few decades, there has been increasing recognition by health researchers, that morals are human inventions that are culturally constructed. Culture plays a significant role in guiding moral judgement and behaviour, and therefore decisions about health (Ramsden, 2002; Johnstone, 2004; Leininger, 1990).

The concerns of health researchers have led to a number of practical difficulties, as noted by Johnstone (2004), who gives the example of language differences and the difficulties in making culturally thick translations of ethical concepts meaningful. Johnstone asserts the application of moral constructs across societies is impossible, and the translation of ethical concepts across cultures is problematic. Notwithstanding the complexity of informed consent, the added cultural dimension intrinsic to ethical processes is significant, because it sets the foundation for standards of ethical behaviour as these apply to the subject matter at hand, and the specific community involved.

The second key issue arising from the literature concerns two quite different philosophical approaches to ethical and decision discourses. Western philosophy draws on biblical scripture and textual foundations for ethical beliefs and practices, most often attributed to a specific person's theorising. Western philosophy emphasises the concept of individuality. Smith (2005) cites ethical Codes of Conduct and ethics processes that are framed around a western sense of individuality and of individualised property. Individuality is also emphasised by the Universal Declaration of Human Rights (General Assembly of the United Nations, 1948), and reinforced by New Zealand law, human rights legislation and health legislation and policy.

In contrast, collectivity is fundamental to Māori ethical and decision discourses drawn from philosophical foundations of which the integrity of the universe is central. Explanations of phenomena are derived from the natural world. Preserving the natural world as a whole system is critical. The collective grouping of human communities for example, is a phenomenon of the natural world. As such, maintaining the integrity of

collective groups is akin to preserving the natural environment, because the actions of individuals have potential implications for others.

Notions of wholeness are thus fundamental to Māori philosophy and there are no methodologies in western intellectual systems that examine “wholeness” (St-Denis, 2005, p 8). Collectivity is a concept reinforced by Maori knowledge conventions. An orientation toward collective rights is a common feature of the philosophy of other indigenous peoples and the concept of collectivity permeates the International Declaration on the Rights of Indigenous Peoples (General Assembly of the United Nations, 2008).

The third key point concerns two broad approaches to Māori health research, a deficit and a transformation approach. Jackson (2005) describes health research as a site for the perpetuation of colonisation, because Māori identity is positioned in deficiency mode, linked to ill health and aimed toward influencing government policies, rather than reclaiming Māori ideals in the pursuit of health. Consequently, health research becomes driven by the priorities and objectives of the government of the time and is therefore subject to change. Health as a concept is determined according to the dominant paradigm.

While Jackson’s argument forms the basis of one approach, it is equally true that health research is a potential site for transformation of the health research sector. The reclamation of Māori intellectual territory as a change agent for improving Māori wellbeing, offers huge potential for translating philosophical principles into practical solutions, not confined to health strategies.

Māori intellectual ideas expressed through symbolism, bridge an important gap between research theory and practice, because such knowledge facilitates the education of the health research workforce to promote the application of Māori conventions that benefit whānau. The description of health embedded in Te Whare Tapa Whā is an example of a transformational approach to research that has practical application to health and, continues to be relevant for Māori 25 years since the model was first described.

Regardless of the approach used, all health research is subject to the same set of constitutional, political and social conditions, but for Māori the implications of

colonisation forever loom near, because of dominant structures extant in the health research sector.

The fourth key issue concerns the systems that facilitate the potential for whānau to engage in decision making in health research. A western legal system is the dominant tradition in New Zealand. As stated earlier, the formulation of meaning of concepts of law privileges the philosophical origins of that tradition. The ethical review system relevant to health research practice has evolved from the same origins as the law, and overall, a prescribed set of moral norms dictates both systems.

Ethics committees are gatekeepers of their own processes, and they are not legally bound to respond to recommendations for changes to their own processes as pointed out by McGoogan (2002). Such gate keeping places additional limitations on the ability of whānau to observe their own decision practices, and have those practices enforceable by law.

The fifth point being made concerns the application of the Treaty of Waitangi to health research, because the way the Treaty is applied in the health sector, is symptomatic of the way it is considered constitutionally. Palmer (2001) suggests that the Treaty is expressed too generally within the law to have clear implications for most detailed legislative clauses (Palmer, 2001). He gives the example of clauses of the New Zealand Public Health and Disability Act 2000. Formerly the purpose of the Act was to 'recognise and respect the principles of the Treaty of Waitangi'. According to Palmer (2001) a Court, or anyone else, could focus on interpreting how Parliament intended to recognise and respect the principles of the Treaty. The Act has been amended to include in the purpose that it is "to reduce health disparities by improving the health outcomes of Māori and other population groups" (Palmer, 2001, p. 211).

Part 3 of the Health and Disability Act provides "for mechanisms to enable Māori to contribute to decision-making on and participate in the delivery of, health and disability services" (Ministry of Health, 2000, p. 8). In reality the provision largely constitutes the appointment of at least two Māori members of District Health Boards (DHBs) and Māori representation on DHB advisory boards and ethics committees.

Palmer (2001) proposes that the setting out of specific provisions in legislation is a way of operationalising the relationship between the Crown and Māori and other New

Zealanders expressed in the Treaty. He suggests that politicians are best placed to analyse detail of policy and its translation into legislation, rather than the Courts, because it is essentially a policy making job of balancing interests under the Treaty of Waitangi (Palmer, 2001). A problem with Palmer's proposition however, is that politicians, as agents of the Crown become the sole arbiter of legislative decisions. Politicians retain the balance of power in deciding how they have met their moral obligations according to the Treaty, a long-held practice that has not served Māori well, and by implication, the country, since the Treaty was signed.

Advancing the Treaty Relationship

All health research in New Zealand is relevant to Māori, whether it is intended or not, whether Māori are involved or not, and whether Māori are directly or indirectly affected. The reason being, that Māori are an integral part of New Zealand society that the puzzles of health research try to understand.

Crown-designed and implemented health policies since the signing of the Treaty of Waitangi have not made significant inroads in reducing health inequalities between Māori and non-Māori (Winiata, 1998). To this day, the Treaty of Waitangi is the only constitutional document that sanctions a relationship between Māori and other New Zealanders (Jackson, 2006b). While the principles of the Treaty capture its intent, the principles cannot be understood in isolation from the full context of the Treaty, nor from the communities for whom the Treaty is intended. Application of the Treaty across public-funded government sectors, including health, is dependent on good will rather than deliberate management. The fact that Treaty provisions only exist in some legislation and not all legislation, suggests the government considers the Treaty only relevant to certain aspects of its' work. However, this also implies that for Māori the Treaty is only relevant to certain aspects of their lives.

A common myth is that Treaty-based grievances and the Waitangi Tribunal[17] process, pose a threat to the future of the country because Māori, the minority, are perceived to have power over government and receive special treatment above other sectors of society (Brash, 2004; Berry, 2006). On the basis of a range of determinants of health, the perception that Māori are privileged is ill-informed and incorrect. Such a view is

[17] The Waitangi Tribunal is established under the Treaty of Waitangi Act 1975 to hear grievances about breeches of the Treaty.

underpinned by inaccuracies about Treaty of Waitangi grievances, and a lack of understanding about the link between the Treaty and its intent, and the cumulative effects of colonisation on a specific part of New Zealand society, Māori. Persistent misinformed attitudes reinforced by various government actions, overshadow the potential of the Treaty as a philosophical framework for relationships in New Zealand.

As long as the Treaty is not fully recognised or utilised to its full potential, there will be ongoing struggles to improve Māori health with a range of consequences. Notwithstanding the social implications, the financial costs will be far reaching. The amount of government spending to improve Māori health is not necessarily the issue. Winiata (1998) refers to a wasteful management style coined GIRA: Getting it Right Accidentally, that he says characterises the approach of New Zealand governments over time to reduce socio-economic disparities in Māori health among other factors. Winiata (1998) maintains that if unsound economic decisions continue in health through applying strategies and initiatives that do not equate with significant improvements, there is justification to question policies that are implemented to address Māori health, of which health research is a part.

Summary

As described earlier in this chapter, Māori rules of moral conduct derive from an intellectual tradition of which the natural world is central and the world is viewed as a whole. Each person is symbolic of the indigenous world and their health or more correctly, hauora, is akin to maintaining a harmonious balance between different components within their world. Consequently, maintaining hauora requires behaviour that preserves the balance of each contributing component of health, and such behaviour has cultural and ethical foundations.

Western approaches to ethics behaviour also assume a particular moral stance. Although individual members of Māori society may find favour with the value system expressed through New Zealand law that manifests in the health system, Māori ethical values are not captured by dominant paradigms.

Attempts to significantly reduce inequalities in health between Māori and other New Zealanders can only be fully realised when there is social equity, equity of justice, equity in education and employment, to be able to truly achieve equity for Māori health.

Constitutional arrangements between Māori and the Crown are far from equitable. While government health policy and legislation promotes informed decision making at the level of whānau, challenges impact on the implementation in practice. Ultimately a trade-off occurs between the needs of the greatest number of the population and those in greatest need of health services. The utilitarian approach to health sector decisions that is widely adopted in New Zealand, does not favour Māori as a minority population, which poses a serious challenge for achieving health equity. Consequently, the impact of dominant decision practice and the moral and theoretical underpinning of such practice, filters through the health system and manifests in the utilisation of health services and health research of whānau.

It was noted earlier in this chapter the way morals are internalised through a process of socialisation. Māori children, who are naturally surrounded by their whānau, internalise their knowledge of whānau structures and processes through observation of roles, actions, behaviours and relationships, thus they learn culturally relevant constructs and the culture is preserved, which contributes to their identity.

The system of ethical review of research must promote whānau decision processes otherwise Māori society is denied access to culturally relevant constructs that are intrinsic to their cultural identity. The important link between identity and health reinforces an argument that the ethical review system contributes to inequalities in health.

Hudson (2004) was previously cited for his critique of the current framework for research ethics. He proposed a broader approach to ethics that takes into account Māori moral conduct because the status quo is only geared towards western society. The ethical principle of justice for example, as an objective and impartial concept, is illusory when applied to Māori society, because equity of justice on the basis that Māori have access to their own ethical constructs is not achievable.

Broadening the ethical system requires attention to systemic factors. A Treaty-informed health research workforce is necessary, as well as constitutional strength to ensure health researchers recognise whānau as legitimate Treaty parties. In this way, health researchers are supported to engage whānau deliberately in decision making.

The application of western ethics to a Māori orientation of ethical conduct is problematic. The framework for ethical decision processes available to whānau as participants of health research favours the dominant western standard of ethics and the knowledge and processes familiar to that worldview. Mainstream ethical practice may include mechanisms that are acceptable to individual Māori. However, the argument being forwarded in this thesis is that Māori members of society should also have access to decision processes according to their own cultural norms.

The Treaty of Waitangi is the key to ensuring that the ethical review system that accommodates health decisions, privileges all societies in New Zealand. If a core principle of western health research ethics according to an international standard is 'to do no harm' (Beauchamp & Childress, 1994), then it is necessary to have safeguards built into the constitution to ensure this is achievable for all members of society (Jackson, 1988).

It is also essential that attempts be made to elicit the perceptions of Māori society concerning the nature of ethics, if an understanding of the way to conduct Māori research ethically is to be formed. From the perceptions may come an understanding of the processes that facilitate ethical practice according to Māori values (Jackson, 1988).

The construction of Māori moral standards and therefore Māori ethical practice is relevant to decision making. There has been no research of whānau decision processes and this chapter has provided the fundamental building block for the methodology and methods chapters that follow.

CHAPTER THREE: METHODOLOGY

Te More[18]

Introduction

This chapter discusses the methodological principles that have informed the conduct and analysis of this research into whānau decision processes. As participants in this study also participated in genetic research, this is justification to also explore western research inquiry that informs genetic research.

The chapter begins by discussing qualitative inquiry and the notion of a research paradigm as this is defined by a western research tradition. It then describes the nature of a Māori research tradition by reference to frameworks that are articulated in various contexts - education, hauora, kawa (cultural practices) and mātauranga (Māori intellectual system). The chapter argues that the frameworks collectively demonstrate the existence of unique intellectual methodologies, underpinned by a fundamental philosophical framework that is a Māori worldview.

The chapter then describes commonalities between Māori and western research traditions which are referred to as a point of interface. The interface is discussed as a useful way to acknowledge the unique qualities that the traditions bring to research, so as to be better understood in the application and limitations of the traditions within health research.

The chapter moves to a description of the conceptual framework developed for the study to guide the research process and analysis, and concludes with a discussion about the implications of using a Māori inquiry paradigm, including a process for the researcher's own development called cultural competence.

Qualitative Inquiry

Qualitative researchers stress the socially constructed nature of reality, the intimate relationship between the researcher and what is studied, and the contextual constraints that shape inquiry (Denzin & Lincoln, 2000). Qualitative research emphasises the value-laden nature of inquiry and seeks answers to questions that stress how social experience

[18] Te More – the vine, symbolizes tangible potential. The words are used as a metaphor to represent the foundations of this study based in Māori philosophy.

is created and given meaning. In contrast, quantitative studies emphasize the measurement and analysis of causal relationships between variables, not processes (Denzin & Lincoln, 2000).

Qualitative inquiry has western research origins and is described as a “metaphor for colonial knowledge, for power, and for truth” (Denzin & Lincoln, 2008, p. 1) because it represents the colonialist way western researchers interpret and reconstruct indigenous knowledge back to western society (Smith, L.T., 2005). As an approach to research, qualitative inquiry emerged from the disciplines of Sociology and Anthropology “out of concern to understand the other” (Vidich & Lyman, 2000, p. 38). With its limitations, qualitative inquiry is the standard approach for exploring the qualities of phenomena, and it refers to a set of ideas and assumptions used to classify a family of research traditions, involving the interpretation of phenomenon in their natural setting, using a range of practices that help researchers to get a better understanding of the object of their research (Denzin & Lincoln, 2008).

Qualitative inquiry is characterised by some common themes which are summarised in Table 3.

Table 3: Themes of Qualitative Inquiry

(Denzin & Lincoln, 2008)

Naturalistic inquiry	Studying real-world situations as they unfold naturally; non manipulative, unobtrusive, and non-controlling; openness to whatever emerges – lack of predetermined constraints on outcomes
Inductive analysis	Immersion in the details and specifics of the data to discover important categories, dimensions, and interrelationships; begin by exploring genuinely open questions rather than testing theoretically derived (deductive) hypothesis.
Holistic perspective	The whole phenomenon under study is understood as a complex system that is more than the sum of its parts; focus on complex interdependencies not meaningfully reduced to a few discrete variables and linear, cause-effect relationships.
Qualitative data	Detailed, thick description; inquiry in depth; direct quotations capturing people's personal perspectives and experiences.
Personal contact and insight	The researcher has direct contact with and gets close to the people, situation, and phenomenon under study; researcher's personal experiences and insights are an important part of the inquiry and critical to understanding the phenomenon.
Dynamic systems	Attention to process; assumes change is constant and ongoing whether the focus is on an individual or an entire culture.
Context sensitivity	Assumes each case is special and unique; the first level of inquiry is being true to; respecting, and capturing the details of the individual cases being studied; cross-case analysis follows from and depends on the quality of individual case studies.
Unique case orientation	Places findings in a social, historical, and temporal context; dubious of the possibility or meaningfulness of generalisations across time and space.
Empathetic neutrality	Complete objectivity is impossible; pure subjectivity undermines credibility; the researcher's passion understands the world in all its complexity – not proving something, not advocating, not advancing personal agendas, but understanding; the researcher includes personal experience and empathic insight as part of the relevant data, while taking a neutral non-judgemental stance toward whatever content may emerge.
Design flexibility	Open to adapting inquiry as understanding deepens and/or situations change; avoids getting locked into rigid designs that eliminate responsiveness; pursues new paths of discovery as they emerge.

Inquiry Paradigm

A paradigm is a worldview or set of basic beliefs, held and shared by members of a community. The members have undergone similar experience and absorbed the same knowledge, including that which arises from institutions inherent in the community like

social structures and intellectual traditions (Denzin & Lincoln, 2000; Kuhn, 1996). The members of the community "see themselves and are seen by others as uniquely responsible for the pursuit of a set of shared goals, including the training of their successors" (Denzin & Lincoln, 2000; Kuhn, 1996, p. 177).

The concept of a paradigm represents the lens with which a researcher conducts research, observes, interprets and analyses research material (Denzin & Lincoln, 2000). Denzin and Lincoln (2000) refer to the researcher's net to describe the framework of a paradigm that encompasses four concepts: ontology, epistemology, methodology and axiology.

Ontology is concerned with the general theory of what there is (Mautner, 2000) and raises basic questions about the nature of reality and the nature of how we as human beings come to know that reality (Denzin & Lincoln, 2000). Based on a theory or set of ideas made up of its assumptions about what there is, ontology forms the basis from which a research question or set of questions is posed. Using the example of whānau decision making, ontology assumes that whānau decision making is a phenomenon and the purpose of ontology is to describe the properties that define it.

Epistemology is concerned with the nature and possibility of knowledge and how such knowledge is formed, and therefore it is primarily concerned with asking how do I know what there is? (How we come to know reality) (Mautner, 2000). In the case of whānau decision making, a question posed by epistemology is what is the nature of the phenomenon (whānau decision making)?

While epistemology is the philosophy of how we come to know the world, methodology is the practice (Trochim, 2006). Methodology is concerned with the practical methods of inquiry or the best way to uncover the truth and qualitative epistemology assumes there are multiple truths or realities. Methodology will ask: What will help me know about the phenomenon (whānau decision making)?

Ontology, epistemology and methodology all deal with reality: What is really there? What is the nature of reality as we know it? How do we know reality? (Heron & Reason, 1997). These questions can be described as comprising an analysis of explanation about a phenomenon (Adams, 1950).

Axiology on the other hand, deals with value or worthiness (Denzin & Lincoln, 2000; Heron & Reason, 1997), and is concerned with posing questions about the valuing of

knowledge itself (Heron & Reason, 1997). Unlike the other three components of a paradigm, axiology is concerned with an analysis of justification (Adams, 1950). By using the subject of whānau decision making, axiology will ask: Why is whānau decision making of value?

As outlined by Denzin and Lincoln (2000) an inquiry net influences the nature of the research question, the research approach and the tools used to answer the question. In addition to the paradigm, a researcher's personal history influences the way they look through a paradigm lens and, how they move to the next stage of research – namely, working with a specific strategy of inquiry (Boulton, 2005; Denzin & Lincoln, 2000; Ratima, 2001).

It is important to consider major areas of inquiry prominent in western philosophy which dominate and inform health research and genetic research specifically. Four major areas of inquiry are described by Denzin and Lincoln (2000) – positivism, post positivism, critical theory and constructivism.

Positivism holds that there is only one reality and science is the way to understand reality. Through observation and measurement (or empiricism) science uses deductive reasoning to postulate theories that can be tested. The strength of positivist research lies in its reliability, because research is controlled in such a way as to generate the same results each time a study is replicated (Tolich & Davidson, 1999). Through a controlled process, the world can be understood well enough to predict and control it (Denzin & Lincoln, 2000; Trochim, 2006).

Post positivism emerged in the mid 20th century and is a rejection of the central tenets of positivism. Post positivists claim that scientific reasoning and common sense reasoning are the same process. Critical realism, one of the commonest forms of post positivism, is critical of the positivist ability to know reality with certainty, by claiming that all observation is fallible. Therefore, multiple measures and observations are necessary to reach the truth (Trochim, 2006).

Critical Theory "presupposes freedom, even if not yet existent freedom" (Horkheimer, 1982, p. 230) and is broadly distinguishable by its specific purpose to liberate the human being from situations that enslave them. The emergence of Critical theory marks another shift in research that is not content with increasing knowledge, but aims to be a transformative endeavour (Denzin & Lincoln, 2000). Inquiry that aspires to critical

research must attempt to confront injustices of a particular society within the society. Four traditions of social inquiry come under the broad field of critical theory: neo-Marxism; genealogical inquiry; post structuralism; postmodernism.

Constructivism is oriented to reconstructed understandings of the social world. Knowledge is viewed as arising from an active adaptation of the human being to their environment (Denzin & Lincoln, 2000). In other words knowledge is not something we acquire, but something that we produce (Mautner, 2000).

Berger and Luckman (1967) suggest that knowledge is a human product derived from social order. Society provides direction and stability for much human conduct. According to them, social order or social institutions are humanly constructed to satisfy a biological need for social contact. The products of social institutions like language and knowledge, articulate their socially constructed reality.

Thomas Kuhn (1970) advanced Berger and Luckman's theorising further, by proposing that knowledge is socially and culturally constructed. He makes reference to the science community as an example, by suggesting that scientific theories derived from observation of phenomena, are human interpretations and not objective reality. Kuhn refers to the scientific publications by Nicholas Copernicus to illustrate his point. Copernicus was the first astronomer to publish new information about the solar system as a heliocentric model, displacing all previously held ideas that the earth was the centre of the universe. His work was largely accepted by the scientific community of the time because it satisfied their social and cultural intellectual norms and standards.

Foucault reiterates theories about social and cultural constructions of knowledge, but he emphasises the way historical and cultural foundations influence the power and authority of knowledge systems. As an example, he refers to the status of medical knowledge, which he describes as being considered the only true authority on illness and as a result, it has been favoured over the voice of the sick (Foucault, 1994).

Singularly and collectively, the four major paradigms outlined by Denzin and Lincoln (2000), form the main framework for western qualitative research. They also suggest that other perspectives such as feminism and cultural studies have specific inquiry criteria, assumptions and methodologies, which are applied within the broader framework.

The basic beliefs of the range of inquiry paradigms described by Denzin and Lincoln (2000) are shown in Table 4 with a modification for the purpose of this thesis to include axiology. Primarily the table shows the basic features of western inquiry on the left hand column, and the characteristics of four major areas of western research inquiry described in each column.

Table 4: Basic beliefs of alternative inquiry paradigms

(Denzin & Lincoln, 2000, p. 165)

Item	Positivism	Constructivism	Critical Theory	Constructivism
Ontology: *The nature of reality*	Naïve realism – "real" reality but apprehendable	Critical realism – "real" reality but only imperfectly and probabilistically apprehendable	Historical realism – virtual reality shaped by social, political, cultural, economic, ethnic, and gender values: crystallised over time	Relativism – local and specific constructed realities
Epistemology: *The philosophy of how we come to know reality*	Dualist/objectivist; findings true	Modified dualist/objectivist; critical tradition/community; findings probably true	Transactional/subjectivist; value-mediated findings	Transactional/subjectivist/created findings
Methodology: *The practice of how we come to know reality*	Experimental/manipulative; verification of hypotheses; chiefly quantitative methods	Modified experimental/manipulative; critical multiplism; falsification of hypotheses; may include qualitative methods	Dialogic/dialectical	Hermeneutical/dialectical
Axiology *Values*	Excluded – influence denied		Included – influence of values acknowledged	

Māori Research Tradition

Following on from the previous discussion about western inquiry, and to illustrate the distinct characteristics of Māori research inquiry, this section considers the range of discourses that exist in a Māori research tradition.

Three positions are held in this thesis. The first is the existence of a unique intellectual framework with its inherent set of universal principles that constitute a value system distinctively Māori. The second concerns the different kinds of understanding about phenomena that arise from using tools derived from a Māori intellectual framework. The third position is the recognition that Māori as a society has always existed beyond a single generic group, within a variety of distinct social realities, which have evolved in response to environmental challenges that include ecological, political and social adaptations. The implication is that Māori knowledge as a dynamic phenomenon develops according to the natural evolution of its society.

Mason Durie (1998) recommends "analysis based on frameworks relevant to Māori must be a fundamental goal of Māori research" (p. 412). Māori research has grown out of its Pacific traditions (Boulton, 2005) and can be traced from the conception of the universe (Royal, 1998).

Denzin and Lincoln (2000) suggest that a proven research framework is one that stands up to criteria from within its own epistemological community.

As outlined in the previous chapter, Māori ethical frameworks are underpinned by Māori philosophy. This chapter considers further frameworks that are articulated in various contexts – education, kawa (practice norms), mātauranga (intellectual system) and hauora (health). Each framework is described within the context it emerged, and all the frameworks collectively provide an insight into Māori philosophy, by the fact of drawing on many of the same values or principles.

Each framework has relevance to Māori health and therefore health research because of the holistic way in which Māori health is comprised and an overview of the frameworks is given in Table 5 later in this chapter.

Education

Three frameworks that have been described in modern education are: *Kaupapa Māori*, *Whakawhanaungatanga* and *Te Ao Mārama*. Each of these is discussed separately and the emergence of these frameworks marks a time when Māori scholars began to make academic space for Māori intellectual discourse.

Kaupapa Māori

Kaupapa Māori is a term that coined a prescriptive approach to Māori education (Smith, G., 1997). The introduction of Kaupapa Māori marks a milestone in the development of Maori academic discourse. Underlying the approach are six principles: tino rangatiratanga (self-determination); taonga tuku iho (cultural aspirations); ako Māori (culturally preferred pedagogy); kia piki ake i ngā raruraru o te kainga (socio-economic mediation); whānau (extended family structure); kaupapa (collective philosophy).

Linda Smith (n.d.) explains that Kaupapa Māori is underpinned by assumptions that inform the formulation of research questions and analysis. She explains:

> One assumption is that being Māori is quite normal and so you're not going to ask questions which question the normality of being Māori. Another kaupapa Māori assumption is that our tikanga, our practices, our identity, our language, is legitimate, so you're not going to ask questions that question the legitimacy of those things. (Smith, L., n.d.)

Within a Kaupapa Māori framework, the legitimacy of whānau is assumed and it logically follows that whānau will engage in their own decision processes.

Whakawhanaungatanga

Russell Bishop (1998) describes another research strategy which he calls Whakawhanaungatanga (establishing relationships in a Māori context), located within the domain of Kaupapa Māori. His framework reconfigures power relationships between researchers and research participants so that research becomes a shared discovery along a collaborative journey.

Three overlapping implications are inherent in his model. Firstly, establishing and maintaining relationships is a fundamental, long term and ongoing process. Secondly, researchers are engaged in research with participants at a number of levels including spiritually and morally, as opposed to research being a mechanical process. Thirdly,

whakawhanaungatanga demands a shared approach and therefore, participant-driven research practices (Bishop, 1998).

Bishop's model for research essentially places the onus of control with those being researched. His model proposes that researchers are facilitators of a collaborative journey and it recognizes that researchers may have a personal relationship or whakapapa to their participants. This is a reality of a Māori research tradition.

Te Ao Mārama

Te Ao Mārama is a framework, albeit in development (Royal, 1998), that draws on whakapapa to describe the nature of, origin, and location of phenomena, and to show trends and relationships between phenomena (Royal, 1998). The central idea of Te Ao Mārama is that whakapapa begins with two phenomena that come together and give birth to a third phenomenon. Thus "all things occur through some kind of parental phenomena under study... a truth held by the whakapapa tool" (Royal, 1998, p. 80).

A description of phenomenon according to the experience of a particular whānau for example, would occur in the context of their origins and their ancestral links. The strength of Te Ao Mārama as an analytical tool lies in the ability of whānau to draw on their own resource or whakapapa to articulate their own experience. In a decision situation for example, whānau might employ the idea of relationships between phenomena by reflecting on a decision event etched in their history. As whakapapa is the fundamental structure of that history, whakapapa may act as a mechanism for drawing wisdom, answers or solutions.

Whakapapa is additionally embedded in traditions like karanga, whaikōrero (oratory), waiata (music), and whakairo (carving) (Whaanga, 2004), so these may become additional sources of evidence to inform whānau decision processes.

Kawa

As explained in the previous chapter, kawa embodies Māori ethical practice underpinned by philosophical values. One custom that can be applied to research as a model for the research process is the pōwhiri, a ceremony of welcome, of which kawa abounds. The next chapter will demonstrate the application of the pōwhiri in more depth, but for this purpose, the ceremony generally involves a visiting group that ascends on the territory of a host group. An exchange of salutations and

acknowledgements is laid out in three ways. Firstly, by way of the karanga (call) from a woman host, who receives a similar response from the visiting side. Secondly, kaikōrero (orators) for each party endeavor to reinforce whakapapa connections initiated by the karanga, thus the more knowledgeable a person is about their own whakapapa, the more likely they are, to identify common ancestry with others. Thirdly, waiata (musical embellishment) that follows each orator consolidates the connections that have been identified.

Through the process of whakawhanaungatanga (connecting by whakapapa) embedded in pōwhiri, orators search for common interests, conflicts of interest and points of difference. Provided the observer is proficient in the language of the process and understands its intricacies, they can draw new insights about the realities of those who are drawn together for a specific kaupapa (purpose).

One of the objectives of whakawhanaungatanga that occurs through the process of pōwhiri is for each party to gain greater understanding of the other (Bishop, 1998). This is the same objective aspired to by western approaches to qualitative social science research and according to Denzin and Lincoln (2000):

> Qualitative researchers stress the socially constructed nature of reality, the intimate relationship between the researcher and what is studied, and the situational constraints that shape inquiry. Such researchers emphasize the value-laden nature of inquiry. They seek answers to questions that stress how social experience is created and given meaning. (Denzin & Lincoln, 2000, p. 8).

Mātauranga

The application of a contemporary lens to early ways of thinking is one of the major challenges in using Māori intellectual systems (Royal, 2003). The whānau is a core element of whakapapa (common ancestry) and whakapapa is the skeletal structure of mātauranga (a Māori intellectual system) (Tau, 1999; Mead, 2003b).

Māori society's experience of phenomena is crucial because society is not static and experiences of new phenomena become explained and translated into new knowledge (Kuhse & Singer, 1998). Such knowledge has the potential to inform modern research and to demonstrate the application of mātauranga to decision making, specific examples

are described from the narrative traditions of two iwi (tribal groups), Ngāi Tāmanuhiri and the collective tribes of Tauranga Moana.

Whakatauki (proverbs)

Whakatauki are common oral traditions that serve two purposes - the storage and maintenance of whakapapa, and narrative to impart philosophical ideas. The origin of whakatauki vary, but their use as vessels of knowledge and wisdom are generally the same, and typically whakatauki have layers of meaning from which different interpretations can be extrapolated, to express lessons embedded within (Tau, 2003; Jones, 1965).

Ngāi Tāmanuhiri is a tribe belonging to a collective of tribes that include Rongowhakaata and Te Aitanga-a-Māhaki, known as Tūranganui-a-Kiwa (the long waiting place of Kiwa) after the name of a common ancestor, Kiwa. Their geographical tribal area is situated on the East Coast of the North Island of New Zealand and Ngāi Tāmanuhiri has a local whakataukī (proverb):

'Taku hē ki te huatea mō Tawakewhakatō, nō muri ko Te Huauri'.

Two interpretations of the whakatauki are described. One concerns a story of a tipuna (ancestress), Hinenui, and her fertility; the other relates to a specific kai moana (seafood delicacy), called pāua (abalone) (Thompson, 2000).

According to local tradition, Hinenui did not have any children by her husband Tawakewhakatō (Tawake). She yearned for a child and in her feeling of hopelessness she was drawn to the charm of Tāmanuhiri, who lived nearby and he already had a wife, Rongomaiāwhia (Halbert, 1999). Ignoring the consequences of their actions, Hinenui and Tāmanuhiri began a liaison, and soon she became pregnant. Her desire for children was powerful and affect (emotion) can be a significant motivating factor in decision making, that can lead a decision maker to be influenced by positive or negative affect in the deliberation process (Isen, 1997). The words 'Te Huauri' (fruitfulness) refer to their union and their descendants, and thus the whakataukī may be translated as:

'Mistakenly I was drawn to Tawake, when Te Huauri was not far behind'.

The message underpinning this interpretation emphasises the inherent risks and limitations of decision choices. The need for sound judgement is the key idea being promoted through the beginning words 'taku hē' or 'my oversight'.

The second interpretation of the whakataukī is a metaphorical reference to the story of Hinenui, Tawake and Tāmanuhiri, described by way of reference to the pāua. Pāua is a seafood delicacy that contains white roe and green roe. The white roe is more popular for eating yet it is referred to as *huatea* meaning 'without substance'. The hua or green roe is less appealing to the eye and therefore less enticing to eat, but essentially, it is more superior in its nutritional value. The hua is thus referred to by the words *Te Huauri* referring to its superiority (Sunderland, 1985). The story of white and green roe is symbolic of human judgement and in this particular interpretation the whakataukī might be translated as.

'Mistakenly I seek that of little substance, when fruitfulness lies close by'

In describing the qualities of the pāua, the whakataukī suggests that a judgement about something or someone made solely on the basis of appearance, disregards other qualities. Hence the cautionary beginning words again: Taku hē, meaning my oversight or mistake. The whakataukī aims to emphasise that value and worth exist in many forms. The most aesthetically attractive option is not necessarily the right option, so the whakataukī warns of judgements that use limited criteria.

The principal message is that sound judgement requires an examination of phenomena from different perspectives, to help uncover all nature of qualities that prevail. In a decision setting, the message suggests that different ideas add value to the deliberation process.

Kōrero Pūrākau

Kōrero pūrākau or story telling plays a major role in transmitting iwi knowledge because like other tools, pūrākau are a vehicle to articulate whakapapa and narrative that has symbolic meaning.

Ngāi Te Rangihouhiri (or Ngāi Te Rangi) is one of a group of iwi who share the region called Tauranga Moana. A special landmark of significance is Mauao, otherwise known as Mount Maunganui. The story of Mauao is often told as a romantic tragedy of a once nameless mountain that was in love with a beautiful mountain, Pūwhenua. Spurned by

her in favour of Ōtānewainuku, the angered nameless mountain begged the patupaiarehe (fairy-like creatures of the forest) to drag him into the ocean and end his misery. As he slowly journeyed towards the ocean, he panted and sobbed saying: "ka haere, ka mapu" meaning "I go and sob". His tears became the Waimapu River that flows to this day. As he neared the water's edge, the first rays of dawn sent the patupaiarehe fleeing to the forest for safety, because the shards of light meant their certain death. This left the mountain transfixed on the spot, hence the name Mauao meaning 'caught in the light of day' (Waitangi Tribunal, 2004).

Of course a mountain romance and the story of unrequited love, desperation and despair, is an allegory with philosophical dimensions that involve aesthetics (the imagination), prudence (wisdom) and morality (principles of conduct). One message intrinsic to the story of Mauao has to do with the limitations of human mortality and the power of subjective experience. The key message is that subjective experience is a significant element of human reality, and human experience of phenomena shapes and informs our encounters with other phenomena, our actions, conduct and decision making.

Other tribal groups may interpret the whakataukī and kōrero pūrākau described in this chapter quite differently. Their interpretation is no less valid, but there is a tendency in Maori intellectual systems to acknowledge that whānau/hapū and iwi are the authority of their traditions. This ethic can be likened to the academic practice of obtaining evidence from primary sources.

Traditional sources of knowledge and particularly the philosophical ideas intrinsic to Māori knowledge, inform contemporary Māori experience and the next section considers models articulated in the context of contemporary health.

Hauora

Māori ideas about wellbeing or hauora have always co-existed alongside conventional measures of health in New Zealand (Durie, 2004b). Three models of note are *Te Whare Tapa Whā*, *Te Wheke* and *Te Pae Mahutonga*.

Te Whare Tapa Whā

A four dimensional model of Māori health referred to as Te Whare Tapa Whā (a four sided structure) was articulated in health forums in the 1980s (Durie M., 1984; Murchie,

1984). The model depicts the image of a traditional whare (housing structure) and each side of the structure is symbolic of an aspect of health. Metaphorically speaking, the depths of the philosophies which prescribed traditional Māori life, beliefs and the rules of behaviour that flow from them are compared to the parts of a sheltering whare (Durie, M., 1984; Jackson, 1988), "the foundations which supported the society, the walls which enveloped its members in security and the roof which protected them from disorder and imbalance" (Jackson 1988, p.43). Hauora is a Māori philosophical concept of health, a manifestation of the holistic interwoven nature of tinana (physical wellbeing), wairua (spiritual well-being), whānau (social well-being) and hinengaro (mental and emotional wellbeing). The whare is likened to a person and a person maintains their optimal health by the interrelated *balance* of each of the four dimensions. Te Whare Tapa Whā typifies the holistic idea of wellbeing that is central to Māori philosophy. An important message out of this model is that Māori do not measure their health on the strength of epidemiological data like mortality and morbidity statistics, which is the conventional way of describing the health of populations.

Theoretically, the achievement of optimal health, as aspired to by Te Whare Tapa Whā, should result in an improvement in population health, which is significant philosophically and technically for health researchers. Research should show some congruency between a Māori view of health, intervention measures that are recommended to address Māori health dimensions, and outcome measures that assess the success of those interventions. Te Whare Tapa Whā is a useful tool to understand the complexity of whānau wellbeing, because it provides a framework to think how they might approach decision making about their health.

Te Wheke

Another holistic model, Te Oranga o Te Whānau, otherwise known as Te Wheke, was first described by Rose Pere (1984). Her model of an octopus symbolises whānau health. The body and head represent the individual/family unit and each tentacle represents a dimension of health and wellbeing. Wairuatanga (spirituality) recognises the uniqueness of being Māori sustained through a Māori belief system. Mana Ake (uniqueness) pays tribute to and acknowledges tipuna (forebears). Mauri (life principle), recognises individual and collective mauri. Hā a koro mā a kui mā (breath of life from forebears) recognises heritage links with tipuna. Taha tinana (physical elements)

pertains to the physical body. Material, emotional and social needs are dependent on physical survival. Whānaungatanga (extended family, group dynamics) celebrates whānau relationships and with the collective, comes collective responsibility to each other. Whatumanawa (emotions) and hinengaro (mind) acknowledge the need for learning and emotional development. Finally, waiora (total wellbeing) reflects the holistic approach to wellbeing and the interrelated nature of all phenomena that impact on wellbeing. Waiora summarises the multifaceted approach of whānau wellbeing portrayed by Te Wheke. Like the previous model, each facet is interrelated and will influence and be influenced by whānau decisions. Therefore, the concepts have to be considered singularly and collectively.

Te Pae Mahutonga

Te Pae Mahutonga is the name given to a model of health promotion that symbolises the constellation of stars known as the Southern Cross, a traditional navigation guide (Durie, M., 1999). The central group of stars symbolise four key tasks of health promotion: mauriora (access to Te Ao Māori (the Māori world); waiora (environmental protection); toiora (healthy lifestyles); te oranga (participation in society). The two outlying stars in the constellation, relate to two pre-requisites of health promotion: ngā manukura (leadership); te mana whakahaere (autonomy).

Mauriora relies on a secure Māori identity and cultural identity is a pre-requisite to good health and the goal of Mauriora is to facilitate access to the Māori world including tribal lands, social structures and language (Durie, 2000). Waiora is distinguished from mauriora because it specifically links human wellness with the external environment. The goal is to promote environmental sustainability and ecological practices that improve the nature of human contact with the environment.

Toiora relates to the promotion of healthy lifestyle choices across the gamut of everyday activities including nutrition, exercise, road safety, alcohol and drug use, sexual activity, managing personal finances and occupational health practice.

Te oranga promotes enhancement of wellbeing by improving the extent to which Māori participate in wider society based on recognised disparities in every social indicator of health such as employment, education and the economy.

Ngā Manukura promotes the notion and necessity for local leadership because leaders have an important role in coordinating health promotion alongside health professionals and they will do so in a way that is cognisant of Māori practices with the support of their own community.

Te Mana Whakahaere concerns mechanisms that promote autonomous thinking and acting communities, who are proactive about their own health and wellbeing because of a sense of ownership of their own destiny. Legislation and policy across all government portfolios, has the potential to empower or disempower accordingly in a health promotion context.

In a whānau context, Te Pae Mahutonga draws on basic human rights and resources within whānau, as the means of promoting their health and wellbeing. This model contains the same principles described in other frameworks in this chapter, but it also refers to whānau autonomy that is affected by legislation and policy, and the importance of whānau leadership to help drive their aspirations.

A Māori Worldview

Table 5 summarises the frameworks described so far in this thesis that represent Māori discourses. Underpinning the frameworks is a philosophical base of moral significance that guides how Māori perceive and experience the world. A key element of a Māori worldview relates to its origins or cosmological beginnings located in whakapapa. Whakapapa is a constant phenomenon that is central to a Māori worldview, by the fact that it can describe, explain and justify Māori reality. By its very nature, whakapapa embodies natural phenomena, the past, the present, the future, tangible objects, intangible concepts and all matter of species including humans. This means that all phenomena interrelate to and with each other, in a way that is only explained by whakapapa.

Table 5: Māori theoretical frameworks relevant to Māori health

Context	*Framework/Model*	*Principles*	*Focus*	*Symbolism*
Ethics	Koru of Māori Ethics	Inner values, emerging concepts	Values prescribe conduct	Koru
	Tikanga Māori Model	Five tests relevant to Tapu and Mauri, Take-utu-ea, Precedent, Principles Aspect	Risk approach to decision making	Tikanga
	Research Potential Framework	Domains, values and desired research outcomes	Potential paradigm approach to decision making	
	Consensus Framework	Five principles for functional relationships	Mutuality endeavours lead to prosperity.	
Education	Kaupapa Māori	Six principles prescription for education.	Holistic prescription for education	
	Whakawhanaungatanga	Whakawhanaungatanga dimensions	Connectedness	Equality
	Te Ao Mārama	Whakapapa	Whakapapa can explain all phenomena	
Kawa	Pōwhiri	Whakawhanaungatanga	Connectedness and valuing others	Formal Introduction
Mātauranga	Whakatauki	Whakapapa and narrative	Knowledge and wisdom	Context specific
	Kōrero Pūrākau	Whakapapa and narrative	Knowledge and wisdom	Context specific
Hauora	Te Whare Tapa Whā	Four dimensions of wellbeing: Wairua, tinana, hinengaro, whānau,	Holistic prescription for wellbeing	Sturdy house
	Te Wheke	Eights dimensions of health and wellbeing	Holistic approach to wellbeing	Octopus
	Te Pae Mahutonga	Mauriora, waiora, toiora, te oranga, ngā manukura, te mana whakahaere	Multiple approaches, health promotion, local leadership and autonomy	Crux Australis or Southern Cross constellation

The Interface of Research Traditions

A western paradigm cannot describe Māori reality, because the deductive nature of western reasoning does not permit a holistic description of Māori experience that is demanded of Māori philosophy. Māori researchers have challenged the credibility of western methodologies to describe and explain Māori experience and at the core of the key argument is a basic premise which permeates notions about what makes credible research (Smith, 1992, 2005; Irwin, 1994). That is, western research traditions are assumed to be sufficient to explain all societies because all operate from the same philosophical, political and moral points of reference (Christians, 2000).

Most, if not all, conventional research texts, trace their epistemological origins to the Renaissance and Enlightment periods that are firmly rooted in European history, and there is no mention of another philosophical worldview such as that of Māori (Christians, 2000; Denzin & Lincoln, 2000). The idea of a dominant society is a widely held belief of western philosophers that gained momentum with the emergence of ethnographic research by anthropologists (Patton, 1990). An implied meaning in western philosophical arguments is that all societies exist within the context of the dominant system that prevails. In other words, while Māori society might purport to have distinct features, these are seen as an inherent part of the dominant society and not especially different from it. This stance, however, is contested by arguments that different systems of society have always co-existed albeit survived, at the expense of imperialism (Deloria, 1995). When the constructed discourses of the dominant society are also seen to comprise our moral and ethical system, laws and politics, the dominant traditions are privileged over those of Māori society (Jackson, 1992).

Translating the points of difference between Māori and western research traditions is problematic (Salmond, 1985; Durie M. , 2005). The integrity of either tradition is compromised by applying the conventions of one tradition to the other tradition, and if this occurs in a research context, it is justified to question the reliability of analysis. To emphasise the risks of applying conventions across traditions, an example is used from Henare (1998) to highlight fundamental language challenges. Henare (1998) discusses how the concept of religion as it is understood by dominant society, shapes and limits the perception of it:

> Māori religion is not found in a set of books or dogma such as in the Christian Bible or the Muslim Koran. Neither does Māori religion have a founder or prophet like Jesus Christ or Mohammed. Rather it is a religion that can be observed when experiencing and living life as a Māori in the culture, namely in tikanga Māori and Māoritanga. In this sense, Māori religion is tikanga Māori, Māoritanga, and the culture is the religion. The maintenance of the religious view of life is dependent upon the maintenance of the culture and its many practices and rituals. (Henare, 1998, p. 3).

Any suggestion that Māori society has its roots in western origins is not supported by evidence in Māori knowledge traditions (Tau, 2003; Ngata & Jones, 2005, 2005b, 2006; Royal, 2003), and is disputed by New Zealand academics who are Māori and non-Māori (Smith, 2005; Salmond, 1985b).

Salmond (1985b) suggests that western notions of a society and standards of society are incompatible with those of Māori, on the basis that the language and criteria that define them are literally, worlds apart. Wills (2002) goes further to comment on the incommensurate approaches between western science and Māori knowledge which he suggests shows up as a competition between differing senses of the value of life, conflicting interests in control over domains of culture and nature, and incompatible visions for the future.

This thesis proposes there are common elements between traditions because the objectives of both are the same. The point of commonality is the research *interface* and the grey shaded column in Table 6 draws on the basic elements and limitations of a western paradigm to show the commonalities it has with a Māori research tradition.

Table 6: Basic Beliefs of Western and Māori Research Traditions

Item	Western Research Tradition	Interface	Māori Research Tradition
Ontology The nature of reality	Realism as naïve/critical/historical/ relative or constructed	Intellectual growth critical for the survival of knowledge systems	Holistic realism. Human reality is interrelated with the laws of nature
Epistemology The philosophy of how we come to know reality	Dualist or modified dualist/objectivist – findings true/critical tradition/community; findings probably true Transactional/subjectivist; value mediated findings/ created findings	The nature of reality is explained and justified.	Multiple informants – explanatory power lies with whakapapa
Methodology The practice of how we come to know reality	Experimental/manipulative/ modified/ dialogic/dialectical/ Hermeneutical/dialectical	Context relevant	Layered phenomena
Axiology Values	Excluded – influence denied or Included-formative	Acknowledged	Included – fundamental

Research for both traditions is unquestionably concerned with the pursuit of knowledge. Intellectual growth is critical to the survival of both knowledge systems. The fundamental role of ontology is to determine what exists in each system, a common facet of western and Māori research traditions. The way the traditions come to know reality epistemologically, is informed by their cosmological beginnings, the foundations upon which each tradition is built.

Mechanisms that inform reality and therefore methodology, differ in traditions, nevertheless these exist and are determined by a context. For example, the positivist approach to research posits logic as being the only way to understand reality, whereas phenomenological and narrative methodologies have found favour with the construction of human experience including the influence of emotions (Denzin & Lincoln, 2000). In Māori tradition, reality is a layered phenomenon and often informed by a number of phenomena that happen simultaneously. That is the nature of logic in a Māori paradigm.

Finally, values, while denied by positivism and embraced by constructivism, are fundamental to a Māori research tradition. Regardless of the tradition, values are acknowledged in any case.

Western research cannot fully explain Māori experience because it does not possess the necessary elements required of a Māori worldview. On the other hand, western frameworks should not be completely dismissed, because it is naïve to imply that Māori researchers or Māori communities for that matter have not been influenced by mainstream ideas, and they do not favour some of the ideas that have been imposed on Māori society over the past century (Durie M., 2004c).

The interface of western and Māori research traditions offers an opportunity to explore future research practice differently. A study using a holistic Māori health framework in a joint project with a positivist empirical study whereby both are applied in a coordinated fashion, may well advance research endeavours by bringing closer together the aspirations of Māori communities and mainstream health service providers. For example in an environmental setting, work on measuring water quality has shown that the simultaneous application of differing research approaches is productive for iwi working in collaboration with scientists, because a dual model addresses different values and objectives (Ogonowska-Coates & Ifopo, 2008).

Implications of a Māori Worldview

There is a clear distinction between being Māori by way of descent, and being able to live as Māori, because the latter has to do with access to philosophical and intellectual conventions, in order to be able to live within the context of a philosophically Māori oriented worldview (Durie, 2004d). The philosophical features of a Māori research tradition underpinned by a Māori worldview, as described previously are: multiple constructed discourses exist, values are inherent, phenomena are multilayered, and relationships between researchers and the researched are acknowledged.

A Māori worldview brings with it expectations of the researcher and the research process. Implicit is the idea that a researcher brings to their work their own gender, and their own social and cultural perspectives (Peshkin, 1988). That said there is not one fixed absolute reality about what it means to be Māori, thus there is no single way to analyse phenomena and ideas through a Māori lens (Durie M., 1997; Denzin & Lincoln, 2000). This point is relevant across the spectrum of exposure and access to Māori philosophy.

For the purpose of this thesis, it is accepted that individual Māori are automatically a part of a collective or whānau on the basis that they are born into whakapapa, regardless

of whether they actively participate with the collective or know members of the collective. Belonging to whakapapa means one is able to make a claim to the traditions that arise from it. Having the confidence and knowledge to recite whakapapa, and having an understanding of the depth of knowledge that can be revealed from whakapapa, is a separate matter that will vary between individuals.

If research aims to represent the features of a Māori worldview, then there are two implications, one concerns the philosophical principles or methodology adopted to inform research, the other is the application of the principles in practice.

Conceptual principles of analysis

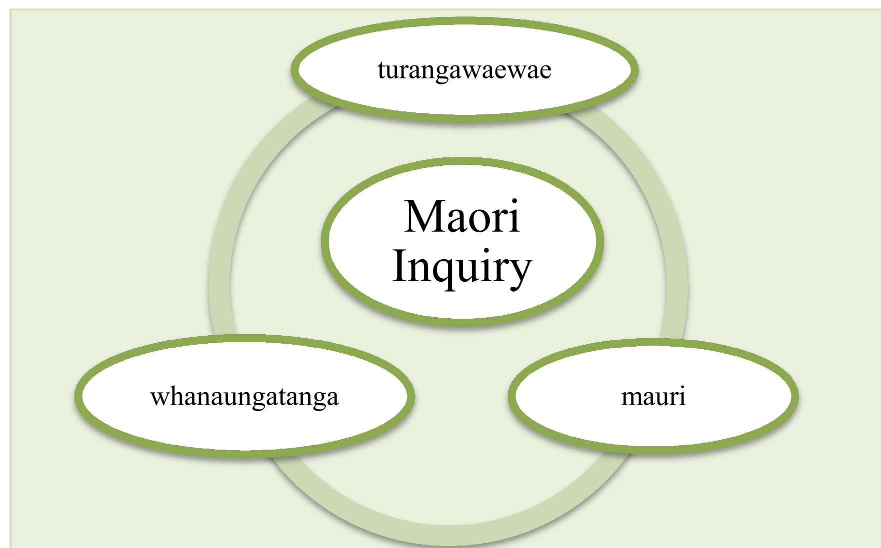
Principles or values (Wenn, 2006) play a critical role in research. Eddie Durie (1998) suggests that "values may represent ideals" (ibid, p. 65) and the values relevant at any one time may vary according to the context. An individual may not seem to be living according to the values they hold true, but a breach of their values "does not invalidate the values themselves" (Patterson, 1992; Durie E., 2004, p. 49). As Māori society changes, the norms and standards that constitute the custom of the society change with it, because custom is not a static convention (Durie E., 1998).

Three conceptual principles inform this research - turangawaewae, whanaungatanga and mauri, which arose from an analysis of the common characteristics of the thirteen Māori research frameworks summarised earlier in Table 5. It is argued that all of the frameworks discussed are a perspective on the same set of fundamental principles. In other words, each framework illustrates a position about Māori inquiry and its common principles, relative to the context in which it emerged.

The nature of this research requires a universal approach that can be interpreted relative to whānau in this study. Therefore, the underpinning principles of the frameworks were found to have greater relevance than the actual frameworks, and the principles met the criteria for Māori inquiry, defined as, the central systematisation of conceptions of reality to which members of its culture assent and from which stems their value system (Marsden & Henare, 1992).

Figure 3 shows a graphic model of the principles of analysis for this study.

Figure 3: Māori Inquiry Principles



The central core of the model symbolises a Māori Inquiry approach adopted in this research. The core is informed by the three aforementioned principles that are of equal significance.

Mauri is an implicit cosmic rather than physical quality. It recognises the inherent worth of all phenomena and fundamentally, it renders all phenomena equal. This is an important distinction between Māori and western philosophy. An implication of mauri is manaakitanga, because manaakitanga is the enactment or practice by which mauri is acknowledged. For example, mauri celebrates difference. Manaakitanga is often translated to mean hospitality or the attitudes and behaviours that are bestowed to another, aim to honour another. Thus actions of kindness, respect, honesty, caring, humility and appreciation give reverence to mauri. This is a demonstration of manaakitanga. Actions that are unkind, disrespectful or uncaring are likely to have an adverse effect upon another, which does not constitute the notion of manaakitanga because another person's mauri is not given proper accord. The saying: 'Treat others as you would like them to treat you' (Mautner, 2000, p. 224) holds true for mauri.

Whanaungatanga derives from the root word 'whānau' (offspring) and the word 'whanaunga' (blood relative). It is a process by which whānau ties and responsibilities are strengthened by all generations supporting and working alongside each other (Pere, 1984). Whanaungatanga is intrinsically linked to the concept of whakapapa because

whānau (family) and the related social constructs of hapū (extended family) and iwi (wider genealogy) all arise from whakapapa.

According to Walker (1996), the worldview of Māori society is encapsulated in whakapapa. In its simplest sense, whakapapa is genealogy. In a wider sense whakapapa attempts to provide an explanation about the relationship that humans have with the natural world (Tau, 1999; 2003), and whakapapa is relevant to all phenomena to expose perspectives, concepts and ideas (Royal, 1998).

Whanaungatanga is an important term of reference in decision making, because it recognises the depth and breadth of consideration relevant to decision processes and the recipients of decision making. By implication whanaungatanga is a collective notion.

Turangawaewae is broadly defined as a place to stand. It includes notions of ahi kā (ancestral settlements) and all matter of identity markers including customary norms, knowledge, language and symbolism. Turangawaewae implies a connection with the local natural environment. In an iwi context this is demonstrated by their reverence for landscape features that are personified to identify the iwi and their tribal region.

Borrell (2005) showed that the notion of turangawaewae is just as relevant for urban South Auckland Māori youth. She identified a range of words, statements and concepts that naturalise the more positive feelings they have for South Auckland such as "Southside" (Borrell, 2005, p.77), "Rewa hard" or "Mangere represent" (Borrell, 2005, p. 78). Strong and meaningful associations to the local land, environment and community are a source of collective strength, pride, individual self confidence and belonging. Borrell showed that localised markers of identity for urban rangatahi (youth) are as important to them as the more conventional markers of identity for iwi. Just like their tīpuna (ancestors) rangatahi in Borrell's study have developed markers that express their identity. Her research dispels misconceptions that gang affiliations in South Auckland mirror those found in the USA. Instead, gang ties are closer to home because family associations with more commonly known local gangs such as Black Power and the Mongrel Mob have a greater bearing on gang preferences. Thus "…some of the positive images about being Māori come from a heightened sense of connection with the local environment" (Borrell, 2005, p 81).

In other studies the concept of turangawaewae was also shown to be important for Māori women across three generations (Houkamau, 2006) and for older Māori (Wenn, 2006). Research by these authors suggests that while older Māori are more likely to have been immersed in customary traditions (Wenn, 2006), the same values of importance to them, have persisted across generations of women, despite stark differences in their exposure to a philosophically Māori oriented worldview.

The fact that Māori values have endured time and colonisation must surely be sufficient test of a moral society. The principle of turangawaewae embedded in Māori research frameworks and contemporary Māori research, is a reminder of the importance of identity as a marker of wellbeing. Understanding about the nature and construction of identity markers is important because research that stereotypes Māori communities, will fail to notice a range of contemporary identity symbols, although based on the same principles as more classical markers.

As health research aims to improve wellbeing, and identity has been found to be an important pre-requisite to good health and wellbeing (Durie, M., 2000) then health research practice must be cognisant of respecting and preserving the integrity of a participant's identity, because their identity is represented within their cultural orientations and both inform decision processes.

Application of the Philosophical Principles for this Research

Principles though broad, require relative application in practice, consistent with a universally held moral system that is applied to a diverse society.

Specific requirements for Māori research are described by Mead (1996) and for Māori health research in particular by Boulton (2005) and Cram (2001). Ratima (2001) proposed the notion of a "culturally competent researcher" (p. 171), derived from a set of attributes and strategies that guide work with Māori communities. Ethnicity is an aspect of a culture and being of the same ethnicity does not mean that a researcher is automatically competent with diversity within their own ethnic group. Having experience of being Māori may position a Māori researcher to better understand Māori communities than a non-Māori. However, it does not mean that all researchers of Māori descent have the same experience of being Māori. Therefore a Māori researcher still has

to consider their preparedness to work with a range of Māori people, and the sort of skills or assistance they need to develop their competence to do so.

Drawing on Ratima's (2001) ideas of cultural competence and seminal work to improve nursing education among diverse cultural groups (Nursing Council of New Zealand, 1992), this thesis utilised a model of cultural competence developed for this research, titled *Te Huauri,* set out in Table 7. Cultural competence according to the Te Huauri model is defined as the preparedness of a researcher to conduct research in a way that promotes and advances the aspirations of research participants who are of another culture to their own. In other words, to avoid making assumptions about the participants in this study, Te Huauri provides a guide, by way of objectives, that I applied to each whānau and participant.

The framework is summarised in Table 7 and shows three guiding principles turangawaewae, whanaungatanga and mauri. Three groups of objectives are set out: personal objectives, local objectives and regional objectives. Each principle is relevant to each objective. Te Huauri describes an organic process the researcher is engaged in, to prepare them to work with diverse members of a cultural group. The model aims to assist a researcher to identity their strengths and limitations, thereby recognising areas for development to improve their competence and confidence as researchers in the area of Māori health.

Table 7: Te Huauri Cultural Competence Framework for this research

Principles	Turangawaewae	Whanaungatanga	Mauri
Meaning	Cultural identity is characterized by specific markers of identity.	Refers to whakapapa and whakawhanaungatanga – encompassing a Māori worldview of relationships	All phenomena are equal and valued.
Practice implications	The researcher will recognise distinctive differences in cultural groups, through an appreciation of their specific identity markers. Turangawaewae requires the researcher to have personal, local and regional insight into cultural nuances. For example, knowledge of language dialectal differences and whenua (land marks).	The researcher needs to be well placed to have developed networks with the research community of interest and research networks of relevance to the same community. Whanaungatanga aims to develop functional relationships between the researcher and the community.	The researcher requires personal, local and regional knowledge of ethical practice to facilitate the behaviours and attitudes that render respect, kindness and humility to research communities expected of a researcher. Manaakitanga is the process by which Mauri is revered and communities are valued.
Personal Objectives	The researcher will engage in a process of self reflection into their own culture. This includes understanding the meaning of identity to them personally and markers of their own identity.	The researcher will explore their own heritage and the way heritage, upbringing and ancestry inform their understanding of relationships and how this impacts on their relationships in a research context.	The researcher will explore the meaning of ethics in a personal context and the implications for their research behaviour, attitudes and research practice.
Local Objectives	The researcher will develop knowledge of the identity markers of their community of interest. This may include the identification of dialectal language differences; any landmarks or historic sites of significance to the community and knowledge symbols of importance.	The researcher will gain knowledge of local networks relevant to the community of interest. In a Māori context this may include identifying the local Māori community, Māori research community, research literature relevant to Māori, Crown policies and legislation that impact on Māori research and development, attending Māori research fora as well as local Māori fora.	The researcher will develop knowledge of ethics according to the ethical standards of the community of interest and practices that facilitate ethical research for that community.
Regional Objectives	The researcher will gain insight into the cultural context of their community of interest within broader New Zealand society and internationally.	The researcher will develop knowledge of the range of allied regional, national and international networks relevant to their local community of interest, and the range of issues that might impact on the community including social, political, and environmental factors.	The researcher will explore diverse notions of ethics that exist in New Zealand society, and how this is impacts on approaches to, and outcomes from research.

To explain the framework in the context of this study, the objectives called *personal objectives* are geared toward insight I have into myself. It is dependent on having been through a process of reflection into my own culture, to be able to recognise differences in the culture of those people I am researching (Ramsden, 2002). The principle of turangawaewae demands that I have insight into my own identity and what defines my identity, before I can recognise how identity is informed for others. Whanaungatanga as another principle of cultural competence expects that I have insight and knowledge into my ancestry, heritage and upbringing, which inform my wider relationships, and thus have an important bearing on relationships I develop in a research context. Mauri on the other hand, requires I have insight into the meaning of ethics from a personal viewpoint, so as to be better positioned to recognise differences in ethical perspectives I come across during my work.

By definition, cultural competence applies to all researchers working with any group of participants. It assumes that the researcher is committed to preventing harm to participants by way of power imbalances inherent in the research process. It requires the acquisition of foundational generic skills relevant across all cultural groups, including knowledge of the health sector, health funding, policies and laws, and communication. Currently, generic learning occurs within the context of western methodologies and methods. Cultural competence is the additional learning that is needed over and above generic learning to prepare a researcher to work in specific communities, because universal principles need relative application. For example in working with Māori research participants, Ratima (2001) identified the need to conduct interviews in Māori community domains and she utilised Māori methods of communication to feed back information to her research participants. On the surface, conducting an interview in a particular place might seem relatively simple to plan. However, Māori research may take place on a marae, and it is the expectation of Māori communities that protocols specific to their marae will be observed by all those who visit. One issue about the marae setting is the fact that a tangihanga (mourning) generally has precedence over any other event, including precedence over planned interviews. This is a consideration specific to Māori communities, but the rules may differ between marae, hence the need for researchers to understand and be able to navigate such constructs relative to each community, that have pragmatic, philosophical and political implications for research.

An example where competence can be tested is a researcher's ability to converse with Māori participants in their native language. There is a strong correlation between speaking proficiency and understanding, reading and writing Māori (Kalafatelis, Fink-Jensen, & Johnson, 2007). How then does a researcher who lacks proficiency in Māori language, effectively capture the full extent of meaning, ideas and philosophy expressed? The answer lies in the way a researcher manages this situation competently to prevent a negative outcome. An example of an adverse outcome is when the nature of what is said by participants is lost or unrecognisable to them, in the process of translation and analysis.

The degree to which a researcher is culturally competent is partly a matter of self-assessment and partly a matter of credibility. By implication, cultural competence recognises that the collective research community and particularly the Māori community, has a role in determining the quality of research by the committed endeavours of the researcher. This means the community is likely to make a judgement about a researcher's ethical and professional integrity, and this will have a bearing on the quality of research outputs.

Rigour

Cultural competence is a process that the researcher is engaged in to ensure consistency between the methodology and the methods, and rigour is the measure of consistency between the methodology and the methods.

Rigour in a western sense is the extent to which research can be said to be truthful (Denzin & Lincoln, 2000). In other words: Can the research findings be trusted sufficiently enough, to warrant a change to, or the development of, new legislation, policy or practice? Alternatively, O'Leary (2004) refers to credibility of research that has the power to elicit belief while Meyrick (2006) promotes a framework for measuring quality in research, underpinned by two principles common in qualitative research, transparency or disclosure, and systematicity or logic.

Denzin and Lincoln (2000) argue that there are two forms of rigour. One is to do with the methods of research or technical rigour, which they argue, has positivist origins. The other kind of rigour, analytical, concerns the philosophical framework used to examine data. In this thesis the worldview or philosophical framework used (Rolfe, 2006)

derives from a Māori intellectual system. Denzin and Lincoln (2000) suggest the need for:

> community consent and a form of rigour - defensible reasoning, plausible alongside some other reality that is known to author and reader in ascribing salience to one interpretation over another and for framing and bounding an interpretive study itself. (Denzin & Lincoln, 2000, p. 178)

Technical rigour follows a standard methods approach, a logical pattern of data collection using an assembled set of criteria whereby research findings can be replicated and therefore predicted. The controlled approach is a cornerstone of scientific research whereby consistent methods give a guarantee of consistent results and therefore, can be said to be trusted on the basis of being repeatable (Denzin & Lincoln, 2000).

In contrast to the empirical approach to technical rigour, Sandelowski (1986) suggests 'a research instrument is valid when there is confidence that it measures what it was intended to measure' (p. 29). Her (1986) seminal work on methods identified two key ways to achieve rigour – auditability; credibility and fittingness.

Auditability literally refers to *audit ability* that involves leaving a clear decision trail in the research report, so that a reader can follow a logical progression of steps in the study from beginning to end (Sandelowski, 1986).

Credibility and fittingness aim to ensure truth value in research findings through a number of strategies such as triangulation, a process of cross checking across data sources; data collection procedures to determine congruency of the findings; checking that data contain typical and atypical elements of the findings; and obtaining validation from the respondents themselves (Sandelowski, 1986).

This thesis proposes two broad audit objectives. One involves a tracking system of the methods of research as described by Sandelowski (1986). The other involves tracking the philosophical ideas that arise from research. Tobin and Begley (2004) emphasise the difficulty of discussing technical methods and philosophical issues in the same context, because the former is highly practical and the latter, theoretical, and both require different attention.

Tobin and Begley (2004) also emphasise the suitability of goodness as a measure of analytical rigor. In their view, 'researchers can move away from the language of

positivist concerns with validity and reliability and embrace a more illuminative approach when offering evidence of goodness' (Tobin & Begley, 2004, p. 391). Their theory of goodness draws on six elements of interpretive research described by Arminio and Hultgren (2002) that facilitate the notion of goodness. The six traits include: the philosophical stance gives context to and informs the research; the methodological approach explains the logic and criteria for the study; the method of data collection makes it explicit how data should be gathered and managed; there should be representation of voice including the researcher's reflection on their relationship with participants; new knowledge should be derived from the study, and this should be presented in the form of implications for practice (Arminio & Hultgren, 2002).

Tobin and Begley (2004) promote the use of triangulation as a well used strategy for rigour, and they make mention of the less known idea of crystallization promoted by Richardson (2000). That is, the image of a crystal with its infinite variety of shapes, angles, colours and patterns is likened to a multiplicity of ways to think about and perceive data (Richardson, 2000).

Rigour is also an objective of Case Study research, discussed in the next chapter, and one of the prominent theorists of Case Study, Yin (2003b), describes quality of analysis in case study or rigour, that is achieved by four principles. Firstly, analysis should show that the research has attended to all available evidence and interpretations should account for as much evidence as is available that leaves no loose ends. Otherwise, analysis is left vulnerable by alternative interpretations based on evidence that was ignored. Secondly, analysis should address all major rival interpretations thereby avoiding vulnerability of the study by the possibility for alternative explanation of the findings. Thirdly, analysis should address the most significant aspect of the case study which relates back to the purpose of the research embedded in the research question. The fourth principle is that the researcher needs to demonstrate expert knowledge and awareness of current thinking and discourse about the research topic. This will be based on previously read literature, new information that emerges, as well as new knowledge gained from the findings of the research (Yin, 2003b).

The kinds of strategies that are used in the research process will impact on the outcomes or findings of research. Sandelowski (1986) for example, points out that qualitative inquiry includes a wide range of methods such as in phenomenology and historical

inquiry. Each has its own set of rules and conventions. Though there are commonalities in the various methods, she says there is sufficient difference to make a single set of criteria of rigour insufficient (Sandelowski, 1986). She also notes a lack of clear boundaries between qualitative and quantitative paradigms, using the example of feminist inquiry which may be either quantitative or qualitative, as can Case Study. The boundaries are blurred even more, when researchers apply the criteria of one research tradition (e.g. qualitative) across another (quantitative), to show the mutually compatible aspects of both.

Western theories of rigour denote logical, accurate, defensible and reasoned research that shows congruency between its philosophical framework and its methods. Congruency between the methodology and the methods of research is the same objective of a Māori approach.

This thesis proposes that rigour as a Māori philosophical construct in health research is akin to the conduct of ethical research. Ethics aims to protect participants of research from unethical practice. Rigour on the other hand, is geared toward protecting the participants by way of unwise decisions made by a researcher that could lead to work of dubious quality, open to adverse scrutiny.

Māori values that are important in ethical conduct are the same values important in the quest for rigour, and there is no reason to believe that a different set of standards applies in either case. Thus rigour derives from a culmination of adopting philosophical principles of Māori research inquiry and consistently applying the principles throughout the entire research process.

Summary

A commonality of western and Māori approaches to health is that both aspire to the same goal. That is, for all people to reach their potential physically, socially, emotionally and psychologically, and with their moral positions intact. Health research should improve health, but to do so, it is important that researchers understand the philosophical underpinnings of various approaches to health, so that health research does not reinterpret the health needs of one society by applying the philosophical system of another.

This chapter has explored the basic assumptions of western and Māori research traditions. Central to this thesis, is a philosophically Māori oriented analytical lens and because of the theoretical approach, there is a set of implications for the research that is mediated by a model of cultural competence in order to strive for rigorous research.

The next chapter traces the application of the conceptual principles through the stages of the research process.

CHAPTER FOUR: METHODS

Te Aka[19]

Introduction

This chapter outlines the process or methods used in this research to explore whānau decision processes. The chapter is divided into three sections: Whakaeke; Paepae Tapu; Whakawātea. Each section is intended to represent three phases of the customary pōwhiri or welcome, in the sequence in which they occur. The aim is to draw on a methodical tradition with its inherent value system, as a model for research practice, to describe the steps taken for this study.

The chapter begins by discussing the Whakaeke (Ascent). It revisits the overall values-based approach to this study to emphasise how the research process arises from, and is guided by its epistemological origins. As such, Māori research inquiry defines the terms of reference for the steps of the research and it serves as a guide for the preparatory phase.

The next section discusses the Paepae Tapu (Dais) and in particular, the implementation of research strategies such as the collection of data and the development of the interview schedule. This section reinforces how kawa intrinsic to Maori inquiry acts as a mechanism to manage the application of western research tools, a reality of contemporary Māori health research. The chapter describes the integration of Case Study design and the use of data management software, NVivo (QSR International, 2007), into the Māori methods framework for this research.

The third section looks at the Whakawātea (Gateway). It discusses the obligations of research to research participants, including feedback mechanisms to enhance accountability back to communities who are the primary sources of data for this thesis.

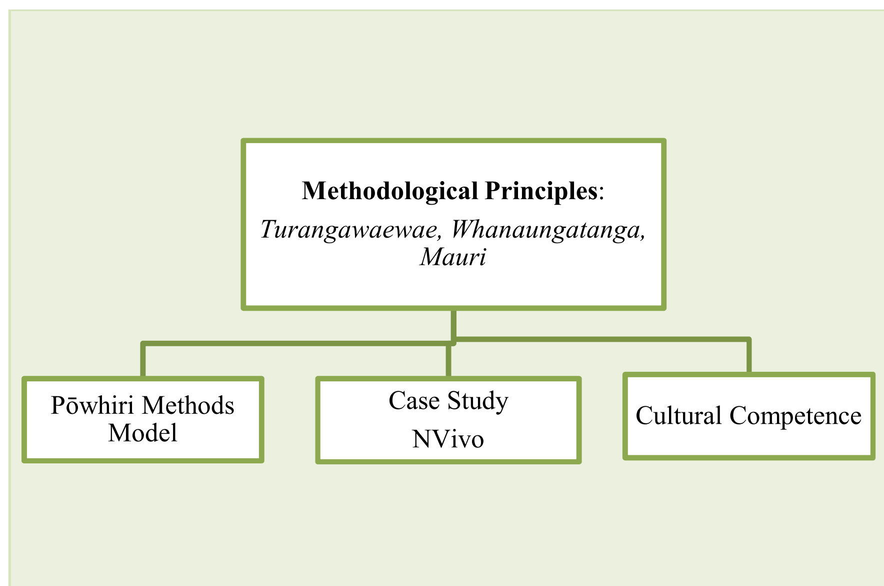
SECTION ONE: WHAKAEKE

Figure 4 maps out the overall approach that guides the phases of the research process relevant to this study. The overarching methodological values discussed in the previous

[19] Te Aka – the root, represents the way a life form takes hold to ensure its survival. The words are used in this chapter to symbolise the application of research theory using Maori philosophy, to research practice.

chapter permeate the framework. The pōwhiri as a model for the process of research[20] (shown to the lower left side of Fig 4) is the mechanism by which the values are embedded into the process. Cultural competence (to the lower right side of Fig 4) presumes the researcher is engaged in a process of self reflection and learning, and the overall goal is the attainment of rigorous research.

Figure 4: Methodological and Methods approach for this research



The nature of Whakaeke

The whakaeke comprises a range of activities that are methodically played out as the first phase of a pōwhiri. Though a pōwhiri is often formal and sometimes elaborate, in actual fact, the process provides sign posts for the way people should conduct themselves with each other on a daily basis. Typically, visitors group themselves together at a gateway or other point designated for them, where they can visualise the host and they simply wait. By way of a karanga (call), a woman from the host side signals to the visitors to advance toward them onto the marae ātea (forecourt). A woman from the visiting group responds to the karanga in a similar manner, and women from both sides engage in an emotional exchange of salutations and acknowledgements.

[20] The pōwhiri model is informed by a talk given by Professor Mason Durie to the Te Rau Puawai mentor programme at Massey University, Palmerston North, 2008, when he described the application of kawa to the care of whānau.

The karanga can be a spine tingling spectacle to behold, that commands the attention of all present, symbolic of generations of ancestors who have conducted the very same practice. There is no restriction on the number of kaikaranga (callers) or the length of time that the exchange takes place. Generally though, they will acknowledge the kaupapa (reason for the groups meeting), their dead ancestors and the groups' connections.

The onus of power in a pōwhiri sits with the host group, because the pōwhiri assumes the kawa of the host side. It is common for the host to accommodate their visitors to be able to meet the demands of their protocol and attention to detail ensures that visitors are not demeaned, by not being able to meet those demands.

Preparation leading up to the whakaeke requires negotiation and planning and the terms of reference are defined by kawa.

Applying Whakaeke to Research Methods

The research process requires the same forethought, planning and negotiation as the whakaeke. Attention to detail ensures there is a smooth progression of the research process because each aspect of the process interrelates and has implications for the next.

The first part of the whakaeke or *tūnga ki te tomokanga* makes reference to the period of a pōwhiri when the visiting group waits to advance toward their host. In research, this is a period of time when research is literally 'in-waiting' while a number of preparatory matters are attended to, and for this study such matters included the development of a project proposal; an ethics application to scrutinise the research project; a literature review to canvas current knowledge of decision making; identification of potential whānau participants for the study; consideration of my own credibility in the chosen area of research as well as my preparedness to carry out the work; identification of research supervisors, and funding to support the work involved.

Cultural Competence

In light of the cultural competence framework described earlier in the thesis, I employed a number of strategies to develop my preparedness to work with whānau participants.

It was important to have counsel with my own whānau. Two reasons for doing so were to get their guidance about contact with other whānau, and to seek permission to use the

intellectual property of my iwi described in this thesis, because iwi knowledge is not the sole property of one person.

I also attended a range of seminars and conferences to identify the Māori health research community locally and nationally. As a health professional who was educated and worked in a discipline dominated by non-Māori colleagues, I had had very little exposure to the Māori health research environment. It was important that I understood who the Māori research community was and what kind of research had been, and was being done.

I actively searched for the range of research conducted around indigenous people, decision making and genetics both in New Zealand and internationally, in order to position this study within the wider research environment. I also gave a presentation of my proposed research to supervisors and peers within my own university, all of whom are Māori health researchers.

Supervisors for this thesis are Māori. They have a mix of academic, professional and cultural expertise in Māori philosophy, health service, health research, science, law, ethics and indigenous politics. The supervisors have whakapapa to different iwi and it was important that they are familiar with the area being researched, of academic processes, and diverse realities of Māori society. The benefit of Māori supervisors is that they have a range of experiences of being Māori, which informed my decision making for the conduct of this research.

In keeping with the tradition of a pōwhiri, participants of the research were considered to be the host for the study, and as such, the kawa of each whānau prevailed. I approached each whānau with confidence that they would accommodate the needs of the research and as there were three whānau involved, it was deliberately anticipated that three approaches to the methods may be necessary. In reality, engagement with whānau was relatively simple to arrange and although there was some variation in the time and setting for interviews, subtle differences did not present major obstacles.

Funding and Ethics

The study was funded by the Health Research Council of New Zealand, the major Crown funding agent for health research. As a Crown funded research project, the application of the Treaty to the philosophy and practice of this research was considered

paramount because participants of this research are descendants of Māori signatories to the Treaty.

The project was also reviewed by Massey University Human Ethics Committee (HEC: PN Application – 05/99). Every attempt was made to uphold the University's *Code of Ethical Conduct for Research* (Massey University: Te Kunenga Ki Purehuroa, 2006). The participants' rights under The Code of Health and Disability Services Consumers Rights (Health & Disability Commissioner, 1996), are also acknowledged.

SECTION TWO: PAEPAE TAPU

The Nature of Paepae Tapu

Once the visiting group has ascended onto the venue of their host, they are directed to a designated place to wait. Kaikōrero (orators) for each party take their place on the paepae tapu or paepae (dais) and this phase of the pōwhiri involves a combination of tasks including: whaikōrero (oration) usually delegated to males, and waiata (composition) by the group, to reinforce what has been said by their speakers. Engagement on the paepae is an opportunity for both parties to learn about each other, define their relationships, and importantly, to debate, deliberate, question and analyse the kaupapa (reason) of the day. Like the karanga, there is no restriction on the number of kaikōrero, the length of time they speak, or the number of topics they may canvas. Kaikōrero have an important role to command and captivate the audience in sending the message their party wishes to promote and sometimes it is possible to hear them receiving subtle prompts from their female counterparts lest they forget to cover an important point.

This phase of the pōwhiri can be filled with a range of emotions: excitement, tension, frustration, pain, humour and politics.

Applying Paepae Tapu to Research Practice

The paepae tapu is a phase likened to the sharp business end of the study. During this phase, the research may be characterized by episodes of time when there is alot of contact with participants. There are other periods of time, when there is little or no contact, and it is during non-contact periods, that participants should sit as an image in the mind of the researcher, as a reminder of their ethical obligations to them.

Critical decisions occur during the paepae tapu phases that have a bearing on relationships with participants as well as the tools selected to obtain information. For example, demographic data was obtained just prior to each interview, using a questionnaire adapted from a tool used for Te Hoe Nuku Roa[21] (a longitudinal Study of Māori Households). A key difference between the questionnaire used and conventional demographic surveys is the inclusion of questions concerning Māori identity markers. Participants were asked to describe their participation in iwi (tribal), whenua (land), reo (language) or marae (traditional settlement) activities. The reason for collecting demographic information and particularly questions about participation in Māori specific activities was to describe the diversity of participants as Māori, fundamental to acknowledging difference in Māori discourses within a whānau.

Sample Criteria

The primary criterion for the sample group was a whānau. The context for inclusion required that whānau had a history of active engagement in genetic research, to investigate their genetic predisposition to a medical condition. The selection and number of participants from each whānau, and the location of interviews, were decisions left with each group.

The reason for the criterion was four-fold:

Firstly, due to the perceived and potential genealogical consequences of genetic research, it is of interest to a wide social network, thus creating decision implications of which individual and collective decision making might somehow be linked.

Secondly, this study sought views of whānau who have firsthand experience of human genetic research. The ethics of genetic research was a topical issue of public debate at the time this study began in 2005. The voice of actual participants of genetic research was absent in all New Zealand studies trying to understand public opinion about genetic biotechnologies at the time.

The third reason for the criterion was because whānau who have been through a process of engagement with geneticists, medical practitioners and the health system, in the context of genetic research, are well placed to reflect on their decision experience.

[21] Te Hoe Nuku Roa, Māori Studies, Te Pūtahi-ā-Toi, Massey University: THNR2003/1/LP

Finally, the researcher assumed whānau had to navigate complex and unfamiliar information; they had to consider the advantages and disadvantages of genetic research against the impact of a medical condition affecting them; and they had to weigh up their individual and collective rights and responsibilities, and consider all these factors according to their preferences, needs and values (Hibbard & Peters, 2003). The combination of issues thus satisfied the broad Western notion of ethical decision making.

Rationale for selecting three whānau.

Three whānau were selected for reasons of purposeful and convenience sampling. They met the criteria for participation in this study and for practical reasons they were accessible to me.

Sample sizes in qualitative research are typically small, because emphasis is on the gaining insights into the *qualities* found from an understanding of verbal data. Analysis is intensive and the further selection of participants depends on the data that emerges (Sandelowski, 1986). The participants are selected because they can illuminate the phenomenon under study. Therefore, sample size is determined by the nature of the data being collected and where data takes the investigator (Sandelowski, 1986).

In contrast, quantitative research sampling is underpinned by statistics principles and conventions of sampling, like random selection and control groups that are observed, to ensure representativeness and generalisability.

I am a registered health practitioner who had knowledge of the genetic condition of one whānau due to information gained from my professional relationship. I also have whakapapa to another whānau in this study and therefore, personal knowledge of the genetic condition of that whānau. I became aware of the third whānau on a television documentary in 2005 (Carey, 2005). Conveniently, knowledge of each whānau in the early development of this research was a factor in their selection.

Purposeful sampling requires the selection of participants who are rich sources of information that will illuminate the research question, and therefore, the purpose of the study (Patton, 1990). The strength of purposeful sampling lies in selecting cases "from which one can learn a great deal about issues of central importance" to the research (Patton, 1990, p. 169), thus a targeted sample group was sought to facilitate the purpose of the study.

The process of engaging whānau in the study

Contact with whānau

I first made contact with the primary investigator for the genetic project relevant to each whānau. Early contact with them was intended to manage my conflict of interest concerning two whānau known to me, and it was an opportunity to signal the intentions of this study with fellow researchers, and to ascertain whether this research coincided with any work underway by them.

Primary investigators were informed by email about who I am and they were given an overview of my proposed research. They were asked to signal if my research coincided with any work being undertaken by them. I also requested citations of published scientific literature relevant to their research with the whānau, and I asked for the name of a contact person in each whānau. The investigators varied in their responses. Two investigators forwarded the names of whānau representatives to talk to in the first instance. Another investigator spoke with a member of the whānau first before responding to my email. All investigators confirmed that there was no conflict with other research. They were in a position to identify the most appropriate person to contact, and they were instrumental for this study, in obtaining conditional and initial consent.

Subsequent communication with whānau by me occurred by way of phone, post, email, text messaging and face-to-face contact. Initially, each contact person was sent an information letter to introduce myself and describe the study (Appendix 3). This was followed up with a further phone call followed by a face-to-face meeting.

Initial Hui

An initial hui was organised with each whānau collectively before any contact with individual participants occurred. The main purpose of the hui was to discuss the research, to introduce myself and to provide whānau with an opportunity to ask questions about the research. I facilitated all three hui that took place within a three-month period in 2006.

The first hui with several members of Whānau Rua took place in the private home of the contact person. The first hui with Whānau Toru involved only one person, at her home, and the first hui with Whānau Tahi involved two contact people at their marae, followed by a further hui with eight of their whānau including trustees for the marae.

The names and contact details of individual members were forwarded to me following the initial collective hui, and thus contact with individuals occurred thereafter. Ongoing communication with individual participants mostly took place on a one-to-one basis, except on occasions when they chose to be with other whānau members.

Koha

The practice of koha (gifting) was applied in this study. Each time I physically met with whānau as a group, or with an individual, a koha was presented to them as a token gesture of my appreciation, to show participants that their contribution to the research by way of their time, thought and energy, was valued. Koha varied from food items to grocery or petrol vouchers, or, in one instance, a sum of money to cover the cost of electricity, room hire and catering for a marae hui organised especially for the purpose of this research.

Case Study Design

The remainder of this section describes a range of tools that were used in this research. It is possible to apply western research tools to Māori research inquiry without compromising a Maori philosophical approach, as long as the principles of Māori inquiry and inherent kawa, guide the application of the tools.

Case Study is one tool used in this study, a common approach to qualitative or quantitative research that draws attention to what can be learned about a *case* or a bounded system. The more bounded, unique and specific a case is, the greater the rationale for doing case study research (Stake, 2000). Case Study considers that there is much to be learned from the case and is defined by interest in individual cases or a collection of cases.

Yin (2003b) describes Case Study as enabling researchers to retain the "holistic and meaningful characteristics of real-life events" (p. 2), and its strength lies in allowing researchers to validate theoretical concepts that are actually experienced (George & Bennett, 2005). Case study is therefore suitable for the investigation of contemporary phenomena within its natural context, especially when "the phenomenon under study is not readily distinguishable from its context" (Yin, 2003a, p. 4; Yin, 2003b).

Robert Yin and Robert Stake are two of the most prominent theorists of Case Study work who promote differing approaches. Yin is clearly positivist and major features of his theory are the formation of propositions or hypotheses, and replication logic to

prove such theoretical propositions. He makes an exception for excusing hypotheses where descriptive case study is the method of choice, because a description of the case and the phenomenon according to him, can adequately explain findings (Yin 2003a; 2003b; 2009).

Stake (2008) on the other hand, has a more liberal approach to case study and more general ideas. He refers to case study as a reflective exercise where "the case researcher digs into meanings, working to relate them to contexts and experience" (p. 128). According to him, qualitative case researchers will gather data on the nature of the case, particularly its activity and functioning; its historical background; its physical setting; other contexts, e.g. medical concern, research interest; other cases through which this case is recognised; and those informants through whom the case can be known. Stake (2008) also proposes that researchers will follow their preference for, or obligation to *intrinsic* or *instrumental* study. Intrinsic case study is undertaken to better understand the case because the case is itself of interest. Other phenomena or curiosities are subordinated "so that the stories of those living the case can be teased out" (Stake, 2008, p. 122). Instrumental study is examined mainly to provide insight into something else and the case is of secondary interest.

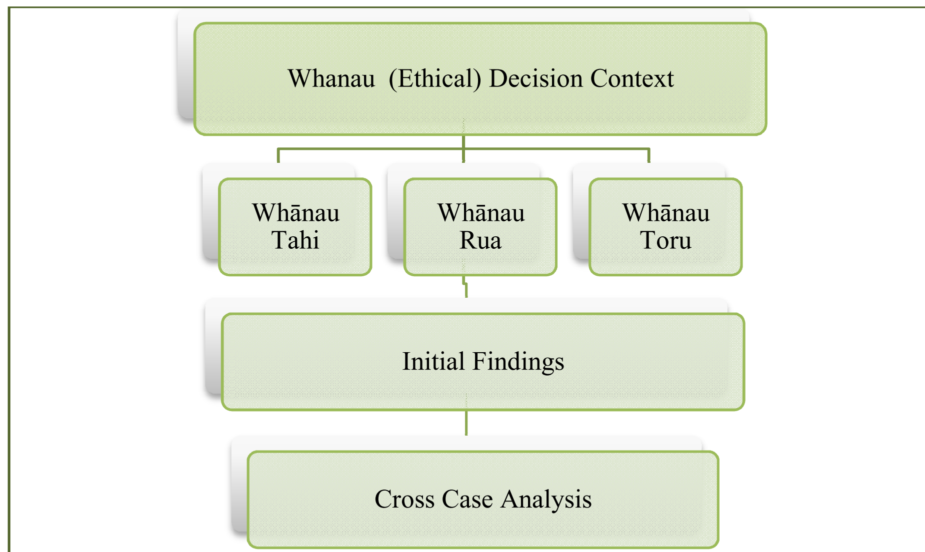
A commonality of both Yin and Stake is their use of Case Study in evaluative research. The use of different forms of evidence is typical of qualitative research overall and especially in Case Study. Stake (2000) suggests that a range of evidence adds rigor, breadth, complexity, richness and depth to an inquiry. In Case Study, the use of multiple sources of evidence is examined collectively in a triangulated fashion to clarify meaning (Yin, 2003b; Stake, 2008).

Case Study in this research

In this thesis three whānau represent three cases, which Stake (2008) describes as a *collective case study.* The phenomenon of interest is whānau decision processes and by an examination of the cases or whānau, greater insight is gained into their decision processes. Stake (2008) refers to the approach in this research as *intrinsic case study*, because an examination of the intrinsic nature of whānau is necessary to understand decision processes by them. The whānau is of primary interest and it cannot be separated from the phenomenon (Stake, 2008).

Intrinsic case study in this study was thus extended to a collection of cases, and the sources of evidence for triangulation in this study are whānau interviews, my participatory observation of the interviews with reference to research notes, as well as print and visual media. Figure 5 summarises the case study design for this research.

Figure 5: Whānau Case Design



The data of each whānau formed the basis of the initial findings, which were then examined as a cross-case analysis to highlight commonalities and differences between whānau. Subsequently, the analysis involved applying the conceptual principles described in the previous chapter, to identify collective characteristics unique to whānau decision processes.

The process of engagement in the research

Individual participants were contacted by phone initially. A follow-up information letter (Appendix 3) was sent to them and they were contacted again within two weeks of receiving the letter. They were asked if they understood the letter and if they had any queries about the research. All those contacted agreed to engage in the study by way of an interview and they were sent a subsequent letter (Appendix 4) with a copy of the consent form (Appendix 5) to read prior to the actual interview. Participants were informed that a transcriber would have access to their recorded interview for transcribing purposes (Appendix 4), and the transcriber would sign a confidentiality agreement (Appendix 9).

Mechanisms for participants to opt out of the study were deliberately put in place. For example, the letter requesting an interview, states: “You have the right to decline to ask any questions and you can withdraw from the research at any time” (Appendix 4).

Development of the Interview Tool

Māori and western research traditions both assume that the perspective of others is worth knowing and is able to be made explicit (Cram, 2001; Patton, 1990). Patton (1990) refers to a method of interviewing which “presumes that there is common information that should be obtained from each person interviewed” (p 280). Rather than a standard interview schedule written in advance, a general interview guide sets out questions or issues to be explored and it was anticipated that the wording and sequence of questions would be adapted to specific participants and the context of the actual interview.

An interview guide provides both a boundary of intent and freedom to explore questions that will illuminate the research topic. Limits are thus placed on the issues to be explored to make greatest use of the limited time available in an interview situation (Patton, 1990). The interview guide can be developed in more or less detail, depending on the extent to which the researcher wants to specify issues in advance (Patton, 1990).

The interview guide is similar to a semi-structured or moderately scheduled format, designed to establish a respondent’s familiarity with a topic or setting (Fontana & Frey, 2000). The semi-structured approach establishes some general topic areas to be covered, but provides flexibility to pursue leads that emerge during the interview process, when the interviewer ‘frequently has to formulate impromptu questions in order to follow up leads that emerge during the interview’ (ESDS Qualidata, 2007, p. 5).

The interview guide (Appendix 6) was developed with five main bands or topic areas of inquiry. A series of questions is laid out under each topic area to serve as a prompt or checklist. The words and sequence of questions were adapted according to specific respondents and leads that emerged. In most cases, prompts were not necessary because information was forthcoming during the actual interview.

Principles of *Strategic Questioning* were applied to the interview guide, an approach which posits that questions are as powerful as answers, and answers to questions are infinite. In other words, the answer a person has to a question “creates knowledge by

synthesizing new information from that which is already known" (Peavey, 2003, p. 3). As such, the interview situation facilitates the construction of knowledge for the interviewee as much as the interviewer.

Using Peavey's theory of Strategic Questioning, levels of questions have different objectives. For example, first level questions aim to describe an issue and such questions are not aimed to be strategic, but simply to gain facts and the point of view of the person being interviewed. There are *focus* questions (to identify key facts), *observation* questions (perception of what one sees or has heard), *analysis* questions (what a person thinks about a situation), and *feeling* questions (emotions).

Second level questions aim to probe the issue/s more deeply. *Visioning* questions are questions which identify the interviewee's ideals, dreams or values. *Change* questions are concerned with consolidating their ideals with what actually occurred. So for example, one question is: Is there anything you would do differently? Other types of questions aim to consider alternatives, consequences, obstacles, personal contributions and actions.

The interview bands relate to the principal question of this study and begin with encouraging participants to reflect on their knowledge and experience of genetic research concerning their whānau. Other questions ask about the nature of decision making in their whānau, the meaning of whānau, sources of information in their decision process and issues they balanced in their decision to participate in genetic research.

Band 1 was designed to ease the respondent into the interview and simply encourage them to talk by reflecting on their involvement in genetic research.

Bands 2 to 5 are designed specifically to address the question of this study. Each of the bands addresses a different topic area and interviewees had to think more deeply about their own context of decision making, their perspective about whānau decision making in the context of whānau research and how diverse views are managed in a whānau decision process. During this group of questions (bands 2 to 5), participants were challenged with thinking about how they feel about their involvement.

Within each band a range of question types drawn from Peavey's work, were used. Specific words like 'ethics' were purposely omitted from the interview schedule to prevent pre-empting answers to questions. That is, the interview aimed to capture their

engagement in an ethical decision process rather than their understanding of the concept of ethics.

Conduct of interviews

All interviews were conducted by me. Participants did not receive the interview guide in advance and interviews were mostly in English, although some participants spoke Māori at times and I responded accordingly.

Prior to the commencement of each interview, respondents were asked if they understood the nature of the research, whether they had read letters sent to them and if they had any questions. The opt-out option was reiterated to participants verbally prior to the start of their interview and they were asked to sign a consent form to agree to an interview (Appendix 5).

Part of the consent form asks if they wish to have a copy of their transcript to read prior to it being analysed for this study, and all participants requested their transcript.

Once they signed the consent form, they were then asked to complete general information questions (Appendix 5) to provide collective data about the demographics of participants.

Table 8 sets out a summary of the number of interviews conducted as well as the transcripts received across each whānau.

Table 8: Summary of interviews

	Whānau Tahi	**Whānau Rua**	**Whānau Toru**	**Total**
Number of interviews conducted.	7	6	4	17
No of people who were interviewed	10	6	5	21
Number of interview transcripts sent to participants to read.	10	6	5	17
Number of consents to use transcripts	6	6	3	15

In total 17 interviews were conducted involving 21 people. The grey shaded cell shows that 15 consents to use transcripts were received which form the basis of the analysis and findings for this study. Two respondents who did not give their consent to use their

transcript initially indicated a wish to do so. However one of those people worked long hours and despite requests from her whānau, her written consent to use her transcript was not received. The other person was alarmed by some of the content in her transcript because of certain issues she had described, and therefore she was unsure about granting permission to use her transcript. Although she indicated being undecided, I made only two requests for their consent form, and did not pursue consent thereafter.

One interview in Whānau Tahi involved five members of a whānau, one of whom was a child who did not participate in the interview. Three of four adults had participated in genetic research, but all four adults were asked to sign a consent form to facilitate ethical protocols such as recording the interview.

Several interviews had children or other adults in close vicinity, but they did not participate in the actual interviews, and no attempt was made to exclude whānau members present from participating, as I considered it inappropriate because I was a guest in their home.

All interviews took place in August and September 2006, and most were in a private home, at a time suitable to participants. Three interviews took place on a marae. Winter was not a preferred time of the year to conduct interviews for most participants because of their sporting commitments. School holidays including Christmas and the New Year period, were mostly not conducive to an interview environment because many participants had whānau activities arranged like a reunion, birthday or other extended whānau gathering. Employed participants were interviewed outside of work hours and parents of school children were mostly interviewed while their children were at school. One participant, a teacher, was interviewed between school terms.

Recorded interviews ranged from 16 – 64 minutes in length and the average time for all interviews was 32 minutes. The actual time spent with participants at each location was about one and a half hours. Recordings of all interviews are stored on a digital audio file.

Method for using interview transcripts

A transcript refers to a documented record of the actual interview that recounts what was said by the participant/s and interviewer. All participants were sent a verbatim copy of their own transcript. They were contacted by phone to expect their transcript in the post, and they were phoned again approximately two weeks later to ensure their

transcript was received. A covering letter (Appendix 8) explained that they could change or delete any parts of their interview they did not want used. Included with their transcript was a form giving their *Authority for the Release of Tape Transcript* (Appendix 7) and a return self-addressed prepaid envelope.

Seven participants made minor changes, deletions or corrections to their transcript. For example, participants generally corrected grammatical or spelling errors including names of people. A few participants' deleted specific paragraphs which contained material that they did not wish to see in writing. One respondent gave permission to use only parts of her transcript. All of the changes did not significantly alter the usefulness of their transcripts for the purpose of the thesis.

The original unedited transcripts, consent and authorization forms, general profile information and edited transcripts have been locked in a metal filing cabinet.

Process of Analysis

There were four phases to the analysis: listening, reading, interpreting and validation.

Listening

The listening phase is relevant the interview and while reading interview transcripts. For case study work "listening means receiving information through multiple modalities… not just using aural modality" (Yin, 2003b, p. 60). Therefore, body language and voice intonation of participants helps with the assimilation of what is being said. Contextualising the words is especially important because some participants found parts of their interview difficult. For example, a reflection by two participants made them tearful and the interviews were stopped momentarily.

Yin suggests that a good listener reading a transcript "hears the exact words used by the interviewee, captures the mood and affective components, and understands the context from which the interviewee is perceiving the world" (Yin, 2003b, p. 60). During the listening phase, some common ideas and themes were repeated by participants.

Reading

Transcripts were read twice initially. The first reading provided a general sense about what the participants had to say, which confirmed or not, general themes that emerged during the interviews. During the second reading NVivo qualitative research software was used to manage data.

As qualitative research seeks to understand the *quality* of data through the analysis of unstructured information such as interview transcripts. NVivo aids the management of such information because it has purpose built tools for classifying, sorting and arranging information. The software does not do the thinking or analysis, but the functions of NVivo enable a researcher to create categories and navigate between the raw data, and to, and across analysis material easily to identify themes, glean insights and develop conclusions (QSR international, 2007).

All transcripts were electronically uploaded into NVivo files from Microsoft word documents. Categories (called nodes) were formed to represent specific themes using NVivo functions. Categories or themes were cross-referenced to transcripts allowing visual tracking of the development of categories.

Nodes of information were created according to the bands of the interview guide. For example, Band 1 of the interview guide contextualises participants' reflections on their engagement in genetic research, and it was created as a tree node. Further subheadings or free nodes were subsequently created to facilitating grouping of participants' responses to Band 1, such as, their involvement in research, their knowledge of the research involving their whānau, their knowledge of the condition affecting their whānau, and their understanding of why the research was done. Quotes extracted from transcripts were entered into each relevant free node and each quote or reference was numbered by an automated system built into NVivo. Most participants had more than one reference in a free node.

A third and fourth reading of the transcripts took place a year later. This mainly occurred as a result of advice from a research advisor, and on reflection the time lapse was useful for thinking about the purpose of the overall study and the benefit it should have for the research participants. From the initial readings, themes emerged across all interview bands or tree nodes and thereafter the interpretation or analysis of the data commenced.

Interpretation

The previous chapter described conceptual principles of Māori inquiry for this research – turangawaewae, mauri and whanaungatanga. The principles were applied to the data on the basis of the meaning of the principles. The analysis was also supplemented with

general commentary notes entered in my research diary. The initial group of findings set up as tree nodes and free nodes, was reorganised into seven free nodes, under the headings - whānau, manaaki, hui, leadership, individual experience, kotahitanga, decision making. While the separate nodes grouped subject matter, the nodes did not represent the full meaning embedded in participants' responses. For example, a Māori notion of leadership only partly captured data expressed by respondents. Data was reorganised from seven nodes to four free nodes to satisfy the extent of the data according the conceptual framework of analysis.

Much of the original coding was retained to facilitate easier location of specific references. In some instances, a reference by a participant was applied to different nodes because their comment has relevance across different ideas, but in most cases, this has been avoided.

Data validation

To ensure participants agreed with the analysis of the data they were consulted about the findings, based on four final nodes or categories. Separate meetings took place with either individuals or the contact person nominated to speak on their behalf. The findings were described verbally and in writing, and respondents were encouraged to give feedback about whether the interpretation of the data represented what they said. All participants expressed approval of the analysis.

Other validation sources

A comprehensive literature search was conducted to inform this research. The range of sources included scientific papers, academic literature, decision theory, ethics philosophy, ethical frameworks in the New Zealand research context, Māori health research, books or papers on Māori philosophy, newspaper reports, visual media and early communication with geneticists associated with the whānau of this study.

Confidentiality

It was difficult to offer anonymity to the whānau in this thesis. The primary reason being that the Māori population is small and knowledge of research involving them is well known nationally and internationally, especially in the field of health research. I initiated a measure, with their permission, to refer to each whanau in this thesis as

whānau Tahi, Rua and Toru. Although pseudonyms for individuals have been used, all whānau remain reasonably identifiable.

This study also followed institutional ethical processes and every step has been taken according to conventional protocols to protect individuals. However, the same processes do not assume that social groups like a whānau need protection, thus collective identity is not able to assured in the same way as for individuals.

SECTION THREE: WHAKAWĀTEA

The nature of Whakawātea

Whakawātea gives closure to a pōwhiri and is characterised by the parties coming together as one entity to engage in hāruru[22] and hongi[23]. At this time the intensity of the previous phase is replaced by a sense of achievement, satisfaction and relief.

Whakawātea literally means to make space, an opening, entrance or opportunity. Conceptually the whakawātea constitutes a new beginning, new relationships and renewed prosperity, bringing with it a potential set of new obligations or responsibilities, and an important time of reflection as future relationships are contemplated.

Applying the notion of Whakawātea to Research

Whakawātea in a research sense is a period of reflection. It is an important time to assess the nature of the findings and how the findings improve our understanding of the phenomenon in question. More importantly, how the findings contribute to the lives of the participants (as the primary source of the findings).

New knowledge arising from research is as much a contribution from participants, as it is from a researcher. Therefore, I felt strongly that this thesis should not only represent their ideas, but it should be accessible to them. Although I acknowledge that a thesis is an academic piece of work, there must be accountability back to the participants. Accordingly, I have attempted to be transparent in bridging the gap between academic research theory and research practice through this thesis, by ensuring it can be read and understood by the whānau, and they have access to a copy of the completed thesis.

[22] Hāruru refers to a hand shake.

[23] Hongi requires two people to gently rest their foreheads together and press their noses as to exchange breaths.

Figure 6 summarises the three phases of the research process described in this chapter.

Figure 6: Pōwhiri Model for Research Methods

Pōwhiri: A Model for Research Methods		
Phase	**Objective**	**Methods**
Whakaeke	Preparation for embarking on research	Supervision, networking, literature search, research proposal, ethics application. First contact
Paepae Tapu	Implementation of Research	Case Study, interviews, analysis - NVIVO
Whakawātea	Reflecting on the research outcome	Write up, reflection and ongoing responsibilities

Summary

The chapter has illustrated a metaphor between the process of a pōwhiri and the practice of research because both are methodical constructs. The aim of developing the framework was to emphasise the way methods arise from their epistemological origins. Values inherent to a Māori inquiry tradition mediate the interface with western research tools, so it is possible to utilise the tools of one tradition while staying true to the values of another.

An important point reinforced in this chapter, as with the previous chapter, is that the objectives of western and Māori research traditions are the same, but the terms of reference that guides how those objectives will be reached differ considerably.

The next chapter describes the findings of the interviews conducted according to the sequence of the interview guide. In all instances where individual people or organisations are named within the body of a quote, the names have been replaced with a pseudonym to protect their identity.

The following conventions have been used in the presentation of the findings.

…	Material edited out – part of a sentence
Italics	Participant's speech
*(*1/AM, IiR: Ref 2)	(Case/Participant, Node (or theme): Ref Number)
[ ]	Editorial comments for clarity

CHAPTER FIVE: INITIAL FINDINGS

Te Ao Hunga[24]

Introduction

This chapter discusses the initial findings of participant interviews of members of three whānau. It begins by describing the medical circumstances of each whānau to give the background to their ethical decision context relevant to this thesis. It then provides information about interviews that were conducted, followed by demographic data about the respondents collectively.

The chapter proceeds to describe the findings of the interviews by reference to the interview guide that comprises five main areas of interest. These are: Context of Decision Making; Whānau Decision Features; The Meaning of Whānau; What Informs Decision Making; and Balancing the Issues. Under each of the interest areas, quotes are used to highlight ideas that emerged and these are grouped by whānau.

The chapter concludes with a table summarising the initial findings.

Ngā Āhuatanga o te Whānau (Description of the Cases)

Three whānau were involved in this study and they are referred to as Tahi, Rua and Toru.

Whānau Tahi (Case One)

Since the 1960s more than 25 members of Whānau Tahi have died with gastric (stomach) cancer and most before they reached the age of 40 years. Local doctors and members of Whānau Tahi were concerned by the rate of gastric cancer and resulting deaths in the whānau, and to try and understand why, Whānau Tahi initiated a project with geneticists. Research began with a pilot study of 105 whānau members in 1995, to identify a gene linked to susceptibility to gastric cancer.

In 1997 a gene mutation predisposing to gastric cancer was identified from the pilot study and wider whānau genetic screening began. Whānau members who were interviewed for this thesis were involved in the pilot study and/or wider familial genetic screening, and/or treatment for gastric cancer.

[24] Te Ao Hunga – the capacity for life is used metaphorically to depict new knowledge arising from this research that begins to emerge from this chapter.

Identification of the gene mutation has enabled early intervention strategies within the whānau to be targeted at those most at risk of developing gastric cancer. Today genetic screening is commonplace for members of Whānau Tahi, from age 14, but the whānau is engaged in ongoing research. For example, Whānau Tahi has shared their knowledge and experience with other whānau who are contemplating genetic research for similar reasons (Kimihauora Health Centre, 2004; Guilford, Hopkins, Harraway, McLeod, McLeod, Harawira, Taite, Scoular, Miller, Reeve, 1998; Shaw, Blair, Framp, Harawira, McLeod, Guilford, Charlton, Martin, 2005).

Whānau Rua (Case Two)

In 1968 a male member of Whānau Rua died during routine surgery to remove his appendix, the first evidence of Malignant Hyperthermia (MH) or Malignant Hyperthermia Syndrome (MHS) in New Zealand. Ten years after the first reported incident of MH, a 20 year-old nephew of the first MH victim also died during surgery for a fractured jaw sustained during a rugby match.

MH is an inherited disorder of skeletal muscle affecting both males and females that is known to arise after exposure of susceptible individuals to triggering drugs. The anaesthetic drugs that have been definitely implicated are a muscle relaxant called suxamethonium (succinylcholine) and all of the anaesthetic gases in current use (halothane, enflurane, isoflurane sevoflurane and desflurane except nitrous oxide). At present it is possible to identify susceptible people only by a reaction, by a family history, by a muscle biopsy, or DNA testing (MidCentral District Health, 2007).

The incidence of susceptible MH patients presenting for anaesthesia in the region where many members of Whānau Rua live, is relatively high compared to other parts of the country, mainly because of this large susceptible whānau. As a result of the high incidence, testing for MH susceptibility in New Zealand commenced in 1978, by scientists in the region, and the research was later taken over by anaesthetists in the same area. A large collaborative research project began in 1994 and the ultimate aim of the project was to develop DNA-based tests that would identify susceptibility to Malignant Hyperthermia (MH). The research approach included clinical diagnosis as well as molecular genetic analysis of DNA prepared from individuals of families known to be susceptible to MH. The major thrust of the project was focused on Whānau Tahi and the research confirmed that affected members of the whānau carry a specific gene

mutation that does not occur in the general population (MidCentral District Health Board, 2007). Some of those whānau members who were part of the research project were interviewed for this thesis.

Whānau Toru (Case Three)

Nine male babies died in Whānau Toru between 1988 and 2005. One of the babies died at 9 days old and the others died at between 2 – 4 hours of age. They were all born prematurely in hospital with congenital abnormalities incompatible with life. Whānau Toru came to the attention of a paediatrician in 1988 because three sisters each had a baby that died in that same year. In order to investigate reasons for their babies' abnormalities, the whānau agreed to participate in genetic research. A study was approved to obtain venous blood samples from all available members of the whānau, as well as fixed tissue from autopsy specimens of at least two deceased babies, for DNA analysis (Robertson, Gunn, Allen, Chapman, & Becroft, 1997; Robertson, Walsh, Oldridge, Gunn, Becroft, & Wilkie, 2001).

Otopalatodigital Syndrome Type II (OPD2) is a severe and lethal dominant X-linked chromosome condition expressed in female carriers and characterised in affected males by skeletal, auditory and palatal defects, linked to genetic mutations found in Whānau Toru. Essentially members of Whānau Toru are more susceptible to OPD2 than any other group, and one of the major issues for the whānau concerns their having to make significant decisions about pregnancy and childbirth (Robertson, Gunn, Allen, Chapman, & Becroft, 1997; Robertson, Walsh, Oldridge, Gunn, Becroft, & Wilkie, 2001).

Demographic Information

Whānau participants

Of 17 consenting participants, seven are from Whānau Tahi, six from Whānau Rua, and four from Whānau Toru.

Place of residence

All participants of Whānau Tahi and Rua reside around their papa kainga (traditional settlement). That is, they live on the whenua (land) of their ancestors. Participants of Whānau Tahi live in and around a city, and participants of Whānau Rua live in a small semi-rural town.

Of the four participants of Whānau Toru, two reside in a major New Zealand city in proximity to their papa kainga, and two reside in a provincial city away from their papa kainga.

Age and gender of participants

Three participants (17.6%) were aged between 18-25 years, five participants (29%) were aged between 25-34 years; three (17.6%) were aged between 35-44 years; two (11.8%) were aged between 45 -54 years; two participants (11.8%) were aged between 55- 64 years; and two participants (11.8%) were 65 years or over.

Of all participants, 14 are female and there are three males. Female participants were represented in all age groupings. The male participants are distributed in most age groupings, but not in the 35-44 or 55-64 age groups.

Employment and Study

Approximately 75% of participants are in paid employment and of those; eight participants are in full-time work of at least 40 hours per week. Two participants are employed for 30 and 32 hours a week and 4 participants have part-time jobs of between 8 to 24 hours a week. One participant is a full-time mother and one receives a Government-funded invalids' benefit. One participant is a full-time student and several participants in paid work are also engaged in educational study. Two people were retired from paid employment.

Sporting Interests: All participants in this study were either involved in playing sports or active supporters of a sports team/s in their local area.

Cultural Identity: Every participant in this study self identified as Māori and they could name the marae and tribal groups they are connected to. Fourteen participants visited their own marae at least once in the 12 months prior their interview. Sixteen participants could name three or more generations of their whakapapa (ancestry) and the remaining three participants could name two generations.

Participants were also asked to rate their ability to speak Te Reo (Māori language) ranging from not applicable to poor, fair, good, very good and excellent. This question was included in the collection of general demographic information, because language is a cultural identity marker and, as explained earlier in the thesis, the collection of such

information is to highlight the diversity of Māori participants in the study. The three eldest participants rated their ability as excellent, two of whom were brought up as native speakers. Ten participants rated their ability to speak Te Reo as poor, four rated their ability as fair, and two rated their ability as good.

Six participants carry responsibilities outside of their employed work which are described as whānau commitments, and included: a committee member for a kohanga reo (early learning centre); a marae health service provider trustee; a member of a rūnanga (iwi representative body), and a kaiawhina (assistant at kohanga reo).

In summary, participants of all whānau represent a cross section of ages, employment, skills and interests that might be described as characteristic of contemporary Māori communities.

Initial Findings

The initial findings are described according to the ideas that emerged from each section of the interview guide, and by each whānau group.

The Context of Decision Making

Band one of the interview guide comprised a primary question and a prompt if necessary. The aim was to encourage participants to reflect on their knowledge of the medical condition affecting their whānau, their knowledge of the subsequent research involving their whānau, and their involvement in that research.

Whānau Tahi

Participants of Whānau Tahi were explicit in recalling events leading up to the start of their own or their whānau involvement in genetic research and reasons for the research. This is demonstrated by the following comments from some participants.

One of the cousins from there (the marae) started doing research on it (cancer) but he died of cancer too. So, another whanaunga carried it on. (1AM, IiR: Ref 2)

The test. I was first contacted by the clinic at the marae. I didn't know anything about it, but they (whanaunga at the clinic) explained to me what it was about; what the blood test was for and what they were actually doing. But I had no hesitation in taking the test. I wanted to know if I had the gene and what was happening to that. (1UJ, IiR: Ref 1)

The blood samples were taken to be used by the scientists, geneticists, to try and find the trigger that was the cause of the cancer and hopefully look for somewhere that they could help the others to live, because in our family there were no age limits. Young or old, and of course having a sister that died from it, and having a nephew that was dying from it, we wanted somewhere that we could do something, that could help stop them from dying, or found out what was causing it. (1AM, KoR: Ref 1)

Participants were unanimous in describing their motivation for participating in genetic research. One person said:

We are getting too many of us Māori dying from this sickness. We've got to try and slow it down, if not stop it at least slow it down. So that's the only way I think, to get your own whānau together and talk about it, you have to talk about it. If you don't talk about it you never get it back. (1UP, Hui: Ref 7)

Participants could describe the rationale for a blood test, as the following person explained.

The blood test, you have to, to find out whether you've got the gene or not. That's what that blood test was for, just to tell you if you've got the gene or you haven't. It's just a thing I had to know, whether I had it or not, for myself, plus for my kids and my moko [grandchild], that's the reason I did it, for them and myself. (1AD, KoR: Ref 1)

Participants referred to members of their whānau who have had a test to identify the cancer gene. One Participant talked about her own siblings.

Six were positive (for the gene) and three were negative. (1APu, IiR: Ref 2)

The same person stated:

One of my brothers, he's got about seven or eight children and two of his children have been positive and they have been done [tested]. He's got younger ones still coming through and one of his daughters has got children. (1APu, IiR: Ref 4)

Participants of Whānau Tahi talked about one of the screening methods to detect gastric cancer (endoscopy or gastroscopy)[25] as follows:

Gastroscopy? It's just a day staying in the hospital, and they just put a camera in your throat and then they look through the camera into your stomach and they just look for any kind of information. (1M, IiR: Ref 1)

A few years ago, in the 90s, I got my blood results back that I was positive with the cancer, not the cancer, just the gene. I just had the blood tests and

[25] Endoscopy refers to the use of an instrument called an endoscope to view a part of the body. A gastroscopy refers to use of an endoscope inside the stomach, to detect changes or growth.

then my brother went. He went in and he had the gene, then he ended up with the actual cancer not long after that. So, we all started having endoscopies from him, because he ended up having it. (1AD, IiR: Ref 1)

Yeah. Oh no it would have been two years, it was the first year I went for an endoscopy and it was clear and the second one I went back the next year and that's when I found out I had cancer. (1UJ, IiR: Ref 2)

Participants of Whānau Tahi also talked about one of the treatment options, surgical stomach removal. One person said:

Like the first one to do it [stomach removal] was my uncle aye, and he had bad complications after the operation because of what happened. I don't know what it was; I think it was an infection afterwards so that's what he died from. Then I was more or less the next one that had the endoscopy and they found the cancer. (1UJ, WRD: Ref 1)

Another person reflected on consultation processes:

I went to see this Professor [and] he was good to me he explained everything and he said he was confident that it would be alright but he said there is always that chance that something could happen during the operation and he said that with any operation no matter what it is, there's always that chance that something could happen. But, when he looked at our tests and that he said yep should be no problem for me because you're fit you know, and being a smoker, he said all the signs were there that I was in good condition especially for being a smoker. Just the confidence that he talked to us, he explained everything clearly and any questions like I had two uncles, my aunty and he said if anyone wants to ask any questions it was there, just ask them. (1JR, Ind Ex: Ref 6)

Two of the youngest participants in this study had their stomach removed and one of them recollected how she felt after surgery:

I was alright at first because I had my son then and he was only four months, so he was one of the reasons why I wanted it [my stomach] out; I wanted to still be here for him [my son]. But when I was actually going up for it [the operation], I was crying and all that, about what was going to become of all of it. The hardest thing was I couldn't hold him (my son) after my op. I couldn't look after him for ages. I had to leave him with mum because I could barely look after myself. That was the hardest thing for me. (1UJ, IiR: Ref 5)

One participant chose not to have her stomach removed, and said:

They did find something in my stomach about five or six years ago roundabout this time, and it was the size of a five cent coin so they confirmed it was cancer. But I went away and did my own thing because I refused to have my stomach taken out. (1M, IiR: Ref 1)

The same person went further to explain:

They [doctors] were really helpful as far as that [informing me about the surgery]. I went to meet the surgeon, but it just looked too freaky for me. Because I sort of maintained myself for a very long time and all of sudden to have your stomach cut up and I've never had any kind of operation before, so it was quite freaky for me. (1M, IB: Ref 1)

Participants also recalled members of their whānau who have died because of gastric cancer.

I've got one child and he's adopted. So I didn't worry about testing him but my sister who died, her daughter who was living with us [she] was tested and she was negative. My older sister her children, her three children were tested and two were positive and one was negative. My sister was positive too. (1AM, IiR: Ref 3)

My brother and sister and my fathers' brothers and sisters died. (1M, WRD: Ref 1)

And one participant reflected on his ability to have choices for cancer treatment as a result of engaging in research:

I just had a decision to make. It wasn't much of a decision but at least I had a decision about what I was going to do. Whereas the rest before me they didn't have that chance to make that choice. (1JR, Whānau Dec: Ref 1)

Whānau Rua

Members of Whānau Rua were also able to describe the condition affecting their whānau. A few participants said:

I think it [MH] has something to do with overheating. I think it's due to when you're given anaesthetic you're allergic to. I've heard that you can't really get overheating through playing sport or other things, but I don't know whether that's known. So mainly being given something like anaesthetic, basically you're allergic to anaesthetic. (2R, KoC: Ref 1)

When I've been in for operations I just know that I had to have a different anaesthetic to put me out. I don't know what anaesthetic they used. Something to do with high blood pressure and it's to do with your muscles, isn't it?…Because I was doing something at the polytech [short for polytechnic, a tertiary learning institution], and it said something about calcium coming out of your muscles makes you stiffen up and is that due to the anaesthetic? (2E, KoC: Ref 1)

I just know that it's to do…when we were first growing up I thought it was to do with the blood, but now I know it's not; it's more to do with the muscles than that. Something to do with, if we get the wrong sort of anaesthetic and it heats our blood up and does something to the muscle. But apart from that I don't really know much else…Yeah, it is very fatal really.

We're supposed to have medic alert bracelets but we don't, well I don't. (2G, KoC: Ref 1)

One participant recalled events leading to the commencement of MH research with their whānau:

I know it's a family history to do with high temperature. Yeah, he [the anaesthetist] started years ago, through one of Dad's brothers that died. He went in for an appendix and he didn't come out of the anaesthetic. One of Dad's nephews had a broken jaw at rugby, so they operated on him and he didn't come out of the anaesthetic… It has to be over 30 or 40 years [ago] I'd say. Over 30 years - nearly 40 years ago. They [doctors] were wondering why [our whānau died], just going in for minor surgery. That's when they [researchers] started looking into things [the cause of the deaths]. Another one of Dad's nephews was in a car accident and he died. (2L, KoC: Ref 1)

Participants also spoke about genetic testing for MH susceptibility by way of a blood sample or tissue sample obtained by a muscle biopsy[26].

No, I haven't [had a gene test]. My brother and sisters all have it strongly. They've all had biopsies done, so there's no point for me to have it, because they're all strongly positive…I think it's because of them all having theirs done, the doctor or whoever has done it, and has said there's no need for me to have it, because of all of them, the other four being strongly positive, so I suppose because I'm the last, I've got it too. (2R, KoC: Ref 2)

Several participants of Whānau Rua referred to the death of a two-and-a-half year old infant of their whānau that was linked to MH. One participant summed up the general feeling amongst them in the following way:

…she didn't have any anaesthetic, she just collapsed at home one morning and passed away…We don't know why she died…, but when she passed away we were like, wow, blown away and wondered why and what went wrong… we had some researchers and the doctor and others looking into it because from her autopsy the coroner's report said she passed away from Malignant Hyperthermia…They (researchers) were meeting with someone in Canada and they were doing studies at the time about this and apparently they'd taken her case to them…I'm not really sure what came out of that… (2A, KoC: Ref 1)

Whānau Toru

Participants of Whānau Toru were consistent in being able to describe the start of their whānau involvement with geneticists. Two participants commented:

[26] A biopsy involves the removal of a sample of tissue from a living person for laboratory examination. MH samples are usually taken from thigh muscle.

At first it was my grandparents saying that it was a makutu, because that's what they believed in. Things that happened years ago with their whānau and stuff like that, so we just started believing that maybe it was a makutu. Then another sister in the same year lost her son, and they were all boys, and then finally a genetics team got together and they realised that there's three babies and the outcome is the same, and from the same family, with the same last name. (3KT, KoC: Ref 1)

Nobody's got that condition [OPD2] because it's only come from me and in the documentary, as you saw, that by the time I was made, the doctor said just one [DNA] letter was missing…And that's what happened and he said to them at home when the elders were there on the marae, that he could prove to them that it wasn't…He could go back 50 years and prove that it wasn't on my mother or my father's side. Then they started to ask him questions. (3JM, KoC: Ref 4)

The youngest member of Whānau Toru recalled how she became involved in research with her whānau.

It wasn't until the doctor got in contact with mum, (I was) at a young age…I can't remember the age, but I was very young when I got involved in it, and Mum was concerned. I thought yeah why not (have the test). I'll help out any way I can. (3NK, KoR: Ref 1)

Participants from each whānau referred to decision making concerning separate matters – participation in genetic research, and participation in familial genetic screening, diagnosis and treatment.

Participants of each whānau demonstrated that they had some understanding of the underlying science of the condition prevalent in their whānau. They could also explain the sequence of events that led to motivation for their whānau to engage in genetic research and they were able to describe methods of screening, diagnosis and/or treatment for the condition affecting their whānau.

Whānau Decision Features

The second band of the interview schedule aimed to encourage participants to move from describing the context of their involvement in research, to how their decision to participate in the research actually occurred. That is, features of decision making relevant to their whānau. Once again the responses are grouped by whānau.

Whānau Tahi

Hui[27]

A hui is an assembly or gathering of people to one place, in order that they may discuss issues face-to-face. Hui were a frequent forum for decision making consistently identified by all participants of Whānau Tahi. The following are a few references to hui.

Yeah. Sometimes it was just us and our whanaunga from the hauora would explain things to us. Sometimes it would be just the local doctor and some other doctor from here, and other times it would be all of them together, and then the person, what's his name, for the ethics and things like that. (1AM, WDF: Ref 3)

Yeah. They [whānau] used to have them [meetings] up there [the marae]. I used to go to most of those meetings. Because I was interested but I didn't know at the time…. I was glad I went to those meetings because I saw a lot and heard a lot, like in my cousins, my brother. (1AD, WDF: Ref 1)

Yeah he [specialist doctor/geneticist] comes up, like we have big hui to keep us up-to-date and they usually have them up the marae for all the whānau that are involved with the stomach cancer. And he comes up; if he can make it he'll come up. Every time I've been he's been there. I've been to two, we've had two hui up [the marae] and he's been there both times, him and the other person, I can't remember her other name. They always explain everything. We all sit there and have a good talk and she explains everything and any questions you've got you can ask her or him. (1APu, Hui: Ref 3)

One participant talked about the resolving of consent issues at a collective level, that she attributed to the process of hui:

I know those things were safely looked after because of all the different meetings we had, and we asked questions about that. We didn't want our blood to be used by anyone and everyone. (1AM, Hui: Ref 2)

Another participant referred to the importance of hui for establishing or consolidating relationships:

Like this family in [another town]. So they approached us early last year and we've had a hui over there since but they're finding what we found. They're scared of it and so they are slow… coming forward to do these tests. They're scared of the outcome. (1Apa, Hui: Ref 4)

One respondent referred to the ongoing nature of hui: we haven't been having many hui on this subject for a while, it must be a couple of years now. We still have our meetings

[27] The letter's' does not exist in the Māori alphabet to indicate whether a word is being used in singular or plural form. The context in which a word is used should indicate which is relevant at any one time.

up here to discuss things like that, but everybody is getting to the positive stage of this kaupapa where we don't need to do what we used to do before. We used to have a lot of meetings over here, just about twice a month or something like that and get all the scientists up and let them talk. (1UP, Hui: Ref 5)

Key people/leadership

Key people were consistently named by participants of Whānau Tahi as having important roles in providing leadership. One role involved the facilitation of whānau control over research processes and practices. This was implied by one participant who said:

We had a smart crew of [our whanaunga]...who made sure that whakapapa was all coded, and we owned our own samples, and they couldn't use it without our consent. So we did all those things and we learnt about ethics and everything like that. (1AM, Leadership: Ref 3)

The same key people or leaders played a role in giving information to whānau:

Yeah. You all get the full information. You'll get that full information. That's what our whanaunga do; they make you feel it's safe. (1AD, WDF: Ref 8)

The same key people were described as having particular personal attributes. For example, they were described as active listeners as one person said:

If you've got something to say, they listen. They won't say that's not good, they will listen and I think that's very important even if it's not the right thing to talk about. It's just listening, making people understand that it is there for everybody. (1UP, Leadership: Ref 1)

The same key people were also considered caring and knowledgeable about health issues.

Excellent it's been excellent because they're [whanaunga] so knowledgeable about the workings of a doctor, how to get there, what to do, and they provide support for families who are going for operations, for the ones who are going for tests and things like that. (1AM, WDF: Ref 1)

Key people were identified as having an advocacy role in protecting whānau interests. One example is the dissemination of information about the results of the genetic research, as described by the following person:

K always get a copy of what's been written, it's got to more or less go through them. Like they get a copy and then they say yay or nay, whether it is to be published. (1APu, Leadership: Ref 4)

Another example of a specific contribution by certain leaders was their securing of legal expertise to scrutinise research contracts. This was embedded in a comment by one participant.

They've [our whanaunga] maintained control of every [aspect]… we had the lawyers and things to check and make sure. Those girls they were onto it. They were fantastic and they're still doing a good job and now… (1AM, WDF: Ref 4)

The key people were identified as reliable and trustworthy as a number of participants stated:

They were always there for us which is good, which you need, people like that, and I really appreciate what they've done. Me and my family anyway, it's our thing towards them because they did a lot for us. (1AD, Leadership: Ref 9)

Yes they [whanaunga] were awesome. They were always there, they were great. (1JR, WDF: Ref 5)

Oh yeah and when she felt that they'd gone to this stage and that stage, they said well could you come and talk to the people. We were well informed. (1AM, Leadership: Ref 8)

Role Models

Participants of Whānau Tahi talked about their sense of responsibility to role model behaviour to their children and grandchildren with regards to screening or treatment. One person described an example of role modelling.

Yeah you do get scared. Like I said you get frightened. But after you've had the op [operation] you know it's gone, it's not there anymore and that's the relief, it's while you're waiting for it that's the worst part. I reckon it's worth it [the operation] if it can save your kids' lives or your grandchildren. Life is important. (1AD, WDF: Ref 6)

Alternatively, participants spoke about role models they observed, and how their own decision making was influenced by the outcomes they saw by way of observation. Two participants said:

Probably all the positive results that happened with my brothers and sister, just seeing them go through and looking good again. I probably would've ended up doing it in the end, plus if I didn't do it they were going to test my children, one of my children to see if they had it. So, rather than them do it [get tested], that was another reason too. They approached my daughter and asked her if she wanted to do the test. I think she was going to, but then they come back to see me and said: It would be better if you do it, because if

you're negative they don't have to worry about it [approaching my daughter]. And then I did it [had the test] - that was another reason too. (1APu, WDF: Ref 1)

Oh when he [Dad] went in [to have his stomach removed] and had all those things [tubes] coming out of him it felt like ouch! But, when he pulled through it, then I thought, well he pulled through it, my brother pulled through it, I can too and we all did, got through it sweet, had no complications or anything. (H in UJ, WDF: Ref 4)

Control

Participants of Whānau Tahi spoke about the responsibility of their whānau to mediate internal take (issues). A couple of relevant comments were:

They [some whānau] had a very negative approach to this project. But as they got to learn more and more about it, you see them coming forward now and have been for the past few years and that's good news. (1UP, WDF: Ref 3)

I was like that [frightened] at the start. I thought it [genetics]was against our culture and all that, but after I actually seen the results of what it's done to these people that had it [cancer], I thought if there is a cure there, why don't we use it, why don't we do what they're doing. And I've got over that now it doesn't even worry me now because I've seen the results of what this thing has done. (1UP, WDF: Ref 4)

Consent processes were considered by respondents as facilitating their control of research practices. As such, one person talked about the need for researchers to consult with whānau, but this was often identified by leaders within the whānau as one person said.

Oh yeah and when she [our whanaunga] felt that they [the researchers] had gone to this stage [a step in the research] and that stage [another step of the research], they [our relatives] said [to the researchers] well could you come and talk to the people [again]. We were well informed. (1AM, Leadership: Ref 8)

One participant believed that the whānau has an educative role with researchers, such as helping them to understand whānau structures:

People want to separate us out into little hapū. (A1Pa, Whānau: Ref 5)

Mediation between whānau and health services was acknowledged as a way of whānau assuming responsibility for their involvement in research. Deliberate mediation was often attributed to key people and this was described by one person in the following way:

There was a lot of mucking around down here [the hospital]. I did all the tests and everything down here and they set it all up, and then they wanted me to do some more tests, and by that time I was getting hōhā [frustrated]. So I rang up my relatives and told them and they said: 'oh well we'll go see this fella in Auckland'. (1UJ, Whānau: Ref 2)

Participants of Whānau Tahi alluded to ways they asserted control of their participation in genetic research. They referred to having an assertive but positive attitude, ensuring they were well informed and being proactive about articulating any concerns or question. One participant summed this up by saying:

So the process was, we decided that when we set this [the research project] up, we decided we were going to drive our thing and not the specialists required to do the mahi. Because it was our kaupapa, our wants if you like, to find out why these people were dying so young and so quickly once it was diagnosed. And that's how it's been. (1Apa, Whānau: Ref 1)

The same participant talked about protection of whakapapa arising from control:

That [whakapapa] was our business, nothing to do with them [the researchers]. But in saying that, because the specialist doctor especially, not so much the others, has become so involved with our thing, he pretty much knows if you've seen him, he knows who that person belongs to. If you send him down some blood samples he can pretty much pick up who they belong to or what line they come from. (1Apa, Whānau: Ref 3)

The role of whānau to protect the integrity of whakapapa was reiterated by another respondent:

I went with my sisters as a family, so we were alright, not that silly. We worked with the whole process all the way through so we knew what the next step would be and we were informed before we went. (1AM, Whānau: Ref 4)

Several participants talked about whānau control over the dissemination of information, specifically, scientific publications. Accordingly, one person said:

I think the hauora [health service] would bring it [publication] up at a meeting and then we decide, and that's it, they (researchers) can't publish it [if we do not agree]. (1APu, WDF: Ref 3)

Another example of where consent is important is storage and use of blood tests. One participant commented:

They [the researchers] can't re-sign this paper [consent form] to say you don't want it [your sample] given out. When you do your blood tests, you sign it [the consent form regarding your sample] and they can't use it for anything [else]. It is stored there [at the research lab] for ten years or

something and no one else uses it except the doctor [directly involved in the research]. (1APu, WDF: Ref 5)

Manaakitanga

Participants acknowledged personal differences between members of their whānau. One person said:

Everybody is a different individual. You're not the same, you have the same thing but you all recover differently and do things differently, so you're all not the same. (1AD, Whānau Dec: Ref 2)

Personal differences (outside of the decision context) were distinguished from individual preferences that emerge in decision processes, as indicated by the following person:

I just did a blood test to see if I had the stomach gene. I was the last to get done out of my family, nine of us, because in my mind I thought 'why should I have that if there is no cure for cancer', because my mother had the breast cancer, so I refused to do it. (1APu, Whānau Dec: Ref 1)

Despite individual preferences, the notion of collective participation in decision making was seen to be an important and some participants saw their decision making as being firmly embedded within their whānau value base. Accordingly, one person said:

It's just that when you're with other whānau their mind takes off in other places where I started to think the same as them. And I just caught up like that, like – 'oh yeah better go for the operation ra ra, instead of sitting down and thinking about it. (1M, Whānau Dec: Ref 2)

The same person emphasised that a collective decision represents the view of the collective and does not supersede individual decisions. However, whānau endorsement plays a critical role by providing a sense of security that there is strength of support for individual decisions, which was implied by the following quote:

He just said to me: 'kōtiro [daughter/girl], I will never want you to go through what I went through'. And then straight away I just went: 'I'm not having the operation'. So he was my biggest mentor or whatever. (1M, Whānau Dec: Ref 1)

Hui, leadership, role models, and feelings of control were features of decision making identified by participants from Whānau Tahi. In addition, they gave a collection of descriptions that represent the notion of manaakitanga, a concept described earlier in this thesis. Similar responses were found with each whānau.

Whānau Rua

Hui

A hui was an important feature of whānau decision processes for Whānau Rua, although only the eldest participant interviewed could recall hui to discuss MH research. The participant stated:

Yeah [the doctor], and [another man], I don't think he was an anaesthetist, I think he was one that tested the muscle, because he used to go with the doctor when they had the different meetings. I'd been to one [of the meetings] down with our other whānau, all of them down there [a specific region], and he came along too. He's probably retired too now. (2L, WDF: Ref 1)

The experience of the same participant contrasts to that the remainder of her whānau, most of whom had difficulty recalling any whānau hui about genetic research that they had knowledge of, or they had attended. One of the participants was asked directly if she has ever been involved in a meeting with researchers and she replied:

Not as a whānau no. Always been separate. I think Mum's had a lot of dealings with the doctor and I have on the phone and he's been here once. I've met with him once, but, no, not together. (2A, WDF: Ref 8)

The difficulty of the majority of participants of Whānau Rua to recall a hui is most probably due to the fact that they were not born or they were infants when research with their whānau started. In light of this factor, they could not reflect on decision processes about MH research involving their whānau. Instead, they were asked to describe the usual process of decision making that occurs for their whānau. Ironically, significance was placed on the importance of hui, as one person indicated:

If we've got a take [issue] and we want to talk. Depending on who's got the take with who, I mean, phone call, I'd ring up or we'd go see one another and say we should have a hui, what do you reckon? Blah, blah, blah, this is the take and we actually had one recently and it was good. We're all quite private people and we do our own thing and when we're aware of something or something comes to our attention and we have to help out, well then we just get together and we do it, help out. (2A, Hui: Ref 3)

All respondents of Whānau Rua recognised that any member of their whānau can initiate a hui, as some of their comments show:

I think one person brings it [the need for a whānau hui] up, then another person tells another person and it's organised that way. It's not really, like it probably should be Mum that organises most of those things that happen,

but it's not…No, it's just whoever feels that something needs to brought up will say to someone, and then that person will pass it on. (2R, WDF: Ref1)

Normally, it just depends who actually wants to have the meeting. They'll call one person and it all just filters from there; they'll call the next and the next. Whoever's got a problem; they just ring and say this is the meeting. (2G, WDF: Ref 1)

If we decide to have a meeting, the kids may have talked about it, and they'll all talk about it, not just one makes the decision, and they'll all agree, then come to me and say Mum we're going to have a Sunday meeting or get-together. (2L, WDF: Ref 2)

All participants of Whānau Rua considered a hui to constitute decision making of a significant nature because it required collective thought. The reason for a hui was described as varied. One person said:

It's [a whānau hui] serious but it's funny. it's to accomplish a goal, and it's really good. I like them… (2N, WDF: Ref 4)

I called it (a hui) one time. We had a meeting about a completely different circumstance. (2N, Hui: Ref 7)

Key People

Key people who assumed leadership roles in decision processes were identified by participants of Whānau Rua. The role of key people appeared to differ, with one role primarily concerned with organising and coordinating whānau, and another concerned with deliberation. In both cases, leadership involves a certain level of experience and knowledge, and participants went as far as commenting about the attributes of key people in their whānau. The following are descriptions they used:

He's honest, that's what I'd put as number one. Trustworthy, honest, and I just respect him. (2N, WDF: Ref 10)

Because of the kind of person he is. Just because he is loyal, he's always been there to help with anything. Just because of the kind nature he has, really. (2R, Leadership: Ref 4]

He's a listener, and he doesn't fly off the handle. (2L Leadership: Ref 1)

He's pretty sensible and he's very laid back (2A, Leadership: Ref 4)

He sort of knows a lot. (2E, Leadership: Ref 2)

Probably P[sister] has a big influence on what is done, and she's not shy to hold back her feelings. (2R Leadership Ref 8)

One person identified as having a lead role in decision making, responded modestly about the perception of his whānau that he is a leader:

Well, I like to think I'm at the top [laughing]. In the pecking order I'm actually in the middle. There's two older sisters and then there's me, and there's two younger, so yeah I'd like to say I'm in the middle of the authority. (2G Leadership Ref 1)

Another person identified as a key person described why she might be perceived as being a leader for her whānau:

Because even though I'm the oldest I don't look at myself as the boss. These things that I can help my brother and sisters with, there's different ways I can help them and same as them, there's different things they can give to me. I wasn't brought up with my brother and sisters, I was a whāngai [adopted] as a baby so I would see them every second weekend or third weekend sort of thing so I wasn't brought up in a whare [home] with them but still I grew up knowing who they were and we're pretty cruisey. We don't see each other that often really. I don't know if I would call us a close, close whānau but when it comes to the time and we do get together we are close, we've got no raru [problems] I don't have any raru with them and they don't have any raru with me and I'm always there for them, just a phone call away and they know that so when we do see each other and get together, it's all good. (2A WDF Ref 6)

Control

Feelings of a lack of knowledge, lack of information and lack of understanding about MH research were implicit in the interviews of most participants of Whānau Rua. One participant reflected as follows:

Yes. I don't really know how to take that fella [the doctor]. I don't know. I just, he was a bit pushy for me and I didn't quite really understand where he was coming from. He was talking a bit too big I suppose and I didn't quite understand. (2A, WDF: Ref 1)

It was mentioned earlier that most respondents of Whānau Rua could not recall whānau hui to do with MH research because they were not born or they were infants when whānau hui were conducted and therefore, they were not involved in collective decision processes related to MH research. The oldest participant of the whānau however, was the only person to report involvement in whānau decision hui and consequently, the same person consistently indicated that she was satisfied with her level of knowledge about MH, her degree of contact with the medical researchers and accessibility to the researchers. Consequently the participant expressed feelings of control over her own participation in genetic research, which contrasts to all other participants of her whānau

who did not have the same experience of decision process and they did not express the same sentiments of control.

Manaakitanga

Feeling valued and valuing the contribution that others bring to decision making was a characteristic of whānau processes identified by Whānau Rua. This was directly or indirectly stated by respondents in the following ways:

I look at them as all being equal, that's how I look at my brother and sisters. And I'd listen to all of them and see what they had to say. I'd listen to all of them equally. (2A, WDF: Ref 3)

I don't really talk much, but when I do say something I do. (2E, Manaaki: Ref 2)

Well, I like to listen to myself. I think I bring up a few good points, and I don't know whether they listen to them or not. (2R, Manaaki: Ref 4)

I think I have my fair share [of input to discussions]. (2R, Manaaki: Ref 1)

If we decide to have a meeting, the kids may have talked about it, and they'll all talk about it, not just one makes the decision, and they'll all agree, then come to me and say Mum we're going to have a Sunday meeting or get-together. (2L, WDF: Ref 2)

Conflict from working through individual views in a collective process was an accepted inevitability, but collective resolve emerged as a general objective. This was implied by the following participant:

It might be three agreeing with something, and then two might not, but at the end of the hui they all agree. No big argument or anything. (2L, Manaaki: Ref 3)

Whānau Toru

As with interviews from the other whānau, similar features of decision processes emerged from Whānau Toru.

Hui

A hui was a prominent characteristic of decision processes for all participants of Whānau Toru and their general attitude to hui was summed up by one person who said:

Yes, I think it was (a whānau decision to get involved in the research) because every time anything was to be made (decided), we always consulted each other, or we had meetings ourselves about it, or once we found out that there was going to be a meeting with the genetics team, we'd all get

together to make sure, even if one of us was missing, at least the majority of us were together to find out, and quite happily and easily did so. We had meetings at my work, or we'd meet at home. Yep, my house. Mum was living with me at the time, so a lot of meetings went down at home, at my job and at the hospital… As long as we're clear on what it (the research) was all about, so that's why we never had any issues (about the research). (3KT, WDF: Ref 1)

Key People

Specific people played important roles during decision making and they were identified by one participant in the following way:

It's both mum and my sister. Normally like them two, we listen to, I say mum mostly because I listen to her a lot. I pretty much blot out everybody else, when she's trying to get some points across, but [my whanaunga] and my sister, are the ones that actually get it going. Her [my relative's] input is really important to me. I may not agree with it but she is normally correct in what she says… (3NJ, WDF: Ref 2)

The same people were described as possessing personal qualities that incited a sense of trust in their ability to provide leadership:

I love it when mum's at meetings because she's got a memory on her like an elephant. Plus she's a lot smarter or whatever, but she knew what they were talking about, and once they change it from doctor's terms to layman's terms it got a lot better for her to explain to us. (3KT, Leadership: Ref 7)

People who were identified as leaders were known to have a positive outlook that their whānau aspired to:

She's bubbly eh? She's a crazy little woman. She's absolutely adorable as well. (3NJ, Leadership: Ref 4)

Those identified as having a leadership role, were asked about their perception of decision processes and why their own whānau perceived them as having leadership in decision making. The following is one response:

I don't really know. I don't want to sound like I'm blowing my own trumpet or anything like that, but I'm close to my older sister. I'm close to my younger sister, and they're not as close with each other, and so I'm close with every single one of them and that's probably why. I've always been head strong about things, and I've always been the one to pull things together, and that's right from when I was younger, too. I was the first to leave home. I left home at 15, and I said I'm not going back, and I didn't go back, so I was out doing my own thing and I don't do a group clone thing, doing what they have to be told to do and stuff like that. (3KT, Leadership: Ref 1)

The same person was described as an organiser of whānau hui and when asked why she is the person who tends to organise hui, she replied:

I have no idea. I can get on with people; anybody and everybody easily, and when it comes to organising something, I can organise it a bit better than the others. I try my best. (3KT, Leadership: Ref 1)

Control

Participants of Whānau Toru alluded to the notion of self-determination or control. A fine balance between individual and collective control is implied in the following quote:

When it comes to the crunch, I think it's not an individual thing, but I would normally speak up first, so maybe I could have a lot of influence on it (decision making) because I say something first, and then the others would follow in tow. (3KT, WDF: Ref 11)

Whānau support for an individual view does not mean that the whānau collectively agree with each person, though individual decision making is premised on the basis that whānau have informed and endorsed an individual stance. This is embedded in the following quote:

I don't talk to anybody, apart from, basically my family and the study ones (researchers). (3NJ, Whānau Dec: Ref 1)

Manaakitanga

Valuing each other's contribution to decision processes was emphasised by participants, a factor described by way of equal say or equal recognition attributed to each person during hui. One person said:

Most authority, I think that would be equal parts. I don't think anybody would over authorise anybody else. That's something that's made together. (3KT, Leadership: Ref 4)

Accepting each other's differences and commonalities was also important to respondents.

We all are completely different, and you'll find that out, but yet we're the same. I think we've got the same views on things, but our own personal things are different, and just the way we are, is different. (3KT, WDF: Ref 2)

Yeah, if they don't like what the others said (about the research), they'll argue it out. Don't worry. I'll just sit there and listen…In what goes on here, with their lives and what they do, sometimes I have got the last say but

apart from that I'll tell them how I feel but they'll do what they want anyway. (3JM, Whānau Dec: Ref 1)

Caring for each other and unity were features of their thinking acknowledged in the following way.

Oh yeah. We've had some pretty steamy arguments and things, because everybody's right. But the outcome is always the same. If we've gone to a meeting, let's say it's a whānau meeting, with us only, without Dad or Mum or something, and it could end up petty, before we go home there's no way we're going to go home in a bad mood. We always leave that house laughing. (3KT, Manaaki: Ref 3a)

The same themes or features of decision making were repeated by each whānau such as the importance of hui, forms of leadership, dimensions of control and descriptions of manaakitanga. The next section of responses concerns another aspect of the interview.

The Meaning of Whānau

Band three of the interview guide was concerned with understanding the meaning of whānau in a decision context, to determine if there is any variation in meaning from current knowledge.

Participants of this study referred to specific individuals and/or the collective group they identified as their whānau, and the range of descriptions of their whānau is consistent with what is already known.

Whānau Tahi

Two participants from Whānau Tahi referred to the notion of whanaungatanga (relationships between people who have a genetic and biological connection). One participant however, applied the term whānau to a church group, implying a group with the same interest. Thus, people who do not have whakapapa links are not precluded from being referred to as part of a whānau. The participant said:

I went to church and I finally told the church whānau what I had [cancer]. No, not what I had, but what the doctors had spoken over me. (1M, Whānau: Ref 1)

The same participant acknowledged that many members of the church have whakapapa to each other, though some do not. Nevertheless, she included all members of the church as her whānau.

Many participants of Whānau Tahi used the word whānau interchangeably with the word family as the following example shows.

[My relative] asked me because I am whānau to the [another] family, asked me to come and have a blood test. (1AD, Whānau: Ref 1)

While the words family and whānau were used, participants favoured the latter to describe their biological whānau because the word itself more closely embodied or represented who they are as a whole.

Whānau Rua

A number of participants of Whānau Rua suggested that the meaning of whānau is dependent on the situation. One person said:

Depends on the circumstances, who you're talking to I suppose, and what about. (2A, Whānau: Ref 2)

Another participant felt whānau is a defined group, inferring that the notion of a family is the same as whānau. The same participant qualified their interpretation by describing whānau as meaning a group of whanaunga (relatives) connected by way of whakapapa (genealogical link):

My whānau is my whānau who live in the house here. And then it's my siblings, Mum and Dad, Grandad and Nanny [grandmother]. I class them all as whānau I suppose. When I'm talking to people about my whānau I suppose I'm talking about my own. (2A, Whānau: Ref 1)

Participants attempted to apply the broad notion of a whānau using western descriptions of family structures. For example the notion of an immediate family emerged from the following person:

Yeah, immediate family comes first. (2N, Whānau: Ref 5)

In describing a specific group, one participant indicated that such application does not necessarily exclude other members of the wider collective:

Immediate [family]. My Mum and sisters and that, are immediate. You can get away with a lot of stuff with them, but aunties and that, I love them all. (2N, Whānau: Ref 4)

Some participants described the notion of whānau as applying to a range of people who have blood ties:

My Dad's and my Mum's, each side. All Dad's whānau, his sisters, brothers, children and then on my Mum's side, the same. (2L, Whānau: Ref 3)

A description of whānau for example, may be in specific reference to one's siblings or one's own children:

Everyone. My brother and sisters, mum, and then I've got another family of my own. (2E, Whānau: Ref 1)

Sometimes reference to whānau is inclusive or not, of cousins:

I've got cousins, I'd class them as whānau as well. (2N, Whānau: Ref 5)

Grandparents were held with special regard.

Probably after my grandparents. I would put my grandparents in a different bracket to my aunties and uncles and cousins. (2R, Whānau: Ref 4)

Though grandparents were singled out as having special importance, this does not mean other members of the whānau are not valued equally. The following participant for example, alluded to different collective groups that comprise her whānau.

I think there are different types of love for each whānau. (2N, Whānau: Ref 7)

Whānau may be inclusive of one's partner and their whānau or family as one participant explained:

So I suppose you could say yes, I think of him as my brother-in-law, even though they're not married. (2G, Whānau: Ref 2)

When people say to me, are you his brother-in-law? I say yeah. (2G, Whānau: Ref 3)

Like other whānau, participants of Whānau Rua used the word whānau interchangeably with the word family such as the following person.

Me and you (partner), and the baby that's coming up, and my two boys, we're a family. (2N, Whānau: Ref 6)

Whānau Toru

Participants of Whānau Toru applied the word whānau in similar ways to the two other groups. For example, the following person described the notion of whānau as contextual:

To me, my whānau is my mum, my brothers and my sisters and nieces and nephews. (3KT, Whānau: Ref 2)

Participants of Whānau Toru used the term whānau to include non-Māori. For example, one person of Whānau Toru spoke about the medical specialist/researcher who they considered a part of their whānau:

We actually class D [the doctor] as well, as part of our family now. (3NJ, Whānau: Ref 2)

Participants of Whānau Toru referred to researchers as a part of their whānau, and they clarified this by explaining they used the concept of whānau as a term of endearment, to represent the positive feelings they had toward them. As whānau developed a close relationship with researchers, inclusion in their whānau was a symbol of their high opinion of the researcher's work ethic and character. Participants also clarified that inclusion in their whānau by way of association, does not render entitlement to the same rights as whakapapa whānau, meaning that decision making by whanaunga about whānau research is privileged.

Summarising the meaning of whānau.

The nature of a whānau as a fluid concept is supported by this thesis and reinforces all previous literature including a prior study into the meaning of whānau (Metge, 1990; Walker, 2006; Durie, 1997; Metge, 1995).

A whānau can be a reference to one person, or a specific and defined group of people, or a section of a large extended group (e.g. hapū), or it can have wider application to an entire natural biological grouping such as their iwi and associated iwi.

Participants of this study had a range of ways to describe their whānau in keeping with what is already known. Most often, they referred to the group they identified as their blood relatives though this was not always the case. The notion of whānau is inclusive of all members, and this is important to emphasise because decision making regarding whānau genetic research, may include whānau members who are not blood relatives, but are still considered to have a legitimate and important role in whānau decision processes.

What Informs Whānau Decision Making

Band four of the interview schedule aimed to uncover the range of ways that whānau were informed about genetic research, in order to make a decision whether to participate in it.

Whānau Tahi

Information

It has already been identified earlier in this chapter that members of Whānau Tahi gained information during hui. Participants identified the need for written information as well as opportunities to speak with experts face-to-face. They were unanimous is pointing out that one episode of interaction and one mode of communication is not sufficient. Participants emphasised the need for multiple interactions and various modes of communication and the following are comments some participants made:

They [genetic counsellors] sent out a letter and everything and if you wanted it explained to you, they would come around and see you, explain what it's all about and what they are actually doing. (1UJ, KoR: Ref 1)

A lot of it [information] I heard just by ear with the old kaumatua [elder] and talk about cancer. But I didn't realise it [the genetic condition] was so widespread. I just thought it was one family being infected with it. But after listening to all the information that I got, it is quite widespread. (1UP, KoR: Ref 2)

One person reiterated the role of information that helped him understand the broader impact of a genetic condition on the wider whānau. He said:

I knew we had the sickness in the family, but I didn't know how bad it was until I got more information afterwards, after the test. It was very handy that information about how the genes come down through certain parts of our whakapapa. It was interesting and I thought I'd better do something about it for my family. (1UP, KoR: Ref 1)

Role Modelling

A number of participants talked about their being inspired by other whānau members who informed their decision making. Two people said:

There wasn't very many before me and my grand-daughter. There was only about four that had it done [tests], three or four. I asked my grand-daughter if she wanted to do it with me and she said yep that's fine. I'm glad she did come to give her an understanding of what these tests are all about, but it worked out alright. (1UP, Whānau: Ref 2)

So, once we found out he had it, others started having the blood tests and then they started having endoscopies and that's how they actually found the cancer for him. And then we all ended up doing the same thing, being brothers and sisters to him. (1AD, Whānau: Ref 2)

One respondent reflected on her having observed her own brother's response to cancer treatment and his being able to resume normal activities of daily life, a crucial influencing factor that informed her own decision to participate in cancer treatment. She said:

You can still live a normal life, only I find I can't eat like I used to eat. Like I could eat a whole plate of food, tea time, breakfast, but now you just sort of got to eat like a baby really, just little weenie bits. You're still hungry, you're still normal really. I used to be ninety two kilos before I had the op and I am now stabilized at fifty four, fifty five so I'm stabilized now. (1AD, WiW: Ref 3)

Values and beliefs

Specific values and beliefs, not necessarily held by the whole whānau group, also informed participants' decision making. For example, a number of people referred to the influence of their religious convictions:

It's the faith you have in yourself as well. If you have faith in yourself and you have the backing of your hāhi [church] it makes all that difference. So easy to come to a decision because there is somebody at the back of you, backing you up. I'm not talking about people, I'm talking about your hāhi. You always have your prayers and all that and it helps so much it really does. Every time you have a bit of trouble you have an inoi [prayer]. When you get sick, it's just something we were brought up in. All the people my age we all understand that, it's how strong your faith is, very strong. Now it's going through to the young people and I think that's good. (1UP, WiW: Ref 2)

I actually relied on God giving my healing and so that's all I looked to. I didn't care how confusing everything was around me I just relied on him, and I just kept eating good foods, I couldn't even afford them because I

finished my job and then my husband finished to take care of me and my baby. So, we didn't have much money as far as that went. (1M, IiR: Ref 2)

It didn't worry me [giving blood], plus we weren't sort of bought up to worry about tapu [sacred construct] things. My mum said 'all you've got to worry about is your church', so that was it for us. (1APU, WiW: Ref 5)

Fear

Fear of cancer, or rather, fear of the consequences of dying, was a common issue for participants of Whānau Tahi. Parents and grandparents, who have an active role in the routine care and upbringing of their own children or grandchildren showed deep concern about who would fulfil the child care roles. Participants however, described an overlap between their involvement in genetic research, the purpose and objectives of that research, and simultaneously being screened, diagnosed and treated for a genetically linked condition, which in their case is gastric cancer. This was emphasised by one person who said:

It's something you got to really think about. But just hearing the word 'cancer'. I think everyone's [thinks] just 'take it [cancer] out, take it out'"…Saving my life. The cancer is there, I know it's only early stages but it's frightening. I thought it was quite frightening. It hurts when you find out that you know you've got it but then you know somebody is there they can help you. (1AD, WiW: Ref 2)

The same person was also said:

My sister hasn't got the gene; well none of her kids will have it, not that particular [stomach] cancer anyway. Doesn't mean to say they won't get another cancer or anything like that. (1AD, WDM: Ref 2)

Fear appears to have been a motivating factor for respondents to engage in screening or treatment, because screening allowed them to more clearly understand their degree of illness and/or closeness to death, so they can plan for the future accordingly.

Whānau Rua

The same factors that inform decision making for Whānau Tahi are also relevant to Whānau Rua. In addition, they acknowledged the benefit of modern technology in obtaining information.

Information

Electronic technology such as the internet was identified as a key source of information for one participant of Whānau Rua. That person said:

Oh yeah I know a bit about it [MH], it's on the internet. I looked up Malignant Hyperthermia on the computer and it came up with the site and all that. Then I clicked onto different ones [websites] and it came up with, we have photos on there - me and my kids, my Mum. (2N, KoC: Ref 1)

Ethical Consent Processes

A number of participants of Whānau Rua reflected on ethical consent procedures, which they recognised as mechanisms by which they were informed about research. They described specific incidents and in some cases, questioned the integrity of ethical protocols. One of the participants reflected on events prior to having a muscle biopsy.

When I went for my biopsy I was under the understanding that they were going to take a little piece of muscle and test it to see if I was negative or positive. I remember that when I was waiting to go into theatre they had the consent form and told me then, that they were going to take two pieces of muscle at that time… I was all laid out ready to go and it was sort of lucky I could sort of say… one [sample] was for their research and one [sample] was for someone at the research unit, to do another type of research, and they said it was to help my children or help our whānau, just help with research. So I mean I did sign it (the consent form) in the end but it was like, I didn't really know about 'two' [samples]. Should have told me earlier. (2A, IiR: Ref 2)

Another participant questioned the right of researchers to use information gained from the research process, and thus the extent or timeframe to which consent applies and the scope of consent. In particular, participants referred to a researcher who spoke about her dead daughter on a television documentary without parental consent.

I saw the adverts on TV that it [the documentary] was coming on, and I thought: 'Got to watch this'; because I know I've got it [the condition] and then I watched it. I thought it was interesting yeah. I remember them talking about the little girl that died, and I thought straight away that they were talking about my daughter. And I was thinking they didn't have my permission to put that in. (2N, WiD: Ref 2)

The same participant talked about a photo of her whānau on a website. She was asked during her interview if she knew the photos would be posted on the website, and though she was aware she had given consent of some kind, her recollection of the exact nature of it was unclear. The respondent said:

No, I knew he [the doctor]) was doing it [the website], but…. Yes. No I didn't think it would be [a photo] and I freaked out when I saw it. (2N, WiD: Ref 2)

To exacerbate the participant's difficulty in recalling the nature of consent she gave, she suggested that a range of consents had been obtained at one time. The participant said:

No, they did, they asked and they took photos and that. They wanted blood samples and that. (2N, WiD: Ref 3)

I made an attempt to purchase a copy of the documentary for Whānau Rua. Educational rights and not personal rights to copies were available on the New Zealand distribution licence, affecting the purchase price of the documentary (available only in VHS format). Based on information from a representative for the New Zealand distributor, decisions of cost and distribution are determined by the overseas corporation that holds copyrights.

A copy was secured from a primary investigator of the genetic research, which was given to the whānau. However it was noted that the investigator had not met participants of the study face-to-face, which is most likely due to the fact that health researchers may be drawn from a range of disciplines such as science. Not all researchers/scientists involved in genetic research, conduct research only in the area of human health. Scientists may not identify themselves as health researchers and an implication is that scientists do not have access to the health sector and therefore face-to-face contact with whānau in a health context.

A meeting between the investigator and the whānau was facilitated during this study to enable participants to ask questions and clarify unresolved issues concerning information divulged on the television documentary. It was my experience, that there is no recourse for whānau to address their concerns arising from the publication of information embedded in their participation in research that is transferred to broadcasting rights specifically.

Whānau Toru

Participants of Whānau Toru identified the same issues as other whānau. In addition they reinforced the importance of relationships with researchers as critical to informing their decision making.

Relationships

The need for direct contact and positive relationships with researchers, and easy access to them, were consistent messages from participants of Whānau Toru. The quality of

relationships appears to have had a bearing on the quality and frequency of information received by participants and their satisfaction with the information, as stated by the following comment.

We had good feedback and whenever something happened the doctor would come back and tell us, he'd get us all together and we'd meet at [the local hospital] in one big building in there and then he'd explain to us what was going on, what's going to happen next and when he came back to Auckland from England or Australia or whatever but he always kept in touch. We might not have heard from him for 6-8 months but if something happened he was there. (3JM, KoR: Ref 1)

One participant added that positive relationships are a two way process.

If you want results, and it may take a while, you've got to be patient. Ask questions along the way with whatever you need to know. If you're not happy about something let them know, but be cooperative, because that's all they're asking for. They want to help you. I mean, whatever questions that they have for you, answer them the best that you can. Anything that they need from you, whether it is blood tests, biopsy, whatever it is, help them out…They're trying to help you at the end of the day, that's all they're trying to do, and whatever it takes, just got to be willing to do it. (3NJ, WiW: Ref 6)

Overall, whānau in this study identified many of the same issues. They described the need for information, the influence of role models, and the influence of their personal beliefs, fear, ethical consent processes and the importance of relationships to decision making.

Participants of two whānau also described how they were given to believe, by their relatives, that the primary reason they were afflicted with a specific medical condition, had to do with mākutu (a Māori spiritual mark). Mākutu is a traditional construct that may be described as a practice of using spells or incantations for a range of uses (Williams, 1992). In modern times, mākutu is often unfairly blamed and/or rationalised as bringing adverse conditions upon phenomena or people, but it is a specialist skill that can be applied to a health context and requires specialist knowledge in controlled conditions.

Issues That Were Balanced

Band five of the interview schedule aimed to identify issues that whānau deemed important to have to weigh up, or, when one important factor has to be weighed up against an equally important factor.

Whānau Tahi

Lifestyle choices were identified by a number of participants as key factors they had to weigh up. For members of Whānau Tahi the decision to participate in cancer research and later, cancer treatment was weighed against their wish for a better quality of life. As an example, two participants referred to their tobacco use.

> *I'm a smoker which doesn't help. And I was older and I think it affects older people. And it makes it worse cause [because] I was a smoker too and that didn't help. They wanted us to give up smoking but I didn't.* (1AD, IB: Ref 1)

> *But, when he [the doctor] looked at our tests and that he said 'yep should be no problem for me because you're fit you know', and being a smoker, he said all the signs were there that I was in good condition, especially for being a smoker. Just the confidence that he talked to us, he explained everything clearly and any questions like I had two uncles, my aunty and he said if anyone wants to ask any questions it was there, just ask them.* (1JR, IB: Ref 1)

Both people acknowledged that smoking cigarettes is not a healthy life choice and they considered that it probably contributed to their susceptibility to cancer. Both have had radical cancer treatment by removing their stomachs. They described the operation as allowing them to resume their normal daily life and this has included continuing their habits to smoke, which they felt unable to stop.

Whānau Rua

A key factor that participants of Whānau Rua felt they often weighed, had to do with keeping themselves sufficiently informed about MH versus participating in MH research in order that health practitioners could learn about MH. One participant referred to the benefits for Whānau Rua in supporting the development of new MH knowledge because their whānau will ultimately benefit from. This was implied in the following comment:

> *In case if I ever had a car accident, they [health practitioners] know straight away that they can't give me some sort of anaesthetic, there's only certain anaesthetics they can give me, otherwise if they don't I'm gone.* (2G, IB: Ref 1)

However, other members of Whānau Rua questioned the extent to which they should engage in research, based on their experience or lack thereof in participating in decisions.

Whānau Toru

As explained earlier, OPD2 is a syndrome or collection of abnormalities which are incompatible with life. Pregnancy poses a specific dilemma for participants of Whānau Toru over and above issues for other whānau planning childbirth.

Increased risk of an affected baby with OPD2, the need for screening and probable termination of pregnancy was a key issue balanced against the desire for children. Despite each participant's understanding of the adversity and probable outcome for affected babies with OPD2, their faith that every pregnancy was potentially a healthy baby equalled their desire for children. Therefore, the difficulty of deciding to terminate a pregnancy was stressed. One participant described the context in which their whānau has had to make decisions about termination of pregnancy by saying:

These people who say that you shouldn't have abortions, they don't know what they're talking about because half the time, it's a necessity. Just to have the baby aborted because you don't want it, that's totally different. (3JM, IB: Ref 6)

The same participant believed that a decision to terminate a pregnancy because of OPD2 is a different kind of decision from one for an unwanted or unplanned pregnancy. However participants did not minimise any reason that would give cause to consider termination of a pregnancy.

Table 9 summarises the initial findings that emerged from participant interviews. Responses to Band 1 comprise the first two rows to show two broad themes that emerged - issues that relate to decision making about engaging in genetic research and issues that relate to decision making about screening, diagnosis and treatment. Each row below the solid green line corresponds to another band of the interview guide.

Table 9: Summary of Initial Findings

	Whānau Tahi (Case One)	**Whānau Rua (Case Two)**	**Whānau Toru (Case Three)**
Context of decision making concerning genetic research	High incidence of Stomach Cancer and death. Genetic predisposition to gastric cancer. Genetic Research	Death due to Malignant Hyperthermia (MH). Genetic predisposition to MH. Genetic Research	Deaths due to OPD2 Syndrome. Genetic predisposition to OPD2. Genetic Research
Context of decision making concerned with screening, diagnosis and treatment	Blood tests, gastroscopy, cancer treatment, surgical stomach removal.	Blood tests, muscle biopsy, medical alert.	Blood tests, amniocentesis, probable termination of pregnancy.
Whānau Decision Features	Hui Key people - leadership Role Models Control (mediation, education, processes, whakapapa, information dissemination) Manaakitanga	Hui Key people – leaders, personal attributes Control Manaakitanga •	Hui Key people – leaders, attributes Control (individual and collective) Manaakitanga •
The Meaning of Whānau	Based on whanaungatanga or common interest	Whakapapa Dependent on situation Specific and defined or has wide application	Inclusive
What Informs Decision Making	Information Role modelling Values and beliefs Fear	Information Ethical consent processes	Information Relationships with researchers. •
Balanced Issues	Lifestyle choices	Whānau knowledge vs. health sector knowledge	Termination of Pregnancy

Summary

This chapter has reported on the initial findings, and provided evidence of the findings, that emerged from 15 interviews with 17 members of three whānau who made a decision to engage and/or continue to be engaged in genetic research.

A common issue raised by each whānau showed overlapping issues in terms of their reflections on their decision making about genetic research, genetic screening, and diagnosis and treatment of a medical condition for which they are genetically susceptible. Participants these separate matters simultaneously in response to questions about their decision making. The relevance of overlapping matters is that participants did not distinguish between consent processes related to research, and those related to screening and diagnostic procedures or treatment. While a few participants appeared to understand that each context requires different decision making and consent protocols, it was not clearly articulated by all participants, nor was it clear in the data.

Another issue that emerged in the data was the catchall phrase, *health researcher*, used to refer to a range of people. The majority of participants did not distinguish between scientists, genetic researchers, genetic counsellors, health researchers and health practitioners. Whilst they may have understood the differences, it was not obvious in the data. Scientists do not necessarily recognise themselves as health researchers, and some health practitioners involved with the whānau had privileged access to them because they are specialists in the medical condition impacting on the health of whānau. The same specialists are also recognised within the health sector as researchers in their area of expertise, and participants did not allude to any understanding about a clear boundary between differing roles and responsibilities.

It should be noted that although the decision setting of each whānau fits the context of being ethical in nature according to the western construct of ethics, the majority of respondents did not identify their decision making as ethical, nor did they distinguish between different kinds of whānau decision processes. The point about identifying ethical decisions is made, because it can be assumed that lay members of the community understand ethics in the same way as the majority of the health sector. Participants in health research might be disadvantaged by the fact they do not differentiate an ethical decision from any other kind of decision, meaning they may not access or activate mechanisms for ethical review in situations where they are unhappy

with research they have been involved in. Accordingly, researchers may be left with a misconception that their research was meaningful for participants, when in fact the opposite may be true.

The next chapter discusses the findings across the cases, and applies an interpretive lens on the findings using the conceptual principles for analysis described earlier in this thesis.

CHAPTER SIX: CROSS CASE ANALYSIS

Te Ao Punga[28]

Introduction

This chapter analyses and synthesises the findings from all three whānau or cases. It begins by arguing that the cases are comparable on the basis of a number of factors notwithstanding the meaning of whānau. It discusses the need for a whānau to function as a cohesive group to facilitate collective roles and responsibilities in a decision context.

The chapter then builds on the initial analysis by describing the characteristics of whānau decision processes that emerged from participants' interviews. It discusses the process of analysis applied to this study with reference to three conceptual principles of Māori inquiry described in the methodology chapter, and it includes a discussion about the concept of wairua (Māori spirituality) that is embedded in the analysis.

Comparing the Cases

The whānau or cases are comparable for three reasons. Firstly, by the fact they identify as a whānau and the /nature of whānau was not defined for the purpose of this thesis. The criteria for engagement in decision making around participation in genetic research pre-empted the membership of whānau participants, but the partners of several participants, sat in on some interviews, as part of the participants' whānau, as listening observers or active participants.

Participants from all the cases had a range of ways to describe their whānau. Their descriptions reinforce what is already known about whānau from existing literature. That is, a whānau will often include individuals across generations and of different ages and genders, which was the finding of this study.

A whānau is not defined by whether it is demographically representative of all whānau; therefore it is not appropriate to reject the validity of the cases on the basis that they do not fully represent all kinds of whānau.

[28] Te Ao Punga symbolises the notion of the proliferation of a life form. The words are used metaphorically to characterise the proliferation of new knowledge that informs our understanding of whānau decision processes.

The second reason the cases are comparable has to do with the medical circumstances of each case, which provide the ethical context of their decision processes. Three medical conditions are relevant to the cases: Gastric Cancer, Malignant Hyperthermia (MH) and Otopalatodigital Syndrome Type II (OPD2). Each case has experienced death and its associated grief as a result of the specific medical history relevant to it. Evidence of the respective conditions of each case is traced back to at least the 1960s and for one case, as far as 1909 (Jones, 1964). The medical context surrounding each case, is known to be more prevalent in each respective whānau, than any other collective in the world.

Each case has been engaged in genetic testing for 10 years or more. Each has featured on a television documentary because of their involvement in genetic research (Carey, 2005; Cameron, 2003). Findings arising from genetic research concerning each case have informed scientific literature (Jones, 1964; Brown, et al., 2000; Davis, et al., 2002; Guilford, et al., 1998; Shaw, et al., 2005; Robertson, et al, 1997; Robertson, et al, 2001).

One participant was screened for susceptibility to gastric cancer and does not carry the predisposing gene. Another participant has never been screened and instead, has relied on the advice of a specialist doctor, that she has a high probability of being susceptible to the condition affecting her whānau, because her mother and all siblings have tested positive for the specific gene mutations.

All other participants interviewed have a genetic predisposition to one of the conditions. Participants of each case could name the condition affecting their whānau and they were generally able to explain the underlying pathophysiology of the condition, and methods of screening used to isolate their genetic susceptibility. The overall knowledge of participants in understanding the condition affecting their whānau is substantiated by the preliminary findings.

The context for commencing genetic research across the cases is similar. Their engagement in genetic research arose partly from their own desire to understand the recurring cause of deaths in their whānau, and partly through questions raised by local doctors who were concerned by a pattern of adverse outcomes in each case. The context of the anxiety confronting each case was the impetus for their decision making, highlighted by one respondent who said:

When you're desperate [to be well], you'll do anything...
And I was at that time, so I've seen so many of my whānau die before me. Mentally it was sort of getting to me because I've never seen any of my

whānau come out of it. They all ended up dying, so my head was sort of playing around as well. (1M, Ind Ex: Ref 1)

Participants of all cases indicated they were seeking an answer as to why the direct line of their whakapapa was afflicted with the condition, and not others. In all cases, genetic research has provided a scientific explanation of the cause of illness and death attributed to their respective medical history. In two cases, as mentioned in the previous chapter, participants have believed that one explanation for their condition lay in a Māori explanation, attributed to mākutu.

The third reason the cases are comparable has to do with Case Study theory. Collective case study research such as this, aims to identify what is common and particular about the case, and an examination of the cases (or whānau) becomes *intrinsic* in understanding the phenomenon of interest, whānau decision processes (Stake, 2008).

All participants of two cases reported they engaged in whānau decision processes about participating in genetic research. In contrast, only the eldest member of the other case could reflect on whānau decision processes in the same way. All other participants of the same case were unable to report any involvement in collective decision making because they were infants or they were not born. Consequently their experience of decision processes is very different and they questioned the adequacy of their knowledge, they did not have a sense of ownership of the research compared to the other cases, but more importantly, they did not have the same sense of accomplishment compared to the other cases, that their whānau has made a major contribution to medical knowledge, which was a primary motivating factor for engaging with genetic science.

Despite their different decision experience, the findings of their interviews resemble those of the other cases. Participants of Whānau Rua (Case Two) demonstrated a reasonable knowledge of MH expected of a lay person and they were able to give an overview of the pathology relevant to MH. In the absence of collective opportunities to be informed, their interviews suggest they were self-motivated toward obtaining information by other means outside of collective processes, and four sources of information identified by them were the internet, media, health service personnel and their whanaunga.

Participants of Whānau Rua were also consistent in their descriptions of the typical nature of whānau decision processes, and the findings from their interviews match the

description of decision processes characterised by the other cases. Data from Whānau Rua strengthens the evidence of the other cases, because while they did not have the same experience of decision making, they reported the same understanding of the way whānau decision processes work.

On all counts - the composition of the cases, the ethical context of their decision making, and replication of the findings, the cases have more similarities than differences.

Functioning as a whānau

A commonality of the cases is that they gave greater weight to decision processes than actual decisions, because the way in which whānau arrive at a decision has wide implications for the dynamics of the group and the nature of the decision.

The cases referred to decision processes that arise at two levels, the group, and the individual within the collective. At a collective level, the cases assumed that whānau have a desire for a collective process. They described their engagement with each other in positive ways that facilitated such processes, and participants talked about their valuing the contribution of other members of their whānau, or a feeling of their being valued by their whānau.

Individual participants were unanimous in identifying that their own individuality was both recognised and respected. They indicated that the support of their whānau was critical by giving them confidence that their own view was not only valid, but it reinforced their philosophical beliefs which they saw as being homogenous with whānau values.

Whānau support was recognised as important in a decision setting, with or without the presence of whānau, demonstrating an inherent power of concepts like whanaungatanga, manaakitanga and kotahitanga that enhanced individual confidence in decision making.

Literature by Mason Durie (1997) and Moana Jackson (1988) refers to the idea of a functioning whānau. The importance of whānau participation in decision processes is reiterated by evidence from the cases. However, for a whānau decision process to be effective, the whānau must have a desire for a collective process and function to facilitate that process.

There was evidence to show that the cases not only valued the contribution of their members, but they work to ensure there is a peaceful end to a discussion as has been described before:

A big thing with us is that we try to stay happy and in focus all the time. We have issues like everybody does. We're not perfect, but we just make sure it's all sorted before we leave. (3KT, Manaaki: Ref 3b)

In a situation where the whānau does not arrive at a collective decision or does not remain intact through the process, begs the question as to whether they were functioning as a whānau, or whether the process is conducive to upholding whānau principles and practice.

Roles and Responsibilities of Whānau

All cases referred to certain roles and responsibilities in a decision context, which they saw as contributing to the overall wellbeing of their whānau into the future.

Control over participation in research

The concept of control in decision processes was articulated by each case as important before, during and following research. The nature of the relationship each case had with researchers was a key factor in determining their feelings of control. Participants described their ability to negotiate their terms of engagement, the objectives of research, negotiate research processes and practice, and the dissemination of findings and access to raw data.

All participants of two cases were confident about their knowledge of screening and treatment options available to them. They appeared more satisfied with their knowledge of the research project, their knowledge of the medical condition affecting them and information they received from researchers.

The same participants were confident in their knowledge of genetic research and they reported confidence in the sincerity of medical specialists to want to address their concerns, demonstrated in a number of ways, including transparency by geneticists to report the progress of research findings, regardless of whether there was a result to report or not.

The geneticists, with whom the cases mainly dealt with, were primary investigators as well as specialist doctors in their field. The nature of relationships between them and the

cases had a bearing on the quality of, access to, and modes of information the cases received. However, not all geneticists were health professionals, a factor that may have impacted on lines of communication with one case in particular.

Communication between health researchers and participants is most often positioned within ethical structures and processes inherent to the health sector. The same protective measures do not necessarily exist for all health researchers such as scientists, meaning that their accountabilities to research participants are neither regulated nor supported in the same way as health professionals.

Regardless of the relationships, direct and frequent contact with geneticists, and easy access to them, were identified by two of the cases, as having made a difference as to whether they felt informed or not to proceed with research.

Face-to-face contact was the main preference of communication identified by the cases, followed by phone or texting, emails, hard copy documents and the internet.

All cases identified that a failure for their fears to be allayed by geneticists was the result of a lack of knowledge about their medical condition, or about the research process or protocols. Consequently, participants described feeling unable to properly consider the pros and cons of research, the recommended management of their condition, a lack of trust in health practitioners, and a corresponding lack of confidence in the wider health sector.

An openness by researchers to respond to individual queries was seen as a way that whānau developed positive and trusting relationships with researchers. This was inherent in the quote by one participant:

And people who care and they do care. They show a lot of real emotion, same with Dr ... he's another one. He really cares. (1AD, Leadership: Ref 10)

The cases valued direct negotiation with, and ongoing contact with the key or primary researchers in particular, whom they saw as being better positioned to answer their questions quickly and with authority.

Strength of negotiation with the primary research team was most evident for one case. A characteristic of their research project, which set them apart from the other cases, was their access to financial resources to employ a small group of whanaunga (relatives)

who were dedicated to the research project. Their resources also enabled them to seek independent legal advice to scrutinise their research contracts.

The importance of negotiation also emerged for another case. While they comprised a small collective in numbers, they had strong advocacy leadership within their group. A commonality of both cases is the positive relationship they described with researchers.

While it was considered that medical specialists were largely accommodating of the needs of whānau, it was also recognised by the cases that specialists have little control over the wider health sector including laboratories, hospital clinics, general practices and iwi health services.

The responsiveness of health services to the cases, contributed to their feelings of control. For example, any feelings of anxiety and stress experienced by participants during screening procedures were influenced by the empathy of health service personnel they encountered. The more kindness showed to the cases, the more the cases were likely to feel respected and thus able to discuss their anxieties.

The nature of the relationship geneticists had with the cases appears to strongly correlate with the levels of satisfaction and confidence about their decision making, reported by the cases. While participants of two cases described positive relationships with their research team, only one respondent of the other case expressed the same sentiments. The same person was the only member of her whānau to have participated in whānau decision processes at all. Of her whānau, she was the most confident in her knowledge of the medical condition affecting them, and she was also most confident about her access to the medical specialists. The same confidence is not typical of other participants of her whānau. Instead, the majority reported a lack of involvement in decision processes, a feeling of being dissatisfied with their knowledge, particularly about advancing genetic information to do with the condition pertinent to their whānau, and a lack of understanding about how to access information. One of the major differences between this case and the other cases is the quality of their relationship they described with the research team. But it has been explained that there are extenuating circumstances regarding transmission of information across generations.

All the cases emphasised that their whānau is best placed to identify potential issues that may arise for them out of research, and ways to mitigate adverse consequences. A

common factor expressed by the cases when researchers need their guidance is whakapapa (genealogy).

Whakapapa

Genetic researchers are by default, privy to knowledge of whakapapa. Access to whakapapa information as the mechanism for genetic tracing was typical of all the cases. Regardless of the relationship with geneticists, each case was cautious about a researcher's access to such knowledge. More specifically, how a researcher's knowledge of whakapapa might be used in practice.

Protecting and monitoring access to whakapapa was deemed important by all cases. Uncovering concealed, unknown or forgotten knowledge about biological heritage for example, is a potential outcome of a researcher's examination of whakapapa [ancestral knowledge]. Careless use of such information was considered to have major implications for whānau, thus all information including the dissemination of published material, was taken seriously. An example is a whānau member who is found to have different biological parentage from what is known, and they are excluded from whānau decision processes or even property ownership as a result of new information. For such reasons, one respondent stated:

> *Whakapapa belongs to us, nobody else. And the only whakapapa I do in here is A [the whānau involved in the research]; because theirs is the whakapapa we are researching to get where we are. If we do that and somebody says to me, can you have a look for B [into another whānau whakapapa] and it has got nothing to do with A or his issue [the genetic line being researched], nah, not me.* (1APa, Whānau: Ref 4)

Essentially, guardianship over whakapapa was seen as a safety mechanism to protect the integrity of the whānau. A general consensus of the cases is that it is in a researchers' interests to deliberately engage whānau in decision making, because while they have common objectives, how they reach those objectives are the point of difference, hence the need for negotiation.

Ethical processes and collective decision making

Mainstream consent processes were generally recognised positively by the cases as enhancing their ability to be individually self-determining. Ethical conventions such as consent forms provide a safety mechanism for researchers and research participants. This was described in the following way:

I know those things [consent issues] were safely looked after because of all the different meetings we had and we asked questions about that [consent]. We didn't want our blood to be used by anyone and everyone. (1AM, Leadership: Ref 3)

However, consent forms are constructed for individuals, and each case consistently referred to collective consent. Collective decision making is not a new phenomenon and has always existed in Māori society. A simple example is the determining of marae protocols. Marae practices can and do occur unchallenged by subsequent generations. This is not to say that the rules of conduct upon marae never change, but whānau have the ability to direct change and the evolution of norms.

The same application of collective decision making in a genetic context is quite a different matter. Firstly because genetic research settings are underpinned by a philosophical system that is western in origin. Whānau decision making is unlikely to lead to their being in control of such environments. For example, a laboratory that collects blood and tissue samples for genetic analysis. Though whānau might frequent a laboratory as part of their engagement in genetic research, their actual control over a laboratory environment is minimal, if it exists at all. The alternative is for health services to adapt, so that users of those health services have a positive experience.

The second reason the application of collective decision making in a genetic context presents challenges is because the ethical system that facilitates decision processes is not geared toward collective aspirations. Health researchers cannot promise to deliver on collective needs because, in reality, they are confined by regulatory mechanisms that are designed to only meet individual needs.

During the course of this study a hui was mediated by the author of this thesis, between all participants of one case and a key geneticist. The intention of the hui was to allow the case to speak directly with the investigator about their concerns over information divulged on a television documentary, which they believe was outside the scope of the consent they had given. Essentially, permission was not sought from the case to speak about their deceased baby. To their knowledge, a coroner's report made a link between the baby's cause of death and the medical condition of the whānau. However, the context surrounding the baby's death was a significant departure from the context of other whānau deaths for the same medical condition, and participants of the case said they were not consulted about the theoretical link described in the documentary, nor was there any agreement from them to discuss the infant's death. The experience of the

whānau highlights the kind of situation that can arise where an event has implications for a collective group.

Mediation

Another responsibility of the whānau identified by the initial findings is the area of mediation. For example, participants described the way certain key people acted as mediators between whānau members and genetic counsellors.

A number of participants felt that researchers need ongoing guidance about the way a whānau operates, so they understand how to engage with a whānau. One person suggested that a social structure called a hapū is a construct that has emerged theoretically. Over time it has been taken up and accepted by members of their whānau as a concept constructed by them. The concern expressed by the same participant, is that unless researchers understand Māori social structures, different names for the same group of people can give the illusion that there is a separate group, when in fact, their whakapapa is common. The same participant indicated that insight into the whānau structure is key information for researchers, because any misconceptions can have political and social ramifications such as being able to identify leaders and optimal lines of communication, consultation strategies and resourcing. For example, it cannot be assumed that all members of a whānau have in-depth knowledge of whakapapa. Identifying the best person with such knowledge can help prevent inaccurate conclusions being reached about ancestral lines, which protects whānau members, reduces confusion for researchers, and saves time and money by avoiding the pointless pursuit of information. The role of mediation was often described as occurring through leadership and accordingly one person said:

It's good to have someone to do all that for you, say if someone is scared or not quite sure, they know exactly what has to be done and they can come and explain to you what the procedure is going to be and things like that. It's wonderful to have someone [whanaunga or relatives] like that. (1AM, Leadership: Ref 5)

One participant who was identified as having leadership reiterated the importance of mediation by saying:

We are actually an advocate for our people on behalf of them, with the specialists, making sure that there is a direct line from us to the specialists. (1APa, WD: Ref 1)

The next section moves to describing the principles and practice that whānau utilise in decision processes.

Whānau Decision Principles and Practice

Hui

A hui was the most common feature of decision processes described by the cases in this study. A hui was the forum of choice of all the cases and the primary mode of communication for discussing any issue of importance among whānau themselves, or between whānau members and researchers or others. Two cases in particular indicated they controlled the nature, frequency and quality of hui, which they described as being important for their overall knowledge and understanding of genetic research. The same cases also suggested an important link between their control of hui and a positive relationship with researchers, because a hui facilitated their feelings of being in control.

Some participants were observed to have access to electronic forms of communication such as the internet and email, and they had technical capability to use electronic communication, but this cannot be said for all participants. Income and educational qualifications are the two most important variables that determine access to communication technologies like the internet (Statistics New Zealand, 2008). Higher income levels provide greater potential for disposable income to use on communication technologies. Differences in income and education qualifications mean that whānau members have unequal access to disposable income and therefore electronic communication (Statistics New Zealand, 2008). This means that whānau members can be disadvantaged when information provision is reliant on telecommunications and electronic technology.

The strength of a hui lies in its accessibility for whānau and in the way it legitimises whānau practices and facilitates wairua Māori (a spiritual dimension) that does not exist in non-Māori fora. A hui was identified by all the cases as an everyday experience suited to discussing collective issues, and thus it was identified as the most accessible means of communication for all the cases and was noted to have special significance for bringing whānau together.

Participants of the cases were in general agreement that a hui promotes their participation in decision making more than other forms of communication. The only requirement of a hui is that they turn up (attend). Though increased geographical

distance would present challenges for whānau members, a hui was identified in this thesis as conducive to collective decision making. A hui for participants of this study was made easier by the fact that the majority in each case lived in close proximity to each other.

All the cases indicated that any member of a whānau can initiate a hui. Sometimes the word meeting was used interchangeably with the word hui, although participants applied their understanding of a hui to the construct of a meeting.

A participant from one case attributed the resolving of consent issues at a collective level through the process of hui. Another participant from the same case referred to hui as a way of developing relationships.

Participants of two cases consistently reflected on their attendance at a hui, their awareness of whānau hui, and/or their positive satisfaction with knowledge they gained from attending a hui. Most participants of the other case could not comment retrospectively about hui, because they did not have the same decision experience as other cases by being involved in whānau hui. Incidentally most participants of the same case were more consistent in reporting dissatisfaction with their knowledge illustrated by the following comments:

There are other triggers (for the condition) and I don't even know what all of them are. (2N, KoC: Ref 2)

I wouldn't mind being tested to see if I do have it [the condition], but I haven't been called up, or no one has said that I have to have it. (2R, KoC: Ref 6)

Yeah, we should [know more], but it's [the condition affecting us is] something that I've just pushed to the side and just forgot about. It is quite scary in some ways, if you look at it deep, so you just push it [knowledge of the condition] to the side and one day it might pop up. (2G, KoC: Ref 2)

A hui is a dynamic construct that has always existed in Maori society (Salmond, 1985). Participants' credited hui with having many important functions such as imparting knowledge. Although a hui is likened to a meeting a hui is unique to Māori because of the practices facilitated by hui. Two practices are karakia (words of thanks) and mihi whakatau (informal greeting).

A karakia has its origins in whakapapa (Marsden, 1992). The application of karakia to public worship is a modern development and early settler missionaries equated karakia

to the Christian construct of a religious prayer, and they had a corresponding influence on transforming the nature of karakia (Williams, 1992). In common with a prayer, a karakia is generally used to acknowledge people. The other common practice, mihi whakatau (introduction), is also facilitated by a hui. A mihi whakatau has an inherent function similar to the karakia by recognising people, places and events. Individuals may declare their ancestral lines and in doing so, they provide others with the opportunity to identify how they are connected to each other by whakapapa. The practice embedded in a mihi whakatau constitutes the process of whakawhanaungatanga explained in the literature review. The modern practice of a round of introduction by attendees may well have been borrowed from Māori tradition. The difference however between a mihi and an introduction concerns the priority that is given to whakapapa. A mihi might for example include a reference to identity markers like rivers and mountains. Western practice does not have such a norm.

When a hui is conducted according to Māori custom, the detailed nature of it may vary between iwi, hapū and whānau. Regardless of the kind of kawa that takes place, a hui facilitates the intrinsic possibility of Māori oriented practices.

The underlying dissatisfaction expressed by participants of one whānau is derived from the fact that decisions by their whānau about their engagement in genetic research, occurred before they became adults. Hence the reason these participants found it difficult to identify any kind of informing or educative relationship with researchers, and decision forums that preceded the formation of such relationships. The majority of participants of the case described feeling a lack of ownership over the research and a lack of knowledge of the condition, and they questioned their capacity to hand on information to subsequent generations. The same issue of responsibility for transmitting information is also relevant for researchers, who will be limited by the resources available to them to engage with the future members of the case.

In general, participation in hui equates to participation in decision processes, and evidence from all the cases points to the importance of a hui as a critical feature of whānau decision making.

Rangatiratanga

So far in this thesis, the word control has been used as a preliminary title to label a feature of whānau decision-making that emerged in this study.

Control is a critical aspect of autonomy that matters for any social group involved in making decisions, defined as 'the power to influence people's behaviour or the course of events; the restriction of an activity, tendency or phenomenon; a person or thing used as a standard of comparison for checking the results of a survey or experiment; to command' (Soanes & Stevenson, 2004, p. 311). By this definition, control does not adequately capture the range of ideas expressed by the cases, because it assumes the idea of a superior/inferior or powerful/powerless stance.

Self preservation is an objective of control described by the cases, but it is also not entirely representative of the ideas the cases conveyed. The notion of rangatiratanga on the other hand, more aptly captures a range of ideas about control including self preservation. A prominent feature of rangatiratanga is leadership as the following person expressed:

These lot [our whanaunga/relatives] travel all over the North Island to put across [talk about] what they are doing and they're doing so well, I can't say enough about them. (1UP, Leadership: Ref 2)

Rangatiratanga was also described as the ability of whānau to exercise their autonomy in decision making such as their right to lead and determine their own future goals:

..our choice was to get answers [about why our babies died] and this [research] was our way to get our answers. (3P.S, KoC: Ref 1)

Kaitiekitanga or guardianship was mentioned earlier in this chapter in relation to whakapapa, and kaitiekitanga is an aspect of rangatiratanga, because whānau also reserved the right to have their privacy embedded in whakapapa, protected, as one person indicates:

Going back in the whakapapa. It is quite hard to talk about that [tracing whakapapa] because I feel like I'm breaching a trust if I'm talking whakapapa. (1APa, Whānau: Ref 2)

All of the characteristics embedded in the notion of rangatiratanga are relevant to the cases and individuals within those collective groups.

Leadership

Leadership emerged as a significant component of rangatiratanga that emerged from the cases. Leadership was described as having importance for two reasons. Firstly, leadership assists the facilitation of a hui, and secondly leadership aids the deliberation process.

All cases referred to leadership in decision processes, indicated by way of people who were named consistently by the cases. Participants of Whānau Rua, despite being unable to comment retrospectively about whānau decision processes, also named key people who assume specific leadership roles as part of typical whānau decision processes.

All key people named by the cases were whanaunga and they were credited with leading a range of matters such as the coordination of hui, mediation within the whānau and with external agencies, negotiation with researchers, and scrutiny of research processes and outcomes. In addition, they were acknowledged as having personal attributes that lent positively toward them being accepted as leaders. That is, they were considered to be knowledgeable, respectful of others and they are positive role models. Each of the attributes is discussed further.

Knowledgeable

Within each case, leaders were singled out because they were considered to be knowledgeable, a characteristic assigned to individuals who had specific knowledge and/or life experience relevant to the take (matter) in question. Those leaders had proven the usefulness of their knowledge to whānau in the past that had benefit for the whānau. Participants from each case consistently described the importance of knowledge. On the basis of their experience of their leaders the cases demonstrated confidence in their leaders to sort through complex information and to translate that information to them in simpler terms. Accordingly, participants described how their leaders shared knowledge and one person said:

> *We just talked. We would talk and talk and talk until we understood what we were talking about. M was always there, because we were all at the same meeting, but M heard a lot more than we did. She's really concentrating, and so M was really good. She taught us a lot herself, because she was listening to what they were saying and just giving it back to us in an easier way.* (3KT, WDF: Ref 12)

Respectful of others

Leaders shared another common attribute. They demonstrated a respect for others and one way, is by being an active listener, because they were known to respond cordially to other whānau who are talking and they showed interest in what is being said.

Leaders also demonstrate respect for others by being sensitive to individual needs. An example is their ability to keep information private when whānau members confide in them. This is highlighted by the following quote:

...I can just tell her anything. Sometimes I would go to her about more things than I would to my mum. (2R, Leadership: Ref 5)

As a result of their ability to maintain confidentiality, key people were trusted by their whānau.

Positive Role Models

Positive role modelling was a collective responsibility that emerged from the cases. Participants indicated that their whānau has a duty to role model behaviour that influences or supports the positive message their whānau wants to promote.

An example is the promotion of health screening. A number of participants spoke about their observing particular behaviours and attitudes from one or more whānau members whom they wished to emulate. Alternatively they described a sense of responsibility to role model certain behaviours and attitudes to inspire other whānau members to engage in health screening.

Another commonality of leaders is that they lead by example, in that they role model behaviour or characteristics that their whānau aspire to. One respondent of Whānau Rua said:

He's got himself set up. He's got study and he's got a wife. We've all got that too and he's always there to help. He's helped us all, I know that much. (2A, Leadership: Ref 3)

Leaders have positive relationships with whānau members and they are also accessible and available. They were described as readily accepting of advocacy roles which was demonstrated in a range of ways and one person described a specific instance:

I went in [for a Vitamin B12 injection] and it cost $28 each, so I went to see P [our relative] and them [other relatives]. They jacked it up [sorted out the cost issues] at the hospital... (1JR, WiD: Ref 7)

Types of leadership

Two types of leadership emerged from the findings, which are described in this thesis as *motivational* and *judicious* leadership. Each is discussed separately.

In order for a whānau hui to occur, one or more people take a leadership role to organise and coordinate the whānau together. Motivational leaders are primarily credited for their organisational strengths and they were described as taking on organisation roles readily. They often self-identified as having organisation skills and therefore were often self-appointed. Their natural tendency for leadership was generally validated by their whānau, although they did not call themselves a leader. Motivational leaders were noted to have more contact with each member of their whānau than others. As a result, they are often more aware of the skills and abilities within their whānau, they are more aware of the pattern of movements of their whānau, so they know how to access them readily. Motivational leaders are therefore well placed to rally their whānau together and this capacity was commonly affirmed by each case.

The judicious leader is chosen by the whānau and for this reason they are different from a motivational leader. Judicious leaders are primarily credited with providing wise counsel. They tend to be identified by whānau as an authority or delegated spokesperson for the whānau. Judicious leaders have a history of making sound judgements and offering well thought out advice, consistent with whānau aspirations. They are considered to be kind, trustworthy, honest and loyal, which were major reasons their opinion is valued. One judicious leader was described as the quietest participant in every whānau hui, yet his opinions were held in high regard. Those people identified by the cases as judicious leaders, did not call themselves a leader, though they recognised their role and the expectations of their whānau, but they were modest in reflecting on this.

Both types of leadership were attributed to mainly elder members, though younger members were referred to as having leadership when they possessed the generic attributes described previously. Fundamental to leadership described by the cases, is the value system that underpins the cultural framework within which the whānau operate.

The attributes of leaders as described by the cases is consistent with existing literature about Māori leadership. For example, a Maori leader in the sixteenth century was acknowledged only if his mana (influence, authority) and military prowess remained above reproach (Evison, 2006). While military prowess is not necessarily a measurement of a leader in modern times, the roles and attributes of leaders found in this thesis are consistent with Evison (2006).

Traditional Māori leaders were organizers of their people and they had exceptional abilities including the capacity to lead (Kawharu, 1977). They are also generally astute and visionary about advancing the interests of their people (Winiata, 1979). Of a traditional leader Evison (2006) says:

> Oratory, skill in debate, accurate memory, and truthfulness were therefore highly esteemed. Dishonesty and lying were considered disgraceful. A chief's mana was derived in the first place from his ancestry, but it was sustained only by his reputation (Evison, 2006, p. 20).

Regardless of the status afforded to leaders 'no Māori chief, however powerful, was entitled to override the customary rights of free-born members of his tribe' (Evison, 2006, p. 20). Disputes were aired publicly on the marae ātea (courtyard) and every person was entitled to their say and everyone's conduct or view was open to debate (Evison, 2006).

The nature of leadership as described by the cases has resonance with traditional descriptions, in that leaders were seen to possess knowledge and personal qualities aspired to by others, and their rights do not supersede the rights of the collective.

Different types of leaders were shown to co-exist amongst whānau and in this thesis some leaders have a predisposition toward organisation while other leaders have a predisposition towards wise counsel. It is possible that a leader might do both. The combination of intrinsic and demonstrated qualities by leaders augments their propensity to lead. By exercising their choice of a leader using their own criteria, the whānau is assured that their individual and collective rights are not compromised by their leader, and they have more of a guarantee that the true sense of rangatiratanga can prevail. It must be emphasised however that leadership contributes to the concept of rangatiratanga and the following discussion about additional features of whānau decision processes is also relevant to the broad notion of rangatiratanga.

Manaakitanga

Manaakitanga is not a word that was used by any participant, and it is not a word included in the interview schedule or used by the interviewer. However, based on the definition of manaakitanga described earlier in this thesis, it aptly depicts a collection of activities and attitudes described by participants of this study.

One participant explained that differences between individuals are acceptable in decision making, constituting an expression of respect encompassed by the notion of manaakitanga. Manaakitanga also concerns the preservation of individual and collective integrity that happens in two ways. Firstly, all members of a whānau are acknowledged as having a contribution to make. Each person has an inherent right to speak, to be heard and to be consulted. Secondly, there was recognition from all the cases, that different perspectives add value to a collective decision process.

As a practice concept, manaakitanga does not discriminate on the basis of age, gender, financial status, education background or personal persuasion. Each case and all participants placed importance on the concept of manaakitanga as a platform for different personalities that comprise their whānau, to present their diverse perspectives. A commitment to collective resolve was a key objective arising from manaakitanga, commonly emphasised by the cases. Closure to any conflict was a common goal for the cases. A number of participants indicated age is not a barrier to being able to contribute to whānau business. In fact, it appears to be a general expectation, that the youngest members are more likely to initiate cause for discussion as the following person described:

If we decide to have a meeting, the kids may have talked about it, and they'll all talk about it, not just one makes the decision, and they'll all agree, then come to me and say Mum we're going to have a Sunday meeting or get-together. [2L, WDF: Ref`2]

Manaakitanga provided participants with a right of entry to whānau decision processes by the fact they belong to the whānau, facilitating their own point of view to be heard. This was embedded in the following comment from one person:

Yeah, if they don't like what the others said (about the research), they'll argue it out. Don't worry. I'll just sit there and listen…In what goes on here, with their lives and what they do, sometimes I have got the last say but apart from that I'll tell them how I feel but they'll do what they want anyway. [3JM, Whānau Dec: Ref 1]

Kotahitanga

The concept of kotahitanga (unity and collectivity) was firmly embedded in all cases. Participants placed greater weight on the process of reaching a decision than actual decisions. They also described an overwhelming desire to protect the unity or integrity of their whānau in the process.

Kotahitanga works to combine the views of the collective. At the same time it legitimises individual perspectives by not attempting to move or persuade members of the whānau to take a specific position. The adoption of a single choice is an assumption that one position or view within the whānau is of greater value or greater benefit than another. Instead, kotahitanga aims to establish a collective position that sits comfortably with the group.

All of the cases described a sense of confidence that their own perspective and the perspectives of other members of their whānau were recognised and accepted. Such an approach to decision making is unlike a consensus agreement, a unanimous decision or a democratic process, that are conventional approaches to decision making, based primarily on a competitive model in which the majority rules and one choice is assumed to be sufficient.

Whānau support for an individual view does not mean that whānau collectively agree with each person. Differences between individual members of whānau were accepted and based on the findings of the cases, individual decision making is premised on the basis that whānau have informed and often reinforced individual positions. Therefore, whānau were seen to play a key role in supporting and reinforcing diverse perspectives.

Kotahitanga does not preclude individual decision making, but it is an inclusive approach that aims to support all perspectives within the collective. Differences were generally accepted by the cases as the following quote demonstrates:

We all are completely different, and you'll find that out, but yet we're the same. I think we've got the same views on things, but our own personal things are different, and just the way we are, is different. [3KT WDF: Ref 2]

The decision process can be likened to a journey. Attention to detail is important to ensure that the journey is both comfortable for all concerned and safety issues are covered off.

Members of the collective have to manage each other's personal traits, and while the group may travel the same route, their perception of the journey may be quite different because they will be enjoying it from different vantage points. In a decision setting, this translates into the mix of individual perspectives that are brought into deliberation.

Kotahitanga is both a process and an objective, concerned with protecting the integrity of the whānau, and integrity refers to a range of ideas including participation of their membership, the cohesiveness of relationships, and the wellbeing of the membership.

This is represented in a quote from one respondent stated in the previous chapter:

A big thing with us is that we try to stay happy and in focus all the time. We have issues like everybody does. We're not perfect, but we just make sure it's all sorted before we leave.

All respondents indicated that their whānau is a key influence on their individual decision making, a point indirectly made by one respondent who indicated that individual thinking is embedded within their whānau value base:

It's just that when you're with other whānau their mind takes off in other places where I started to think the same as them. And I just caught up like that, like – 'oh yeah better go for the operation ra ra, instead of sitting down and thinking about it. [1M Whānau Dec Ref2]

As a whānau is greater than the sum of its individual members, a whānau decision process is cognisant of managing and accommodating a range of views. It is unlikely that a whānau decision would exclude individual positions, but instead allows for multiple perspectives to be represented.

The complex nature of kotahitanga that emerged from the cases is consistent with descriptions of pre-19th century Māori practice, whereby individuals had recourse to their tribal group, to the extent that the tribe was interested in any action of their part that might affect them (Kawharu, 1977).

Kotahitanga is intrinsic to the notion of whanaungatanga described in the literature review, that refers to the idea that whānau have the capacity to function positively for the benefit of the collective; their members acknowledge and are committed to their ancestral links and practices that enhance the links (Pere, 1984; Durie M., 1997; Boulton, 2005; Durie, Black, Cunningham, Durie, Palmer, & Hawkins, 2005).

Wairua

Wairua is not a construct that is obvious in any data. However wairua is a conceptual reality of a Māori worldview that is embraced in both modern and traditional narratives. Examples of the application of wairua were mentioned in earlier chapters.

Wairua is often translated as referring to something spiritual or the notion of spirituality, and thus it is sometimes confused with the western notion of spirituality and Christianity.

Earlier in the thesis, Manuka Henare (1998) was quoted as saying:

The maintenance of the religious view of life is dependent upon the maintenance of the culture and its many practices and rituals (Henare, 1998, p. 3).

Henare likens the construct of a religion, to living as a Māori. To maintain a Māori way of life, one has to be able to maintain the practices of it.

Wairua is the manifestation of all phenomena oriented towards living as a Māori philosophically. Ohia (2005) refers to the notion of "Kaupapa Wairua Māori" (p. 228), a spiritual construct that he discusses in an education context. He proposes that Māori theory needs to connect with people as well as the set of moral and ethical imperatives foundational to Māori cultural life. Henare (1998) reinforces Ohia's view by emphasising that in developing the practices of Māori, then the culture or religion underpinned by wairua, is developed and vice versa.

At times wairua converges with western religious constructs. Newman (2006) gives the example of the Ratana Church, of which he describes its members as deeply spiritual people who can 'easily identify with spiritual principles and deep truths of the Bible' (ibid, p 461).

The earlier discussion in this thesis about the origins of western and Māori research traditions is pertinent to this chapter, because Christianity as a religious orientation has western origins located in a time before the birth of Jesus Christ. Wairua on the other hand, has very different beginnings entrenched in cosmology described by a whakapapa tradition.

What is common about Christianity and wairua is the search for truth according to the terms of their traditions. By acknowledging the existence of wairua, one is able to acknowledge the plausibility that phenomena can be explained by a worldview in which wairua is the reality. A consequence of accepting wairua as a legitimate construct is that western knowledge traditions such as science are acknowledged as a means of explaining reality and not reality itself. Therefore, the potential for other worldviews to explain the universe is accepted.

The relevance of the latter point is that decision processes arise and are formed by the values and ideas of the society in which those processes are valid. In this thesis, the society is Māori and the social structure is the whānau. If whānau processes are examined by western society according to western reality, then a different set of values will be applied and decision processes will not be seen to have a sense of logic or legitimacy. Even by western scientific principles, it is illogical to measure a phenomenon using a set of standards not designed to measure it in the first place.

Conceptual Analysis

Turangawaewae, whanaungatanga and mauri constitute the principles that were used for a conceptual analysis of the findings. The findings were extrapolated by considering each principle against the data. An additional element of the analysis was the investigator's observations of the context of each interview, including the people present, the setting, the mood and the respondent's intonation and affect.

To recap on the principles, turangawaewae concerns identity and the range of ways that identity is formed and informed. Data from respondents showed that characteristics unique to their identity emerged in decision processes, informed by culturally constructed social and intellectual norms.

Whanaungatanga refers to a process by which whānau strengthen and support each other, recognising the decision makers as well as the recipients of decision making. Greater responsibility is thus placed upon the shoulders of those who are engaged in the decision process.

Mauri is an implicit cosmic rather than physical quality that recognises the inherent worth of all phenomena and renders all phenomena equal. Manaakitanga is the enactment or practice by which mauri is acknowledged. In a decision making forum for example, a person is likely to feel valued if they are given opportunities to be heard and their opinion is considered seriously. Acts that facilitate people feeling valued are an expression of manaakitanga and many instances were identified from the data.

Wairua Decision Framework

Table 10 illustrates a framework that summarises decision principles and practice derived from the study, founded upon the notion of wairua.

Across the top of the table is each broad analytical principle used to examine the data. Down the left side of the table are the findings of this study with a corresponding description of how each finding manifests in relation to each conceptual principle.

The framework intends to visually demonstrate that there is a cultural framework that determines the mode of operation of whānau in a decision context.

Table 10: Wairua Decision Framework

Wairua Decision Framework			
	Turangawaewae Whānau identity is paramount for wellbeing.	*Whanaungatanga* Whānau identity is embedded within whakapapa and whakawhanaungatanga.	*Mauri* All phenomenon are equal
Hui *A dynamic construct for communication*	Whānau refer to their own distinct protocols and practices for hui.	Whānau utilise their own skills and abilities to engage in hui.	Whānau facilitate maximum participation in decision making by their membership.
Rangatiratanga *Self-determination*	Whānau determine their ground rules for decision making.	Whānau engage with and foster their leadership.	Whānau are inherently aware of their worth and they promote activities to enhance pride within their group.
Manaakitanga *The whānau as a collective is valued*	Whānau adopt inclusive decision practices.	Whānau promote positive relationships.	Whānau recognise diversity within their collective group and promote inclusive solutions.
Kotahitanga *Whānau integrity is maintained through actions that promote collectivity and unity*	Whānau ensure safeguards for free and frank discussion in decision processes.	Whānau draw on their inherent knowledge and wisdom to inform decision making.	Whānau value the contribution of their members.

Summary

It is difficult to label the features of whānau decision processes using the English language, because English words do not adequately capture the depth and breadth of Māori constructs. The linguistic challenges have been an ongoing tension in this thesis.

This chapter has analysed and synthesised the findings from the cases, comparing and contrasting them. A number of key features emerged: hui, rangatiratanga, manaakitanga and kotahitanga, all of which are underpinned by a philosophical base that is Māori.

The cases placed more weight or importance on the collective decision process rather than the actual decision, and all the cases talked about the importance of whānau in affirming their collective and individual decisions. All cases believed their whānau is a key influence on their individual decision making, in so far as; decisions are firmly embedded within their whānau value base.

All the cases identified individual diversity within their group as a strength of their collective and they valued the preservation of their collective character. A whānau decision does not preclude individual members from making diverse choices, but whānau endorsement was considered critical to validating individual autonomy.

Consequently, a whānau decision appears to comprise a range of views that more accurately represent the collective. There is unlikely to be a collective decision for which a single choice is made. Rather, a collective decision is more likely to be a position that reflects a range of solutions.

Emphasis was consistently placed on the validity of whānau constructs to reach important decisions, regardless of the context of the decision to be made. A hui provides a platform for rangatiratanga, manaakitanga and kotahitanga to be played out.

A general consensus of all the cases is that whānau integrity must be able to weather the decision process and ultimately remain intact at its conclusion. Such an outcome is more likely when whānau are in a position to conduct decision processes on their own terms and in this way, they have a guaranteed right of entry, they can set the parameters according to their own terms of reference that are achievable for them, framed by their own value system.

CHAPTER SEVEN: DISCUSSION

Taku hē ki te huatea nō muri ko Te Huauri[29]

Introduction

This chapter discusses more fully the implications of the findings about whānau decision processes described in the previous chapter, with reference to the case studies and existing literature.

The chapter revisits the theoretical bases of Māori and western philosophical discourse that underpins decision processes. It is proposed on the basis of evidence provided in this thesis that whānau decision practice is neither fully nor partly explained by western decision theory, and therefore it is justified to suggest that whānau processes fit with another theory embedded within a Māori intellectual system. Of central importance is how the findings change what is known about decision processes in general and whānau decision processes specifically. The principles and practices whānau utilise to guide decision making have social, cultural, economic, philosophical and political implications for their wellbeing.

The chapter then describes the implications for health research in enabling whānau decision processes to occur and it reflects on the contribution of the study to health policy, research and education, and the strengths and limitations of the thesis.

The chapter concludes by reviewing the aims of the thesis and identifying how the aims have been met.

Reviewing the basis of western decision practice

The literature review and methodology chapter of this thesis discussed western philosophy that forms the foundation of dominant decision theories. Approaches to decision analysis are categorized as descriptive, prescriptive or normative, and if decisions are of an ethical nature, then ethical theories are also applied to decision processes. All of the approaches are derived from western assumptions about decision making and are underpinned by the intellectual framework of that society.

[29] A whakataukī or proverb belonging to the tribal group, Ngāi Tāmanuhiri, described earlier in this thesis, and used in this chapter as a metaphor for *new potentia*l possible in the area of health research through understanding of whānau and their engagement in decision processes.

Science or empiricism has a major role in western thinking and as such, empirical deductive methods of rational and reasoned analysis are a prominent feature of western decision practice.

The evolution of western theoretical discourse has reinforced pluralist concepts such as superior and inferior reality, which manifests in practice by way of the goal of western decision making - a preferential choice of a range of options.

A democratic process is a key instrument used in western society to reach a decision. The preferred decision is one that the majority of people choose. In this way, democracy invokes a decision that has consequences or utility for the most people consistent with utilitarian ethics. Consequently, democratic processes do not always favour minority populations.

Māori, for example, are likely to agree with the general population that research into causes of lung cancer is important because of the disproportionate number of sufferers who are Māori women. But they might not agree with the general population about the kinds of methodologies or methods that should be applied to cancer research to advance understanding of cancer prevention and treatment.

The history of health research illustrates that decisions favoured by those who have the balance of power are not always consistent with protecting basic individual human rights and equity. Decision practice and ethical theory in New Zealand are dominated by western intellectual and philosophical traditions. Health legislation, the ethical review system, health policies and health research practice privilege western definitions of health, its customs and mores.

Dominant decision theory is drawn from the same western foundations as the laws that facilitate decision practice, and it makes claims that informed decision making is most relevant to an individual and thus the individual should be able to conduct decision making independently.

The language used in the health sector centres around western health discourse. The context of the experience of whānau in this thesis is firmly flanked against a science paradigm. It is therefore no surprise that the language they used to express Māori concepts privileges western words. The use of the dominant language might give the perception that the thinking of whānau is also immersed in western philosophy, when the contrary was found to exist in this study.

Locating whānau decision processes

The findings of this thesis cannot be explained wholly or partly by western decision theory for two reasons.

Firstly, the philosophical principles used to analyse the data, are derived from a Māori intellectual framework that has major philosophical distinctions from a western theoretical framework that informs western decision practice. Secondly and as a consequence of the intellectual foundations, the beliefs that flow from western decision theory are unable to explain the characteristics of whānau decision processes that emerged from the analysis.

Holism is a key feature of Māori philosophy, described in the literature review and the methodology chapter, and substantiated by the findings. Holism as a philosophical premise is as much about retaining the holistic meaning of the principles of analysis, as it is about applying the principles to phenomena to preserve the integrity or wholeness of phenomena. In this thesis, the phenomenon of interest is whānau decision processes.

A deconstruction of the concept turangawaewae, for example, is an analytical endeavour incompatible with the philosophical foundations that informed the construct. In order to adequately utilise Māori philosophical concepts like turangawaewae, such concepts must be applied in total.

As a moral benchmark, holism manifests in whānau decision making through practices that preserve the whānau. Maintaining whānau integrity occurs through the conduct of a hui and the practice of manaakitanga, kotahitanga and rangatiratanga.

The findings of the study are summarised in Table 10 and correspond with the nature of Māori philosophy. Each construct has layered meanings. Thus, the principle of rangatiratanga as interpreted from the data has many meanings, and all are equally relevant to whānau decision processes.

Whānau decision practice is identified as amounting to a collective ambition. The western pursuit of a single choice or decision applied to a whānau is not sufficient, because it cannot be assumed that a decision reached by an individual member of a whānau will be the same decision of their whānau.

Whānau acknowledged their own diversity and the safeguarding of individual autonomy within the collective was a positive contribution toward enhancing the collective.

How the findings change what is known

This thesis does not deny the validity of western theory or the constitutional entitlement of individuals and the applicability of western discourse to modern Māori society. The findings of this thesis may not resonate for all those who identify as Māori, because Māori are not the same, and Māori society is as diverse as any society. However, for whānau who wish to live as Māori, this thesis challenges the capacity of the New Zealand health research sector to accommodate their decision processes because of existing limitations.

The first reason this thesis changes what is known about decision processes, is that decision practice in a whānau context, is a collective exercise. Individual members of whānau rely on the principles of decision making that are drawn from the collective they associate with, and their decision making is underpinned by a collective value system.

The second reason this thesis changes what we know about decision processes, is that whānau utilise conventions that are culturally constructed. The nature of whānau and the processes that they employ are culturally oriented to reflect a Māori concept of wellbeing or hauora.

Comparing and contrasting western and whānau decision practice according to differential terms of reference is problematic. As explained earlier, any attempt to apply a western framework to rangatiratanga for example, would require a linguistic deconstruction of rangatiratanga, a deconstruction of the ideas embedded in rangatiratanga and then an examination of those ideas separately. A reinterpretation of rangatiratanga by a deductive paradigm constitutes the reconstruction of conceptual thought that no longer fits a Māori intellectual tradition.

Table 11 summarises the components of a western decision tradition and the principles of whānau decision practice that are described in this thesis.

Table 11: Interface of Western and Whānau Decision Practice

Characteristics	Western Decision Tradition	Interface	Whānau Decision Characteristics
Intellectual Framework	Realism as naïve/critical/historical/ relative or constructed	Underpinning philosophical assumptions	Holistic realism. Human reality is interrelated with the laws of nature
Origins	Statistics, Mathematics, Economics, Management Science, Operative Research, Psychology, Behavioural Science	Decision making explained by the intellectual system of origin	Multiple informants – explanatory power lies with whakapapa
Methodology	Expected Value Reasoned Analysis	Context relevant	Motivated toward the maintenance of Māori moral standards e.g. manaakitanga, rangatiratanga, kotahitanga
Methods	Analytical Task oriented	Philosophically aligned	Consistent with enabling Māori philosophical principles to be applied to research e.g. Hui

The grey column in Table 11 shows the interface of decision traditions. The interface usefully identifies areas of commonality, and it serves as a beginning point of analysis, to better understand the nature of whānau decision processes and the whānau practices and principles are or are not, accommodated by dominant ethics processes. The point has already been made that western and whānau decision making is informed by their respective traditions. The next important step is to facilitate whānau decision processes that are culturally and therefore ethically oriented to improving their health.

Implications of the findings

There are two sets of implications arising from the findings of this thesis. One set concerns the implications for whānau wellbeing and the other set of implications concerns the role of the health sector in facilitating whānau decisions that contribute to improving their health.

The findings of this thesis illustrate that whānau utilise concepts in decision processes that are culturally unique. The findings are consistent with the nature of Māori ethical

practice described in the literature review, and are also consistent with fundamental characteristics of a Māori research tradition described in the methodology chapter.

Whānau decision practice is thus aligned to a Māori intellectual framework and although this research is insufficient to propose the existence of Māori decision theory, the weight of evidence indicates that such a theory exists. Thus, new insight from this thesis has implications for whānau and for health research.

Implications for whānau

Social implications

Earlier in this thesis, the importance of socialisation to the development and maintenance of the value system of society was noted by Mulholland (2001). He described socialisation as a process by which children learn the beliefs and ideas or values of their society, predominantly through their home environment and the education system. Socialisation aids the internalisation and perpetuation of societal values and the literature review describes the relationship between the values of society reflected in law, and the way the law informs the ethical review system, a cornerstone of modern health research. It is for the reasons explained by Mulholland (2001) that the process of socialisation makes a significant contribution to Māori cultural identity through the perpetuation of Māori social norms.

Decision processes are a mechanism for socialisation, thus whānau decision processes are an important way in which the internalisation of Maori practices and values is facilitated.

Through their being able to practice the collective act of decision making, whānau perpetuate the norms of their culture, and sustain the maintenance of their cultural identity. Consequently children are exposed to, and they learn about their own whānau practice and principles through cultural norms embedded in decision processes. Being able to live as a Māori constitutes being able to maintain ones' identity, an important social determinant for wellbeing (Durie, 1999). A hui for example, was the most commonly cited characteristic of whānau decision processes. Participants not only identify with the concept of a hui, they relate a hui to collective processes, they recognise the importance of hui for collective decision making and they identify with intrinsic practices of a hui. This is emphasised by the following person:

If we've got a take [issue] and we want to talk. Depending on who's got the take with who, I mean, phone call, I'd ring up or we'd go see one another and say we should have a hui, what do you reckon? Blah, blah, blah, this is the take and we actually had one recently and it was good. We're all quite private people and we do our own thing and when we're aware of something or something comes to our attention and we have to help out, well then we just get together and we do it, help out. (2A, Hui: Ref 3)

A sociological explanation for inequalities in health between Māori and non-Māori emphasises the impact of dominant social constructs. Whitehead (1992) explains that there is sufficient evidence to show that social behaviours cannot be separated from a social context, and thus health policies aimed at reducing inequalities which focus entirely on the individual are 'misguided' (p. 336). With Whitehead's advice in mind, it is critical to expect that health policies would aim at promoting collective conventions such as those that manifest within the whānau.

Cultural Implications

In order to preserve a Māori intellectual system, the constructs that make up the system must be maintained. Mātauranga, like any other knowledge system of a society, is critical to Māori society. Earlier in this thesis, examples of mātauranga were drawn upon to demonstrate the depth and breadth of a Māori research tradition. Retaining the form and function of the whānau constitutes a vehicle for the growth of mātauranga, because, the practices embedded in whānau processes are mechanisms by which experiences of phenomena occur, and those experiences can be expressed through and manifest in the development of mātauranga.

Manaakitanga for example, is a concept intrinsic to certain behaviours and actions, and collective processes like decision making, facilitate whānau to be able to practice manaakitanga. When manaakitanga needs to be expressed in the context of new phenomena like genetic research, it presents both a challenge and an opportunity to articulate whānau practice in a new environment that contributes to the growth of mātauranga.

Whānau therefore have the potential to construct and articulate new knowledge in response to their experience of new phenomena. Through whānau decision processes they perpetuate Māori moral constructs, a contribution to the preservation of culturally constructed moral standards.

Whānau also have the potential to sustain their unique identity as a group, and when they engage in decision processes, they are making a major contribution to their individual and collective well-being.

Resource implications

Whānau decision practice has a basis in kawa. Time, space and boundaries of negotiation are inherent. The cost of promoting whānau decision processes is a short term investment for a long term gain. The benefits for research and health outcomes in facilitating whānau decision making, significantly outweighs the cost of failing to accept that whānau have specific health needs.

Decision processes involving whānau must be resourced sufficiently to ensure focussed attention can be given by researchers, and ultimately lead to positive and productive relationships, and achievable research outcomes.

This thesis demonstrates that ethics is not understood the same way by all members of society. Māori may not utilise mechanisms embedded in ethical protocols, if they do not recognise Western ethics as constituting their definition of a moral safety net and specifically, with respect to health research.

Health researchers are typically expected to determine if their research requires consultation with Māori. What *Māori consultation* actually means, or should mean, is well overdue for examination. Health research for example, that does not target Māori participants, does not necessarily exclude Māori either. Should consultation in such a case take place? If so, what nature? Much work is needed to inform health researchers about how to develop research proposals that include Maori communities. Although current ethics processes may be useful in highlighting gaps in health service provision, there has not been sufficient engagement with Māori in order to establish, in partnership with them, whether consultation with health researchers is useful and beneficial to them.

Ethics committees have the important role of reviewing research to identify harm to participants of research. By the same token they are constrained by the frameworks and policies that guide their work. As such, ethics committee policies may fall short of protecting all participants of health research, and therein, contribute to health gaps.

Equally important is the role of health funders' expectations about working with Māori. The meaning of 'Māori consultation' must be made more explicit, and resourcing should be sufficient enough to enable researchers to achieve funders and community expectations. For example, consultation might mean negotiation with the Māori community intended to be researched, as well as with Māori who are experts in the subject matter, those who have experience in Māori health research, and/or Māori who have experience of working across a range of Māori sectors. Consultation practices such as face-to-face meetings or hui need to be factored into the resource needs of researchers. Health researchers may otherwise resort to alternative strategies to manage under-resourcing such as, shoulder tapping Māori for consultation purposes because they are Māori.

Ongoing deficiencies in the health system are perpetuated by a lack of recognition by governments to address fundamental philosophical, constitutional, legislative and policy issues to facilitate whānau decision processes. As a result, the same health gaps remain with long term financial implications not confined to the health sector alone.

Philosophical implications

Whānau have a key responsibility for the care and protection of their group. Genetic research requires an examination into the genetic history of whānau. Therein lies the possibility for exposing information about whānau relationships that may have purposely been concealed, is unknown or forgotten. Whānau members who have intimate knowledge of previous relationships that are unknown to current generations may have died. Such information may first come to light for later generations through the process of genetic tracing, which can have positive and/or negative consequences for research participants.

Whānau need to consider their preparedness to deal with new insights into their whakapapa that might be uncovered by genetic research, because uncovering previously unknown familial information about biological heritage may initiate long term grief, loss and hurt for individual members, rather than for the whānau collectively. Wider implications include questions about rights to inheritance and land ownership and during the course of this study, the researcher heard from participants who were made aware of previously unknown information about their lineage. In one case, such information was being actively guarded to protect whānau relationships, an outcome

that is not generally anticipated by health researchers, nor is it necessarily a consideration of the consent process for participation in genetic research. Consequently, it is an issue raised in this thesis that must be managed by whānau within decision processes.

Despite genuine attempts by researchers to mitigate forms of physical, social or mental harm, they need to be mindful of the indirect negative and long term impact that the research process may have on whānau long after their relationship has ended. A case in point is that the ethical review system does not protect collective groups substantiated by two factors.

Firstly, it was difficult to protect the identity of whānau in this study because, through the application of academic conventions to this thesis alongside the list of scientific literature publicly available, each whānau can be located geographically. As a result, medical and research information about each whānau can be found as well as images of individuals.

Secondly, the experience of one case concerning a television documentary shows that participants of that whānau identified they had a set of rights, located within their collective, which were imposed upon. Not only does their scenario raise questions about the liberties that are taken from the consent of individuals, this thesis asserts that when a matter imposes on the rights of the collective, individual consent is not sufficient.

The two factors described are specific examples that demonstrate the necessity of health researchers to actively engage participants of their research in decision making, to ensure that research protocols are consistent with whānau values and international protocols, and protect the collective. Where this does not happen, research practices may cause ongoing and irreparable harm.

Political implications

Whānau will be better able to address and sustain their own wellbeing when they are active participants in decisions about their own lives, a fundamental human right explicit in New Zealand and international covenants.

Facilitating whānau engagement in decision making requires an enabling environment for both participants of health research and health researchers. The findings of this

thesis assert the need to promote opportunities for whānau to make decisions within their own cultural context. The Treaty of Waitangi is an existing framework for relationships applicable to the health research sector. Playing lip service to the Treaty has never been acceptable and those involved in health research must practice the ethical standards that they profess to uphold, to protect all participants of health research and ensure equity of health outcomes.

Accountability to Māori communities is only possible when those affected by decisions, have ways to ensure their needs and concerns are dealt with reasonable care.

In 1988 the Royal Commission on Social Policy identified three principles that underpin the essence of the Treaty. Over time, the principles, rather than the context of the full Treaty agreement have taken precedence in health policy and legislation inconsistently, which has not served the New Zealand public or the health research sector well.

The Treaty principles cannot be understood outside of the context of the society for whom the principles are meant, and neither should they be interpreted in isolation from the community for whom they are meant.

Why do we need to know about the findings?

As stated in the introduction to this thesis one of the fundamental purposes of health research is to improve the nature of people's lives so they are self-sufficient, maintain wellness, have a sense of their distinctive identity and their cultural systems, and they prosper in whatever setting they find themselves (Durie M. , 1998).

Active engagement in research decisions by research participants is an important step toward their achieving self-sufficiency. There is little point in applying methodologies and methods to health research that have little theoretical or practical application for the societies they are designed to investigate.

Decision processes provide an important link between researchers and communities being researched, and it is imperative to engage both parties to ensure research is relevant, purposeful and targeted.

Active involvement by whānau in decisions about their own health underlies the government's Māori Health Strategy *He Korowai Oranga* and it will only be fully

realised when whānau decision processes are not only better understood, but they can actually occur.

The Health and Disability sector is expected to work in partnership with whānau so that decision making leads to whānau ora improvements and supports the achievement of Māori health aspirations (Ministry of Health, 2002). To do so effectively, requires an understanding of the characteristics of whānau decision processes which can then be given full recognition within health policy.

This thesis makes a contribution to wider the health and education sector by providing greater insight into the nature of whānau decision making and ways whānau processes must be accommodated within the health sector to ensure shared decision making is possible. Such an approach will significantly contribute to the overall goal of reducing inequalities in health between Māori and other New Zealanders.

The following are implications of the findings for health research.

Implications for health research

Enabling Constitutional Environment

In order to effect change for the benefit of whānau wellbeing there must be a political will and strength to give force to the Treaty of Waitangi in law as Māori understand it. Such an approach will never be achieved by redress through the Waitangi Tribunal. The Tribunal is established to consider grievances that have a basis in breaches of the Treaty, according to the Crown's sole authority about its form and function and recommendations of the Tribunal are not binding on the government.

Legislation must be inclusive of Māori ideals. The introduction of Māori concepts into health legislation for example, would have the effect of broadening the scope of ethical responsibilities for which the health sector is accountable. Policies that arise from broad based changes in legislation need to be oriented toward effecting and promoting whānau engagement in decision processes to effect changes in attitudes and behaviours amongst health researchers.

Funders of health research must raise the level of their expectations of health researchers and at the very least; researchers should demonstrate a history of

involvement with Māori communities and a record of contribution to the same communities.

Capacity Building

Understanding the link between the Treaty of Waitangi, the socio-political context of health and Māori society, must be compulsory education for all health researchers in New Zealand. Most Treaty education in New Zealand currently occurs far too late and during adulthood.

The inclusion of compulsory Treaty education in education curriculum from Primary school level and upwards, would be an important step toward the development of an informed society including the health research workforce.

Genetic scientists may not see themselves as health researchers, but if they are engaged in health research projects and/or receive health research funding, they need the same generic education about the Treaty as their health colleagues.

Curriculum differences across health professions and science disciplines which comprise the range of ways researchers become involved in health research, means there is likely to be inconsistencies in their level of preparation for working with a range of communities including whānau. Without a consistent foundation of basic knowledge, the health sector fails in its responsibilities to wider New Zealand society, by ensuring that researchers appreciate the way that worldviews have a real impact on their research communities. Too often the value of indigenous knowledge and norms are more rhetoric than reality as health researchers pay lip service to cultural practices and then impose their own ideas and values.

Deliberate Association of Research Parties

Health research funders and operational policies need to make provision for a genuine consultation period, independent of actual research that promotes deliberate engagement between research practitioners and their community of interest.

It was earlier described in this thesis that a meeting was set up between one whānau and a researcher, to enable the whānau to discuss their concerns about the content of a television documentary. The hui enabled the researcher to meet the whānau, the faces of her research, for the first time. A simple process achieved a positive outcome for both parties and a participatory approach made a significant change for the people involved.

Building capacity within the research sector by providing researchers with tools and support to enable participatory processes to occur is necessary for empowering both whānau and researchers alike. Specific funding for creating deliberate associations between research parties and whānau would have the purpose of providing researchers with resources (time and money) to facilitate their engagement with prospective research participants. In exchange, they must demonstrate their process of negotiation with funders prior to commencing research. For example, an ethics application would need to demonstrate formal endorsement for research, by proposed participants. A consultation period can be built into current funding cycles and precede full applications for proposed research. A consultation need not be onerous, but it is intended to provide sufficient means by which researchers can appropriately engage with whānau, while also facilitating time for whānau processes to happen.

Strengths of the Thesis

Te Pūmanawa Hauora (Rigour)

Earlier in this thesis, it was argued that values are fundamental to a Māori research tradition and important both for the conduct of research and in the quest for rigour.

There are two reasons to justify a values-based approach to rigor. Firstly, since accountability to the research community is of primary importance, it makes logical sense to employ the community's own values as the basis for measuring rigour. Secondly, with the depth and breadth of a Māori research tradition and its inherent values, it is critical that the integrity of health research reaches the standard of scholarship aspired to by the foundations of that tradition.

Contemporary research shows that despite an apparent lack of connectedness by sectors of Māori society to traditional order of Te Ao Māori, values such as turangawaewae persist. For example, this thesis proposes that Borrell's (2005) work gives a modern description of the notion of turangawaewae from the perspective of rangatahi in South Auckland. This means that traditional concepts continue to have application to modern Māori society though this cannot be always assumed.

Te Pūmanawa Hauora is a research framework developed for this research that is described in Table 13, underpinned by a values-based approach to assessing rigor.

Table 12: Te Pūmanawa Hauora Research Tool

Te Pūmanawa Hauora				
		Tūrangawaewae	*Whanaungatanga*	*Mauri*
Principle of the Question	The research identifies and addresses Māori health research priorities as determined by whānau.			
Principle of the Research	The research clearly articulates how it will improve the lives of whānau.			
Principle of Methodology	The methodological framework stands up to criteria from within the Māori epistemological community			
Principle of Methods	The methods of research observe tikanga of the research participants.			

As a research tool, Te Pūmanawa Hauora provides a matrix of assessment points that draw on the philosophical principles of Māori inquiry according to this thesis. Each principle (along the top of the table) is considered against four major characteristics or steps of research: the question, the purpose of the research, the methodology and the methods. The next step is to articulate what, when, why and how the principles have been applied to each stage.

Te Pūmanawa Hauora aims to be an educative and self-reflective analytical tool, which requires an examination of the relationship between the characteristics of research and the underpinning epistemological principles used to inform the research.

Additional benefit could be gained by including research peers and research participants in the reflection process since the tool is focussed on accountability to the primary research community. In this thesis, the primary research community is three whānau

and the findings have been validated by them as being representative of the ideas embedded in their interviews.

Mason Durie (1996) describes a Māori centred framework that can be used for examining Māori driven health research. His framework includes two of the same characteristics used in Te Pūmanawa Hauora, concerning the purpose and practice (methodologies and methods) of research. Two further components of Durie's model have to do with the competence of the research practitioner and the political sanctions that facilitate rigorous Māori research. Te Pūmanawa Hauora as a model assumes the latter components of Durie's model are already in place, hence the earlier discussion in the thesis about cultural competence, legislative and policy matters.

Limitations of the Thesis

Application of the findings

The findings described in this thesis are drawn from a small sample group within a particular context. The findings cannot be assumed to be relevant for all whānau and all occasions. Though it is possible that the practice and principles of decision processes have a bearing for other whānau, further work is necessary to substantiate the evidence. Researchers would benefit from understanding whether the findings more apply broadly to whānau decision making in other health contexts.

Participants also had to rely on recall for this retrospective study. They were engaged in research at different stages of collective decision making and a prospective study would be an important step in greater understanding of whānau decision processes.

Sample of Respondents

Though the primary criterion for participation in the study was a whānau, the provision of inclusion criteria inadvertently excluded certain whānau members from participating. I presumed that active participation in whānau decision making about genetic research and active participation in the same research, were mutually necessary and this is not the case. On reflection, any whānau member had the potential to contribute to the findings. Moreover, members without a genetic predisposition to a medical condition may have helped to substantiate the findings further, because of the fact they do not have a medical issue with which to contend.

More women were interviewed than men. An equal representation of males and females was not actively sought because sample selection was driven by each whanau and not by the research. The sample was thus limited by both the proportion of males and females that met the criteria for participation and those members who were willing to participate in the study. An equally balanced gender sample may or may not have altered the findings. In two cases, the gender distribution of more females than males represents the natural sample of the whanau. In the other case, it is possible that the balance of fewer males compared to females correlates to some gender differences arising from greater mortality and/or morbidity for males than for females. However, a statistical analysis of the relationship between the actual and potential gender sample would be required, an approach that is inconsistent with the qualitative nature of the study.

Confidentiality and Anonymity

As explained earlier in the thesis, it was difficult to offer anonymity to the whānau as a collective because of the range of information about them that is publically accessible. Confidentiality is a gold standard applied to the New Zealand health sector that aims to protect recipients of health services, by ensuring their privacy is both respected and protected. The same standards apply to health research, recognised in legislation. However, there is an anomaly within the current ethical system to sufficiently protect the identity of collective groups, who in the case of this thesis are whānau who have been of special research interest scientifically. Through a range of sources that are essentially reporting on scientific knowledge, disclosure of the identity of each whānau in this study is possible. That collective disclosure must constitute a breach of ethical standards and fundamental human rights under existing ethical parameters, is a discussion worth further attention.

Conclusion

This thesis has answered the research question by describing the practice and principles that whānau utilise in decision making. The findings are derived from a retrospective qualitative case study of the decision process for three whānau, who participated in genetic research into a medical condition affecting their health history.

There are two aims which have been achieved. The first aim was to illuminate some understanding of whānau decision processes and develop a framework for application to health research policy and ethical review of research that will help to improve Māori health outcomes. The second aim was to demonstrate the depth and breadth of a Māori research tradition that arises from a Māori intellectual system.

A whānau is an important social construct in Māori society. The meaning of whānau as a fluid concept is a finding of this thesis that confirms current understanding about whānau.

The implication for health research is that the meaning of whānau must be clarified by whānau themselves, because it does not have the same meaning for all whānau. Researchers must observe due diligence in identifying who is the whānau, and therefore, the extent to which decision processes and consent protocols are relevant. In the context of genetic research, a long term plan is necessary that takes into account the implications for subsequent generations, which provides for them an opportunity to revisit their ongoing rights as well as their responsibilities with respect to whānau research that may have commenced years earlier.

The results of this study place greater significance on the process of decision making rather than actual decisions. Four elements of whānau decision processes emerged from the data - hui, rangatiratanga, manaakitanga and kotahitanga. The findings emphasise the collective nature of whānau deliberation, substantiating philosophical, theoretical and anecdotal evidence that Māori have distinctive ways of knowing and doing that are centred on a collective approach.

Whānau processes and practices contrast to mainstream western ideas about appropriate methods for reaching decisions, because whānau practices are culturally constructed. Mainstream decision processes are premised on the idea that individual rights supersede collective rights.

In contrast, the findings of this study show that individual positions are closely linked to and depend on the collective stance. Individual identity arises from collective identity and individual wellbeing is derived from that of the collective. Decision processes are therefore geared toward the way the whānau operates, underpinned by their value system.

The context of a decision and/or the perceived degree of difficulty of decision factors are managed within the context of collective processes. Whānau decision constructs provide an opportunity for members to participate in decision making. The terms of reference used in whānau decision practice are likely to be more familiar. They are more likely to have a greater sense of control over decision processes. They are likely to feel more able to contribute meaningfully to achieving aspirations for their own health.

The implication for health researchers is that there are logistical and ethical factors they must recognise. While research should be beneficial to participants of research, it must also facilitate the ethical standards of collective groups. For example, the wairua decision framework described in this thesis, will only have benefit for whānau wellbeing if it is couched within an environment in which the characteristics of whānau decision processes can occur to the fullest.

Acknowledging that respective worldviews ponder and analyse a health issue differently is key to recognising that decisions will be reached by different processes to reflect those worldviews. Western intellectual traditions have arisen from centuries of philosophical debate and analysis, and the methodologies of decision making have emerged from those traditions and have long been widely accepted.

This thesis has provided evidence that conventions utilised by whānau are also derived from a long established intellectual system that is Māori. The conceptual framework of analysis used to examine the data in the study, facilitated a description of principles and practice in whānau decision processes, consistent with a Māori intellectual framework.

The thesis has also provided evidence that the New Zealand health sector legislation and policies are largely unfavourable for guaranteeing whānau engagement in decision processes about their health. Understanding about the existence of difference alone is insufficient to guarantee whānau participation in decision processes, if the mechanisms that determine such processes are not designed to facilitate whānau decision practice in the first place.

If health researchers do not recognise that different worldviews can co-exist, they risk omitting important issues within the conduct of their research that can have a bearing on the quality of their findings and thus solutions for improving Māori health. More importantly, if the system of ethical review does not promote whānau decision

processes, then Māori society in general is denied access to culturally relevant constructs that are intrinsic to their cultural and moral identity.

The important link between identity and health is well documented and through the omission of mechanisms that enable whānau decision processes to take place, the ethical review system contributes to inequalities in health, a message that should be heeded for future health policies under any government.

The desire to advance health for all must be matched with the means by which all members of society can practically participate in decision processes as valued members of society. That whānau decision processes cannot be guaranteed, should be of serious concern for all those who strive to make a difference in health for Māori to effect the promotion of a healthy society for all New Zealanders.

Appendix 1: Treaty of Waitangi

APPENDICES

Te Tiriti o Waitangi

[Māori Version]

KO WIKITORIA te Kuini o Ingarani i tana mahara atawai ki nga Rangatira me nga Hapu o Nu Tirani i tana hiahia hoki kia tohungia ki a ratou o ratou rangatiratanga me to ratou wenua, a kia mau tonu hoki te Rongo ki a ratou me te Atanoho hoki kua wakaaro ia he mea tika kia tukua mai tetahi Rangatira – hei kai wakarite ki nga Tangata maori o Nu Tirani – kia wakaaetia e nga Rangatira Maori te Kawanatanga o te Kuini ki nga wahikatoa o te wenua nei me nga motu – na te mea hoki he tokomaha ke nga tangata o tona Iwi Kua noho ki tenei wenua, a e haere mai nei.

Na ko te Kuini e hiahia ana kia wakaritea te Kawanatanga kia kaua ai nga kino e puta mai ki te tangata Maori ki te Pakeha e noho ture kore ana.

Na kua pai te Kuini kia tukua a hau a Wiremu Hopihona he Kapitana i te Roiara Nawi hei Kawana mo nga wahi katoa o Nu Tirani e tukua aianei amua atu ki te Kuini, e mea atu ana ia ki nga Rangatira o te wakaminenga o nga hapu o Nu Tirani me era Rangatira atu enei ture ka korerotia nei.

Ko te tuatahi

Ko nga Rangatira o te wakaminenga me nga Rangatira katoa hoki ki hai i uru ki taua wakaminenga ka tuku rawa atu ki te Kuini o Ingarani ake tonu atu – te Kawanatanga katoa o o ratou wenua.

Ko te tuarua

Ko te Kuini o Ingarani ka wakarite ka wakaae ki nga Rangitira ki nga hapu – ki nga tangata katoa o Nu Tirani te tino rangatiratanga o o ratou wenua o ratou kainga me o ratou taonga katoa. Otiia ko nga Rangatira o te wakaminenga me nga Rangatira katoa atu ka tuku ki te Kuini te hokonga o era wahi wenua e pai ai te tangata nona te Wenua – ki te ritenga o te utu e wakaritea ai e ratou ko te kai hoko e meatia nei e te Kuini hei kai hoko mona.

Ko te tuatoro

Hei wakaritenga mai hoki tenei mo te wakaaetanga ki te Kawanatanga o te Kuini – Ka tiakina e te Kuini o Ingarani nga tangata maori katoa o Nu Tirani ka tukua ki a ratou nga tikanga katoa rite tahi ki ana mea ki nga tangata o Ingarani.

(signed) William Hobson, Consul and Lieutenant-Governor.

Na ko matou ko nga Rangatira o te Wakaminenga o nga hapu o Nu Tirani ka huihui nei ki Waitangi ko matou hoki ko nga Rangatira o Nu Tirani ka kite nei i te ritenga o enei kupu, ka tangohia ka wakaaetia katoatia e matou, koia ka tohungia ai o matou ingoa o matou tohu.

Ka meatia tenei ki Waitangi i te ono o nga ra o Pepueri i te tau kotahi mano, e waru rau e wa te kau o to tatou Ariki.

The Treaty of Waitangi

[English Version]

HER MAJESTY VICTORIA Queen of the United Kingdom of Great Britain and Ireland regarding with Her Royal Favour the Native Chiefs and Tribes of New Zealand and anxious to protect their just Rights and Property and to secure to them the enjoyment of Peace and Good Order has deemed it necessary in consequence of the great number of Her Majesty's Subjects who have already settled in New Zealand and the rapid extension of Emigration both from Europe and Australia which is still in progress to constitute and appoint a functionary properly authorised to treat with the Aborigines of New Zealand for the recognition of Her Majesty's Sovereign authority over the whole or any part of those islands – Her Majesty therefore being desirous to establish a settled form of Civil Government with a view to avert the evil consequences which must result from the absence of the necessary Laws and Institutions alike to the native population and to Her subjects has been graciously pleased to empower and to authorise me William Hobson a Captain in Her Majesty's Royal Navy Consul and Lieutenant-Governor of such parts of New Zealand as may be or hereafter shall be ceded to her Majesty to invite the confederated and independent Chiefs of New Zealand to concur in the following Articles and Conditions.

Article the First [Article 1]

The Chiefs of the Confederation of the United Tribes of New Zealand and the separate and independent Chiefs who have not become members of the Confederation cede to Her Majesty the Queen of England absolutely and without reservation all the rights and powers of Sovereignty which the said Confederation or Individual Chiefs respectively exercise or possess, or may be supposed to exercise or to possess over their respective Territories as the sole sovereigns thereof.

Article the Second [Article 2]

Her Majesty the Queen of England confirms and guarantees to the Chiefs and Tribes of New Zealand and to the respective families and individuals thereof the full exclusive and undisturbed possession of their Lands and Estates Forests Fisheries and other properties which they may collectively or individually possess so long as it is their wish and desire to retain the same in their possession; but the Chiefs of the United Tribes and

the individual Chiefs yield to Her Majesty the exclusive right of Pre-emption over such lands as the proprietors thereof may be disposed to alienate at such prices as may be agreed upon between the respective Proprietors and persons appointed by Her Majesty to treat with them in that behalf.

Article The third [Article 3]

In consideration thereof Her Majesty the Queen of England extends to the Natives of New Zealand Her royal protection and imparts to them all the Rights and Privileges of British Subjects.

(signed) William Hobson, Lieutenant-Governor.

Now therefore We the Chiefs of the Confederation of the United Tribes of New Zealand being assembled in Congress at Victoria in Waitangi and We the Separate and Independent Chiefs of New Zealand claiming authority over the Tribes and Territories which are specified after our respective names, having been made fully to understand the Provisions of the foregoing Treaty, accept and enter into the same in the full spirit and meaning thereof in witness of which we have attached our signatures or marks at the places and the dates respectively specified.

Done at Waitangi this Sixth day of February in the year of Our Lord one thousand eight hundred and forty.

(512 signatures, dates and locations)

Appendix 2: Declaration of Independence[30]

THE DECLARATION OF INDEPENDENCE 1835

On 28 October 1835 James Busby called a hui (meeting) at Waitangi. Thirty-four northern chiefs, known as the Confederation of United Tribes, signed 'A Declaration of the Independence of New Zealand' and called upon King William IV of Britain to become their 'father and protector'. They also thanked the King for acknowledging their flag.

The handwritten declaration of four articles was later printed by the mission printery and asserted the independence of Nu Tirene (New Zealand) under the rule of the 'United Tribes of New Zealand'. This body planned to meet in Congress at Waitangi each autumn to frame laws.

Maori had no say in the preparation of this document. Nevertheless, by 1839, 52 chiefs had signed the declaration, which was acknowledged by the British government. Busby saw it as a significant mark of Maori national identity and believed it would prevent other countries from making formal deals with Maori.

1. KO MATOU, ko nga Tino Rangatira o nga iwi o Nu Tireni I raro mai o Hauraki kua oti nei te huihui i Waitangi i Tokerau i te ra 28 o Oketopa 1835, ka wakaputa i te Rangatiratanga o to matou wenua a ka meatia ka wakaputaia e matou he Wenua Rangatira, kia huaina, Ko te Wakaminenga o nga Hapu o Nu Tireni.

2. Ko te Kingitanga ko te mana i te wenua o te wakaminenga o Nu Tireni ka meatia nei kei nga Tino Rangatira anake i to matou huihuinga, a ka mea hoki e kore e tukua e matou te wakarite ture ki te tahi hunga ke atu, me te tahi Kawanatanga hoki kia meatia i te wenua o te wakawakarite ana ki te ritenga o o matou ture e meatia nei matou i to matou huihuinga.

3. Ko matou ko nga tino Rangatira ka mea nei kia kia huihui ki te runanga ki Waitangi a te Ngahuru i tenei tau i tenei tau ki te wakarite ture kia tika te hokohoko, a ka mea ki nga tauiwi o runga, kia wakarerea te wawai, kia mahara ai ki te wakaoranga o to matou wenua, a kia uru ratou ki te wakaminenga o Nu Tireni.

1. WE, the hereditary chiefs and heads of the tribes of the Northern parts of New Zealand, being assembled at Waitangi in the Bay of Islands on this 28th day of October, 1835, declare the Independence of our country, which is hereby constituted and declared to be an Independent State, under the designation of the United Tribes of New Zealand.

2. All sovereign power and authority within the territories of the United Tribes of New Zealand is hereby declared to reside entirely and exclusively in the hereditary chiefs and heads of tribes in their collective capacity, who also declare that they will not permit any legislative authority separate from themselves in their collective capacity to exist, nor any function of government to be exercised within the said territories, unless by persons appointed by them, and acting under the authority of laws regularly enacted by them in Congress assembled.

3. The hereditary chiefs and heads of tribes agree to meet in Congress at Waitangi in the autumn of each year, for the purpose of framing laws for the dispensation of

[30] New Zealand History Online retrieved 30 June, 2009 from http://www.nzhistory.net.nz/media/interactive/the-declaration-of-independence

justice, the preservation of peace and good order, and the regulation of trade; and they cordially invite the Southern tribes to lay aside their private animosities and to consult the safety and welfare of our common country, by joining the Confederation of the United Tribes.

4. Ka mea matou kia tuhituhia he pukapuka ki te ritenga o tenei o to matou wakaputanga nei ki te Kingi o Ingarani hei kawe atu i to matou aroha nana hoki i wakaae ki te Kara mo matou. A no te mea ka atawai matou, ka tiaki i nga pakeha e noho nei i uta, e rere mai ana i te hokohoko, koia ka mea ai matou ki te Kingi kia waiho hei matua ki a matou i to matou Tamarikitanga kei wakakahoretia to matou Rangatiratanga.

4. They also agree to send a copy of this Declaration to His Majesty the King of England, to thank him for his acknowledgement of their flag; and in return for the friendship and protection they have shown, and are prepared to show, to such of his subjects as have settled in their country, or resorted to its shores for the purposes of trade, they entreat that he will continue to be the parent of their infant State, and that he will become its Protector from all attempts upon its independence.

KUA WHAKAAETIA katoatia e matou i tenei ra i te 28 Oketopa, 1835, ki te aroaro o te Reireneti o te Kingi o Ingarani.

AGREED TO unanimously on this 28th day of October, 1835, in the presence of His Brittanic Majesty's Resident.

(Here follow the signatures and marks of thirty-four hereditary chiefs or Heads of tribes, which form a fair representation of the tribes of New Zealand from the North Cape to the latitude of the River Thames.)
English witnesses:
(Signed) Henry Williams, Missionary CMS
George Clarke, CMS
James Clendon, Merchant
Gilbert Mair, Merchant

I certify that the above is a correct copy of the Declaration of the Chiefs, according to the translation of Missionaries who have resided ten years and upwards in the country; and it is transmitted to His Most Gracious Majesty the King of England, at the unanimous request of the Chiefs.

(Signed) JAMES BUSBY, British Resident at New Zealand.

Appendix 3: Information Letter

Massey University

Research Information:

Decision-making at the interface of science and mātauranga Māori.

Tuesday, 21 March 2006

Tēnā Koutou

Ko Hone Harawira tōku koroua, ko Taare Ririnui tōku kuia ki te taha o tōku pāpā. Ko Mataiata Pōhatu rāua ko Rata Wyllie ōku pakeke ki te taha o tōku māmā. Ko Tāmaki Harawira rāua ko Cairo Pōhatu ōku mātua. Ko Hope Ngā Taare Harawira Tūpara tēnei.

My name is Hope Tupara. I am a midwife by profession and I teach student midwives part-time at Massey University in Palmerston North where I live. I am also a PhD student at the Research Centre for Māori Health and Development, Te Pūtahi-a-Toi, Māori Studies, Massey University. For those of you who do not know what a PhD is it is the highest degree that can be obtained at a University in New Zealand and I am required to do research to complete this qualification.

For my research topic, I want to find out the reasons why whānau engage in genetic research because whānau who are participating in such research by giving blood or tissue samples, are in a unique position to contribute to public debate and discussion about the moral issues they have encountered as part of their decision experience. By talking about your personal experience you can provide others with some real-life insight and by being Māori, you give further insight into issues that are raised by other Māori. This information is important for government agencies, ethics committees, health professionals, genetic counsellors and researchers, to give them feedback, to help them make wise decisions about supporting genetic research in the future.

Nāku Noa

Nā Hope

The supervisors for my PhD are Chris Cunningham and Maureen Holdaway. If you wish to talk to them or me about the research I am doing, our contact details are below.

Chris Cunningham
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"This project has been reviewed and approved by the Massey University Human Ethics Committee, Palmerston North Application 05/99. If you have any concerns about the ethics of this research, please contact Dr John G O'Neill, Chair, Massey University Campus Human Ethics Committee: PN telephone 06 350 5799 x 8635, email humanethicspn@massey.ac.nz"

Appendix 4: Interview Letter

Massey University

Request to Participate in an Interview:

Decision-making at the interface of science and mātauranga Māori.

11/07/2006

Tēnā Koutou

Ko Hone Harawira tōku koroua, ko Taare Ririnui tōku kuia ki te taha o tōku pāpā. Ko Mataiata Pōhatu rāua ko Rata Wyllie ōku pakeke ki te taha o tōku māmā. Ko Tāmaki Harawira rāua ko Cairo Pōhatu ōku mātua. Ko Hope Ngā Taare Harawira Tūpara ahau.

My name is Hope Tupara.

I am a midwife by profession and I teach student midwives on a part-time basis at Massey University in Palmerston North where I live. I am a PhD student at the Research Centre for Māori Health and Development, Te Pūtahi-a-Toi, Māori Studies, Massey University. For those of you who do not know what a PhD is it is the highest academic qualification that can be obtained at a University in New Zealand and I am required to do a research project.

For my topic I want to find out why whānau decide to participate in genetic research. This is important because there is an increasing amount of genetic research taking place in New Zealand and around the world, and there is some opposition to such research by many groups including Māori. Whānau who are participating in genetic research are in a unique position to contribute to public debate and discussion because of their lived experience and their personal insight. This information is important for government agencies, ethics committees, health professionals, scientists, genetic counsellors and researchers, to help inform them to make wise decisions about genetic research in this country.

I am seeking whānau for individual interviews and/or a group hui. The individual interviews will take about one hour and I am happy to work out different times to suit each of you. The group hui will be more tricky to organise to get you together at one time.

For both types of interview you will be asked a series of questions about your decision to take part in research involving your whānau.

Your information will be collated with that from other members of your whānau and interviews from the other whānau I am researching. Collectively, this will help provide more insight into the decision-making process as it is relevant to whānau.

All interviews will be conducted by me and they will be taped to help transcribe the interview onto paper in a written format. You can ask for the recorder to be switched off at any time, or for the whole time. You have the right to decline to ask any questions and you can withdraw from the research at any time. All information will be kept strictly confidential to me, the transcriber and my supervisors.

If you wish to see a copy of your own transcript before it is analysed, please tick the correct box on the attached consent form. I will follow this letter up with a phone call or mail-out to you very soon. Thank you for your assistance and please do not hesitate to phone or send an email to me or one of my supervisors if you have a concern or you want more information.

Nāku Noa

Nā Hope Tūpara

Chris Cunningham
Te Pūmanawa Hauora
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Massey University
Wellington Campus
Ph (04) 380 0626 extn 6020

Maureen Holdaway
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Hope Tūpara
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"This project has been reviewed and approved by the Massey University Human Ethics Committee, Palmerston North Application 05/99. If you have any concerns about the ethics of this research, please contact Dr John G O'Neill, Chair, Massey University Campus Human Ethics Committee: PN telephone 06 350 5799 x 8635, email humanethicspn@massey.ac.nz".

Appendix 5: Consent Form

Massey University

CONSENT FORM:

Decision-making at the interface of whānau knowledge and medical science

I have read written information about the study being undertaken by Hope Tūpara.
yes no

I have had a verbal explanation about the study being undertaken by Hope Tūpara.
yes no

1. I consent to a face-to-face interview:
   yes no

2. I consent to the interview being recorded:
   yes no

3. I understand my personal information will be kept confidential to the researcher, transcriber and research supervisors only.
   yes no

4. I would like a copy of the written transcript of the interview to check it before it is analysed for the research project.
   yes no

5. I would like a summary report when the research is completed
   yes no

Name...……….……………………………… Date …………………..

Signed ……………………………………….. Phone …………………

Contact address ……………………………………………………..

Email…………………………………………………………………

General Personal Information

List as many of these that you are involved with as you wish

Employed (full-time)	How many hours a week?	What area of work
Employed (part-time)	How many hours a week?	What area of work
Involved in sport. as a player		
Involved in sport for coaching or administration		
Caring for children or grandchildren	How many children/grandchildren and for how many hours a week?	
Marae Committee		
Studying		
Church Activities	How often and what?	
Any other commitment?		

Gender: Male Female

Age: 18-25 25-34 35-44 45-54 55-64 65+

Cultural Diversity (based on Te Hoe Nuku Roa schedule)[31]

1. Do you identify as Māori?

	yes
	no

[31] Te Hoe Nuku Roa, Māori Studies, Te Pūtahi-ā-Toi, Massey University: THNR2003/1/LP

If you had to choose **one** of these options that best describes you, which would you choose?

	a kiwi
	a New Zealander
	Māori/Pākehā
	part Māori
	a Polynesian
	a Māori
	other

2. How would you rate your overall ability with Maori language?

	excellent
	very good
	good
	fair
	poor
	not applicable

How did you acquire your ability with Maori language?

	Was the main language you were brought up to speak
	You taught yourself
	Learned as a second language from family/whānau
	Learned as a second language at an education institution
	Other (specify)

3. In terms of your involvement with your whānau (blood relations) outside of your usual household. Would you say that your whānau plays?

	a very large part in your life
	a large part in your life
	a small part in your life
	a very small part/no part in your life

How many generations of your whakapapa can you name at this point in time, without referring elsewhere?

	1 generation
	2 generations (grandparents)
	3 generations (great grandparents)
	more than 3 generations

4. This question considers your contacts with people. In general, would you say that your contacts are with?

	Mainly Maori	Some Maori	Few Maori	No Maori	Not Applicable
at work					
at sport					
at church					
at school					
at work					

5. Have you ever been to a marae?

	yes
	no

How often did you go to a marae in the past 12 months? ***Use show card 2***

1	2	3	4	5

Is there is at least one marae that you regard as your marae?

	yes
	no

How often did you go to your marae in the past 12 months? ***Use show card 2***

1	2	3	4	5

6. Do you have an interest in Maori land, fisheries or forestry? Do you….

Yes	No	
		have any financial interest in Maori land as an owner, part/potential owner or beneficiary
		attend owners meetings
		visit the land regularly
		attend Maori land court hearings
		keep well informed about your land
		live on the land
		receive monies from Maori land/fisheries or forestry
		receive any benefit from Maori land land/fisheries or forestry
		Receive monies from minerals or geothermal resources

Disposition towards science

7. Have had formal science education

	yes
	no

Please specify ……………………………………………………

How would you characterize your knowledge of science?

	Very well informed
	Well informed
	Not well informed
	No knowledge

How would you characterise your interest in science?

	positively interested
	interested
	not interested
	suspicious

Appendix 6: Interview Schedule

Massey University

Interview Schedule

Intro: Questions are grouped according to five areas of inquiry.

Band 1: tell me what you know about the research project and why it was done?

Note: Band 1 is designed to 'break the ice' and encourage respondents to reflect on their feelings and thoughts about their decision process.

How did you become involved in the research?

Band 2: how are decisions made in your whānau?

Note: Bands 2 to 5 are designed to 'dig deeper' and describe the decision process.

If you have to get together to make a decision, how does that happen?
Does someone usually lead this?
Are there certain people in your whānau who the others listen to?
Were there key people your whānau spoke to?
Did you have special hui/meetings? If so, where?
Did you have one hui or several?
Can you remember how you felt about the research at the beginning?
Can you remember if anyone in the whānau was against the research?
If you disagreed with a decision/view or one of your children/grandchildren disagreed with a decision/view, how would you deal with that?

Band 3: characterise the setting.

Who do you call your whānau?
Where in your whānau are you?
So you have how many brothers, sisters, children, grandchildren?
What's the difference between you and your children, and say your sister and her children? Are they whānau?
In decision-making, did you think you have a lot of influence about the end decision you arrive at?
Who do you think has the most influence over decisions?
Who has the least influence on decisions?
Do you still feel happy about your decision regardless?
What would you do differently?

Band 4: what sort of information did you get to help you decide about the whānau research? (Information accessed)

Did you talk to the researchers?
Did you read anything?
Did you talk to any other whānau?
Was there anything specific your whānau discussed in relation to the research that the scientists didn't talk about?
Did you talk to other whānau who had the same experience in genetic research?
If any other whānau were considering genetic research, what sort of advice would you give them?
Do you think scientific or medical information was the only consideration?
Are you happy with the information you got?

Band 5: what issues were balanced in your decision?

What were the most important issues for you?
What concerned you the most?
What has been the most important benefit for your whānau?
What has been the least beneficial for your whānau?
Did your whānau have specific worries about DNA testing?
Has there been a time when you thought the research was bad?
Did you feel or sense anything negative about the research?
Is there anything that you would do differently?

Appendix 7: Authority for the Release of Tape Transcripts

Massey University

AUTHORITY FOR THE RELEASE OF TAPE TRANSCRIPTS

Decision-making at the interface of whānau knowledge and medical science

This form will be held for a period of five (5) years

I confirm that I have had the opportunity to read and amend the transcript of the interview/s conducted with me.

I agree that the edited transcript and extracts from this may be used by the researcher, Hope Tupara in reports and publications arising from the research.

Signature:		**Date**	
Full Name Printed			

For any enquiries please contact:

Te Pūmanawa Hauora, The Research Centre for Māori Health and Development; Massey University, Palmerston North; Private Bag 11-222, telephone 356 9099 extn 5269, email: H.Tupara@massey.ac.nz

Appendix 8: Transcription Information Letter

Hope Tupara
Te Pūmanawa Hauora
Research Centre for Māori Health and Development
Massey University
Private Bag 11-222
Palmerston North
Ph (06) 356 9099 extn 5269
Mobile 027 5788 276
Email: H.Tupara@massey.ac.nz

Tuesday, 7 November 2006

Dear whānau (name)

Re: Interview Transcript

Please find enclosed a copy of your interview transcript. The names of all whānau members will not be used unless you specifically ask for your name to be included. Instead pseudonyms (pretend names) may be used.

Read your transcript carefully. You can change or delete parts you feel uncomfortable about. You need to also sign the enclosed consent form giving your authority for your amended transcript to be used for my research, and I have included a stamped addressed envelope to return all the documents to me when you have finished. If I do not receive anything back in the post, I will contact you by phone in early December as you may have some questions you want to ask first.

Nāku noa

Nā Hope

Appendix 9: Transcriber Confidentiality Agreement

Massey University

Confidentiality Agreement:

Decision-making at the interface of whānau knowledge and medical science

My name is …………………………….. I will be transcribing audio tapes from participants in the above project, into a written format. I will have access to information from the research participants which includes one-to-one and group interviews.

During the process of my transcribing work I agree to keep all information private and confidential between myself and the researcher, Hope Tupara, including the identities of people, places and institutions that might mentioned in the audio tapes or written transcripts.

On completion of my work, I agree to return all relevant information/records to the researcher and I understand that all information will be either returned to the research participants or kept according to Massey University protocols relating to storage of research information.

Signed ……………………………………………… Date ……………

Address ………………………………………………………………

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