He Matatika Māori

Māori and Ethical Review in Health Research

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A thesis submitted in partial fulfilment of the degree
of Masters in Health Science

Auckland University of Technology

Auckland, New Zealand

2004

He mihi

Ko te māuri te mana kawe
Ko te wairua te reo
Hono kē ki te kikokiko
Mā tēnei ka rongo
te tīnana ki ōna whainga
Hei oranga mō tāua

Tuatahi rā, ka tuku mihi ki te Matua nui i te Rangi me ōna āhuatanga katoa e manaaki nei i a tātau. Tuarua, ki a rātou kua wheturangitia hei tohu maumahara ki o rātou mahi, ki o rātou wawata. Kei te tangi tonu te ngākau mō ngā kanohi kua riro ki tua o paerau, haere, haere, whakaoti atu ra.

E mihi ana tēnei ki ngā maunga, ki ngā awa e herehere nei i a tāua ki te hākui, a Papatuanuku, ki te hākoro, a Ranginui kia tangata whenua ai tātau ki runga i tēnei motu. Ki ngā waka, ki ngā iwi, ki ngā hapū, tēnā koutou me ngā tini honohono here kei waenganui i a tātau.

He mihi hoki ki te kaupapa i ahu mai i ngā tupuna kia poupou ko ngā tikanga Māori ki roto i te Ao hurihuri nei, hei awhina, hei arataki i a tātau. Ka nui ngā mihi ki a koutou e kawe nei i tēnei take kia ora ai ko te kanohi Māori ki roto i ngā mahi katoa o te whenua nei. Ki a koutou i koha mai ko ngā pitopito kōrero, ko ngā wheako, ko ngā wawata, tēnā rawa atu koutou. Ko te tumanako ka whakamana tēnei tuhinga i o koutou mahi.

He mihi hoki ki ōku whānau, ki a Brandi, ki a Koare, ki a Te Amai. Ka nui ō koutou tautoko, manaaki i ahau kia tūtuki pai ai i tēnei kaupapa. No reira, tēnā koutou, tēnā koutou, tēnā koutou katoa.

Abstract

Māori aspirations for a better future are inextricably linked to their health and well-being. Research is a central element of any strategy to ensure that the inequalities of today will not be experienced by Māori children of the future.

Kaupapa Māori research has been at the forefront of the indigenous challenge to Western research practices which continue to frame Māori as the 'other' and victim blame by measuring differences to non-Māori and then attribute identified negative differences to Māori deficit. A kaupapa Māori framework validates Māori realities and enables the development of research processes that are based on a Māori worldview and endorse Māori values and beliefs. Proponents of distinctly Māori research methodologies have questioned the appropriateness of ethical review processes that are based on Western concepts of ethics that they contend are incongruent with Māori cultural values and beliefs. Māori ethical issues identified in the literature that arise from this interface have similarities with indigenous ethical themes of respect, control and reciprocity.

This qualitative research study was based on a kaupapa Māori approach. The research addressed two main research questions: whether the current system of ethical review in New Zealand is responsive to Māori and how can tikanga Māori inform Māori research ethics. Primary data for this study was drawn from interviews with Māori members of ethics committees and analysed thematically.

The major conclusion of this study was that the current ethical review process is limited in its responsiveness to Māori. The research found that Māori values were generally marginalised within ethical review processes that are based on universal ethics derived from a Western value base. A number of key ethical issues for Māori are not addressed appropriately within the current system of ethical review due to the limited parameters, in Māori terms, of the review process. It is essential that Māori issues and concerns be addressed in order for Māori to benefit from the activities of the research sector. Differences exist between Māori and Western concepts of ethics and the inclusion of tikanga Māori within the ethical review process could

lead to a more transparent and responsive evaluation and greatly enhance the quality of ethical review of health research in New Zealand.

The development of a Māori ethical framework that describes the principles of tikanga Māori and their application within the context of research ethics could provide a culturally appropriate framework for ethical review. Such a framework would address ethical issues of significance for Māori in research. The establishment of a National Māori Ethics Committee and the development of a parallel Māori ethical review pathway would further enhance Māori responsiveness.

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Attestation of Authorship

"I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person nor material which to a substantial extent has been accepted for the qualification of any other degree or diploma of a university or other institution of higher learning, except where due acknowledgement is made in the acknowledgements."

Signed:

Maui Hudson

Acknowledgements

Ahakoa he iti, he pounamu

I would like to acknowledge the contributions of all of the people who are concerned with the development and advancement of the Māori nation. That we remain a robust and vibrant culture is testament to the collective contributions of our people.

I would also like to acknowledge the people who participated in this research study and whose contributions were invaluable. Kay, Nicole, Helene, Moe, Shane, Kura and Jane, I am indebted to you all for sharing your knowledge and experience of the system of ethical review in New Zealand.

To Associate Professor Mihi Ratima, my thanks for your support and guidance with the writing of this thesis. It made what at times seemed like a monumental task, achievable.

To the Health Research Council, your scholarship programme is making a real contribution towards the development of the Māori health research workforce and I express my thanks for the financial support.

I would also like to acknowledge the Auckland University of Technology Ethics Committee (AUTEC) for granting ethical approval to comment on the system of which they are a part.

To my father Ruka who has always been a tower of strength and integrity. Your love for your children is an example I hope to emulate.

But most of all to my beautiful wife Brandi and my gorgeous kids, Koare and Te Amai. You are my source of pride and joy and I thank you for being a part of my life.

Chapter 1: Introduction

It is ironic that the concept of māori, arising from its meaning of ordinary, is now seen as the other. (Moewaka Barnes 2000) pg 14

Background

As a developed country, New Zealand has adopted many of the social structures that have developed within the Western world. This includes structures such as legal, political, scientific and educational systems. These systems are intimately involved with the production and validation of knowledge. Academic institutions have become the powerhouses of the knowledge economy and their research is increasingly used to provide justification for decisions about resource allocation on a variety of levels. Māori involvement in decision making committees is restricted and the same could be said for Māori involvement in the production of knowledge through research (Te Puni Kokiri 1994).

I entered postgraduate studies in health care ethics as a way to develop arguments for the inclusion of traditional Māori healing practices within the health sector. The absence of research on traditional Māori healing meant that in the evidence based practice environment, where evidence prioritises research outcomes over practice outcomes, this was going to be a difficult task. In New Zealand, all research involving human participants has to gain ethical approval prior to commencing and that this forum was in many regards a gatekeeper for the knowledge producers. I quickly came to recognise that ethics committees play a vital role in our society particularly in the production of knowledge.

Research question

The research question emerged in response to calls from Māori researchers frustrated with having research, grounded in Māori values and assumptions, evaluated against ethical frameworks based on a different set of values and assumptions. The primary research question for this study is: Is the current system of ethical review in New Zealand responsive to Māori? The secondary research question is: How does tikanga Māori inform Māori research ethics?

Theoretical framework

This research study is located within a Māori inquiry paradigm that provides the philosophical grounding for Kaupapa Māori and Māori centred research. Themes such as interconnectedness, Māori potential, Māori control, collectivity and Māori identity underpin the Māori inquiry paradigm and therefore these research approaches (Ratima 2001). This theoretical framework validates and legitimises the existence of Māori cultural values and beliefs within the processes of research. It also places requirement for accountability back to the Māori community to ensure that the benefits derived from this study will accrue to the collective and not just the researcher. This research study provides a Māori perspective on ethical review of health research from the point of view of Māori who have been intimately involved with the processes of ethical review within New Zealand.

Research process

This is a qualitative study that utilises processes from kaupapa Māori research to ensure its cultural integrity. In depth interviews, in both English and te reo Māori, were conducted with seven Māori participants. Participants were either present or past members of institutional, regional, or national ethics committees. Some of the participants were involved in the development of the study. The data was analysed thematically to determine key themes and then discussed in the context of the research questions and current literature. Contact with participants was maintained throughout this study and their feedback was sought at various stages of analysis and writing to ensure accuracy of the researcher's interpretations of their views.

Thesis organisation

The literature review for this thesis begins with an examination of Māori health in Chapter Two and the disparities that exist within the New Zealand health sector. Chapter Three examines Māori research approaches and how they have been developed to address Māori concerns about inequalities in New Zealand society. Chapter Four discusses the origins of the ethical principles commonly used within health research. The universality of these ethical principles is challenged in terms of cultural difference in ethics where indigenous approaches to research ethics are highlighted in Chapter Five. Chapter Six describes the current New Zealand ethical review system and discusses recent Māori critiques. Chapter Seven explores

the relationship between tikanga Māori, Māori ethics and ethical issues for Māori in the context of ethical deliberation. The research methodology is described in Chapter Eight. This is a qualitative study situated within a Māori inquiry paradigm, which utilises kaupapa Māori methodology. The research methods used and ethical issues associated with this study are discussed. Each participant is profiled in Chapter Nine. Analysis of participant responses enabled the identification of the central themes to emerge from this study and these themes are arranged in Chapter Ten. In Chapter 11, the results are discussed in relation to the research questions and existing literature with arguments made for changes to improve the Māori responsiveness of the ethical review system. Chapter 12 summarises the research conclusions.

Significance

This research study provides a critique of the responsiveness to Māori of the ethical review system in New Zealand. Issues and concerns have been noted by a number of Māori researchers (Te Awekotuku 1991; Te Puni Kokiri 1994; Durie 1998; Cram 2003). However, there has not been a Māori focussed evaluation of the process of ethical review since 1994 when Te Puni Kokiri examined governance and representation issues within the system of ethical review (Te Puni Kokiri 1994). It is important that the system of ethical review is responsive to Māori as the effectiveness of research to contribute to Māori development goals and address Māori problems will be determined by how the research sector engages with Māori communities. This study has explored the responsiveness of the system of ethical review to Māori and suggested mechanisms through which Māori responsiveness might be improved. It has also provided indicators for the development of a Māori ethical framework to guide the integration of tikanga Māori into the ethical review process.

The positioning of the researcher

My background and experience will undoubtedly affect the shape of this study. Born to a Māori father and Pākehā[1] mother, I spent my formative years immersed within a wider New Zealand culture rather than Māori culture. There were particular moments that heightened my interest in Te Ao Māori[2], the death of my grandparents, listening to Moana Jackson speak at high school and my father becoming a te reo Māori tutor are foremost in my mind. After the

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[1] Non-Māori person, usually of European descent
[2] The Māori world

traditional overseas experience that highlighted Māoritanga as one of the key defining features of New Zealand, I found myself drawn to learn the te reo Māori[3] and Te Ataarangi[4] provided a doorway to both te reo Māori and Te Ao Māori. Through an interest in traditional healing I was introduced to traditional wānanga and some of the depth of knowledge found in mātauranga Māori[5]. I come with an appreciation of what mātauranga Māori offers and a belief that it is as valid as any other type of knowledge. I have worked as a community physiotherapist in rural Bay of Plenty with a predominantly Māori population and have seen first hand disparities in health and the difficulty that Māori have engaging with health services.

Key assumptions

This thesis is written with a number of assumptions that should be explicitly noted. First, that tikanga Māori[6] and mātauranga Māori are valid as explanatory systems that create a unique Māori worldview. Second, while there is no one unitary Māori worldview, there are distinctly Māori indigenous views. Tikanga Māori and mātauranga Māori are subject to regional difference and local interpretation, which is likely to be expressed within Māori ethics.

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[3] Māori language
[4] Māori language immersion course
[5] Māori knowledge and philosophy
[6] Māori values and ethics

Chapter 2: Māori and Health

The foundations of health are complex, often ill-defined, and not necessarily linked in a direct way to either physical or mental disorders. But it is impossible to address Māori health without understanding the wider environments within which health status takes shape. (Durie 2001) pg 35

Introduction

Māori are a growing proportion of the New Zealand population. There are indications of the continuing vitality of Māori reflected in growing numbers of Māori children participating in Māori medium education and Māori health providers, and the increasing Māori involvement in politics and media. However, research has consistently highlighted the differences in health outcomes between Māori and non-Māori, identified inequalities, and proposed a range of contributing factors. Inequalities in health, the Treaty of Waitangi[7], and Māori aspirations to lead development, provide justification for the encouragement of increased Māori involvement in the health sector, including health research.

Māori: the indigenous people of New Zealand

Those who name the world have the power to shape people's realities. Ethnicity matters. It involves our identity, how we view ourselves and how we are represented in society. (Robson and Reid 2001) pg 24

To gain an understanding of Māori health, it is necessary to clarify who Māori are.   Māori are the indigenous people of New Zealand and have a distinct identity and culture within this country. In the 2001 census[8] approximately 15% of New Zealand's population identified themselves as Māori. The term 'māori' means normal or ordinary and was not used to describe the indigenous people of New Zealand until the arrival of European explorers (Williams 1997). Prior to this, 'Māori' identity was based on whānau (family), hapū (sub-tribe) and iwi (tribal) affiliations. Whakapapa (kinship and descent) continues to be a fundamental component of Māori identity and many consider hapū and iwi identity as a prerequisite to Māori identity

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[7] Treaty signed between Māori and the English in 1840 that established New Zealand as a modern state
[8] Official counting of people

(Robson and Reid 2001). Whakapapa not only links people to each other through genealogy but also to other Māori institutions (marae, rūnanga, Māori trusts and incorporations) and the natural environment.

Cultural heritage is another important component of Māori identity and it encompasses those taonga (anything highly prized) that are inherited from the ancestors. This includes Māori values and beliefs, te reo Māori, tikanga Māori, genealogy, natural resources and mātauranga Māori (Edwards 1999; Ratima 2001). It should be noted that Māori live in diverse social, cultural, economic and political realities and that the individual expression of this cultural identity is varied. Identification as Māori is therefore based on self-perception as part of a distinctly Māori ethnic group. Mako (1998) defines the characteristics of an ethnic group as a social group who;

- share a sense of common origins,
- claim a common and distinctive history and destiny,
- possess one or more dimensions of collective cultural individuality, and
- feel a sense of unique collective solidarity. (Mako 1998)

The claiming of 'indigenous' status is politically charged as it implies that this group has special rights that relate to the priority-in-time in relation to a particular area and the special bond between the people and the land (Ratima 2001). This is affirmed by Māori term 'tangata whenua' or 'people of the land' which is also used to describe Māori. Tangata whenua rights have been recognised as indigenous rights and differ from those bestowed by minority status (Robson and Reid 2001). Robson and Reid (2002) summarised tangata whenua rights as;

- the right of self-determination,
- the right to equity of values,
- the right to collective well-being,
- the right to equal quality of information, and
- the right to policy based on evidence that is valid for Māori.

Treaty of Waitangi

In New Zealand, the primary mechanism, which Māori have used to have their unique rights addressed, is the Treaty of Waitangi. It was signed in 1840 between Māori leaders and the British Crown and was intended to lay the ground-rules for the relationship between Māori and British settlers (Ratima 2001). The Treaty of Waitangi marked the foundation of the modern state of New Zealand. The Treaty formalised a relationship between the British Crown and Māori to recognise and protect Māori values, traditions and practices as tangata whenua of this country (Cram 2003). The Treaty is phrased in broad terms and provides for a transfer of sovereignty (article one), a continuation of existing property rights (article two), and citizenship rights (article three) (Durie 1994). Much of the recent debate about the relevance of the Treaty to contemporary society stems from the different interpretations of the two versions, Māori and English, that were signed (Jackson 1993; Williams 1993).

From a Māori stand-point its role and status have never changed however the importance of the Treaty within New Zealand society has changed over the past 160 years (Durie, Temm et al. 1989). Since the signing the Treaty of Waitangi much has been done to marginalise its position as a constitutional document. Successive governments have legislated to remove land from Māori and nullify the promises made in that document (Jackson 1993; Vercoe 1993). This was the prevailing position until the passing of the Treaty of Waitangi Act 1975 which acknowledged the legal status of the Treaty. It also established the Waitangi Tribunal and gave legal authority to decide what the Treaty principles were (Durie 1994). The identification of Treaty principles by the Royal Commission on Social Policy in 1988 has also created varying levels of expectation and debate about what the implications of the Treaty are in contemporary society (Durie 1994). The treaty principles of partnership, participation and protection have been widely adopted throughout government organisations to drive Treaty responsiveness.

Partnership refers to the relationship between iwi or hapū and the crown. While it implies an association of equals it is most frequently demonstrated through limited reassignment of government authority to iwi or consultation between government agencies and iwi. Participation is often used in reference to Māori involvement in a sector or activity. The past 20 years has seen a great increase in the range of Māori involvement in the health sector. Protection, as a Treaty principle, refers to the State's responsibility to guarantee Māori the

same rights and privileges as other New Zealanders (Durie 1994). Taken as a whole the principles of the Treaty of Waitangi imply that the State has an obligation to both recognise Māori aspirations for self-determination and protect the interests of Māori.

> *The Treaty of Waitangi was signed to protect the interests of Māori, and it is certainly not in the interests of Māori to be disadvantaged in any measure of social or economic wellbeing. Cited in (Robson 2002) pg 2*

Māori health status

Conventional indicators of health status are limited in terms of their capacity to accurately reflect the health of Māori. Durie (Durie 1994) notes three particular limitations in assessing Māori Health using a model that compares Māori with non-Māori. First, health statistics are for the most part about hospital activities that provide a rather limited range of information. Second, health statistics focus on illness and injury, which gives a profile of sickness rather than health. And last, health indicators are designed for specific purposes that are unable to provide a comprehensive or accurate profile of the health of Māori people. Nazroo & Karlsen (Nazroo and Karlsen 2001) also noted that research focussing on identifying ethnic inequalities in health was limited as ethnicity indicators were usually one-dimensional and failed to recognise the importance and range of meanings associated with ethnic identity and they often failed to account for the role of social structure in the relationship between ethnicity and health.

Inequalities

Significant inequalities exist between Māori and non-Māori health. For example, Māori, have worse health and die younger than other New Zealanders (Ministry of Health 2002). The collection of ethnic specific data has allowed more comprehensive reports to be made and has highlighted the particular disparities between Māori and non-Māori health in terms of morbidity, mortality, and outcome after diagnosis (Reid, Robson et al. 2000). Māori have higher rates of heart disease, asthma (Ellison-Loschmann and Pearce 2000), sudden infant death syndrome (Tipene-Leach, Abel et al. 2000), dental disease (Broughton 2000), diabetes (Ministry of Health 2002) and numerous other conditions. A key point is that many of these disparities exist in conditions that are largely preventable and/or manageable. He Korowai Oranga (Ministry of Health 2002), the government's Māori health strategy, lists the following

as Māori health and disability priorities; immunisation, injury prevention, hearing, asthma, smoking, diabetes, mental health, oral health, disability support services, rangatahi health, sexual and reproductive health, alcohol and drug use.

There is increasing evidence that inequality of access to health care services is contributing to poor Māori health outcomes (Robson 2002). Access to health services has been a particular concern to Māori and barriers to treatment include information, cost, transport, the geographic location of services and cross-cultural miscommunication (Cram 1998; Ruakere 1998; Crengle 2000). Improving Māori access to appropriate health services is essential to reduce avoidable hospitalisation.

Ethnicity issues in data collection

Difficulties in obtaining accurate information on Māori health lie with the criteria for and the (non)collection of ethnicity data. Census data collected in the later parts of the 19th century and most of the 20th century defined Māori based on the notion of race. Officially you had to have either 'half or more Māori blood' to be classified as Māori. The Māori Affairs Act (1953) defined Māori as *"...a person belonging to the aboriginal race of New Zealand, including a half-caste and a person intermediate between half-caste and a person of pure descent from that race"*. During the 1980s the emphasis moved from the degree of blood to ethnic affiliation (Mako 1998). Recent changes in the design of the ethnicity question have also affected the comparability of census information and the quality of longitudinal data. The definition of ethnicity used by Statistics New Zealand for the 1996 census was:

> *...the ethnic group or groups that people identify with or feel they belong to. Thus, ethnicity is self-perceived and people can belong to more than one group. An ethnic group is defined as a social group whose members have the following four characteristics:*

> - *share a sense of common origins;*
> - *claim a common and distinctive history and destiny;*
> - *possess one or more dimensions of collective cultural individuality;*
> - *feel a sense of unique and collective solidarity. (Mako 1998) pg 43*

Whakatātaka (Ministry of Health 2002), the Māori health action plan aligned to He Korowai Oranga specifies improving Māori health information as a specific objective and lists the following action point,

> DHB's (District Health Boards), providers and the Ministry of Health will collaborate to improve data collection and accuracy of health ethnicity data, in order to improve planning and service delivery for Māori (Ministry of Health 2002). pg 28

Determinants of health

Social inequality is illustrated by the existence of health disparities that systematically burden particular communities (Krieger 2001). Attempts to reduce inequalities in health should be based around an understanding of their causes (Mackenbach, Bakker et al. 2001). Social determinants of health refer to the ways in which societal conditions, natural, economic, social, cultural and political, affect health. Factors such as demographic change, participation in society, environmental adaptation, access to Te Ao Māori and health policies have all been identified as determinants of Māori health (Durie 2000).

> The determinants of good health are complex so that it is not easy to comprehend the impacts of actions in one area or one sector without also considering the flow on effects in another area. Economic growth may be at the expense of social wellbeing while high levels of social adversity may reduce opportunities for economic gain....Conversely, if economic policies lead to high unemployment or decreased access to quality education, more often than not, health status will be compromised. (Durie 2003) pg 157

This has particular relevance to Māori given their marginalised status according to almost every key socio-economic indicator (Ratima 2001). The National Health Committee[9] reported on the social, cultural and economic determinants of health in 1998 and found that Māori cultural conventions, such as those related to a secure identity, are associated with health. Poor Māori health has also been attributed to the following indicators;

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[9] Committee that provides advice to the Minister of Health

- After tax, Māori family income reduced significantly between 1981 and 1993.
- Māori had much higher rates of unemployment than the general population.
- In 1996, 39% of Māori left school with no qualification.
- Over 60% of Māori had low levels of literacy.
- The Māori infant mortality rate is higher than that of non-Māori.
- Māori experience an excess burden of mortality and morbidity throughout life.
- Poor Māori health status was mostly due to poorer socioeconomic circumstances.

(National Health Committee 1998)

Cultural indicators of health are in the early stages of development, however, access to cultural resources is related to the construction of a meaningful identity as Māori. The number of Māori that can converse in te reo Māori fluently limits the ability of individual Māori to access environments where te reo Māori can be heard and spoken. In the 1996 census only 25% of Māori adults were able to speak Māori at a conversational level (Durie 2001).

While people in the lowest socioeconomic groups consistently have the poorest health status, within these groups Māori have been shown to have worse outcomes (Robson 2002). Social exclusion and discrimination in the allocation of resources makes racism a central component of ethnic inequalities of health (Nazroo and Karlsen 2001). As social conditions are created by the dominant sections of society, social determinants of health can potentially be altered by informed action. Socio-economic inequalities are reducible and efforts to improve Māori health have wider benefits to society (National Health Committee 1998).

The importance of Māori involvement in policy development has been stressed as a way to incorporate Māori values and promote a more integrated approach to Māori development (Durie 2001). The proliferation of Māori health providers has also contributed to positive advancements in Māori health that has led to both culturally appropriate health services and opportunities for Māori to develop leadership roles in the sector (Durie 1994). Māori models of health are increasingly integrated within health services to improve the cultural responsiveness of the service.

Māori understandings of health

A number of Māori health models have been developed based on Māori concepts, however, Te Whare Tapa Wha is most widely known and used model (Crengle 2000). Te Whare Tapa Wha grew out of a training session for Rapuora fieldworkers, a Māori Women's Welfare League research project. Contributions from Tupana Te Hira, Dr Henry Bennett and Dr Jim Hodge were combined by Dr Mason Durie to propose a view that the basic ingredients for good health were; te taha wairua (the spiritual), te taha hinengaro (the mental), te taha tinana (the physical), me te taha whānau (the family). This concept describes the person as more than the joining of physical and mental processes. Māori health is holistic, and acknowledges the interactions between each of the elements identified in Te Whare Tapa Wha (Murchie 1984). The characteristics of Te Whare Tapa Wha are illustrated in the following table.

Table 1. Te Whare Tapa Wha

	Taha Wairua	Taha Hinengaro	Taha Tinana	Taha Whānau
Focus	Spiritual	Mental	Physical	Extended Family
Key Aspects	The capacity for faith and wider communion	The capacity to communicate, to think, and to feel	The capacity for physical growth and development	The capacity to belong, to care, and to share
Themes	Health is related to unseen and unspoken energies	Mind and Body are inseparable	Good physical health is necessary for optimal development	Individuals are part of wider social systems

(Durie 1994) pg 70

The model proposes that health is the balance between the four interacting dimensions (Durie 1994). Taha Wairua incorporates aspects of spirituality and vitality. It encompasses spiritual beliefs and practices but is not synonymous with religion. It implies a capacity to understand the links between the human situation and the environment. As Jackson states "Māori are tangata whenua. Not just people in the land or over the land, but people of it" (Jackson 1993). Land, lakes, mountains, rivers and forests all have a spiritual significance to Māori and are

considered integral to identity and a fundamental sense of well-being. Māori acknowledge the wholeness of life in which wairua is ever present (Ministry of Justice 2001). A powerful belief in spirituality governs and influences the way one interacts with other people, and relates to her or his environment (Pere 1991).

Te Taha Hinengaro is about the expression of thoughts and feelings and refers to both verbal and non-verbal styles of communication. The capacity to feel is the ability to recognise emotions and to express those emotions appropriately (Durie 1994). The style of thinking is integrative rather than analytical and understanding occurs through synthesis into wider contextual systems that realise relational factors within the organisation of the whole system. This mode of thinking typically regards poor health as a manifestation of a breakdown in harmony between the individual and the wider environment.

Te Taha Tinana relates to the physical health of the person. While it is a more familiar concept, its nature and importance in the context of a Māori understanding of health is somewhat different. Traditionally, physical signs of illness were seen as a 'tohu', a manifestation of a state of 'dis-ease' often of a spiritual origin rather than a bacterial or viral invasion. Consequently, treatment centred more on the cause of the imbalance (spiritual dis-ease) rather than the result of the imbalance (physical signs). This also reflects an understanding of the integrated and complimentary nature of these dimensions (Durie 1994).

Te Taha Whānau refers to the importance of the extended-family as a cultural, emotional and physical support. It reflects a fundamental principle of the Māori value system, 'whanaungatanga'. As Mead writes,

> *Whanaungatanga embraces whakapapa and focuses on relationships. Individuals expect to be supported by their relatives near and distant, but the collective group also expects the support and help of its individuals. (Mead 2003) pg 28*

The interdependent nature of Māori relationships is deemed to be an integral part of health. It helps to foster a sense of personal identity, purpose and place in society. The distinction between personal and family identity is frequently blurred. Similarly, the boundaries between

each of the dimensions described above are not as defined as they have been in Western thought since the adoption of Cartesian dualism (Durie 1994). The concept of 'Whānau Ora', Māori families supported to achieve their maximum health and well-being, is proposed as the overall aim of New Zealand's Māori health strategy (Ministry of Health 2002). It calls on the health and disability sectors to,

> *...recognise the interdependence of people, that health and well-being are influenced and affected by the 'collective' as well as the individual, and the importance of working with people in their social contexts, not just their physical symptoms. (Ministry of Health 2002) pg 1*

Te Whare Tapa Wha, as a model, has been adopted by many mainstream organisations as a principle or philosophy to demonstrate Māori responsiveness or cultural sensitivity. However, despite a stated commitment to the model, there are few examples within mainstream organisations of its operationalisation in any substantive way in terms of influencing core business delivery style or activities. The one major criticism of Te Whare Tapa Wha is that little else has been written to provide a more explicit description of its characteristics or underlying philosophy. Neither has it been expanded upon to explain how the model might be operationalised within the health sector in a way that reflects a Māori understanding of health. Te Whare Tapa Wha is a representation of what many Māori perceive health to be. It strongly represents the foundations necessary to live as part of a wider community. While there has been some movement within the health system towards more holistic concepts of health, for this model of health to be applied in its entirety, it would require a radical rethinking of the way in which health issues are identified and prioritised.

Summary

That inequalities in health exist for Māori within our society is indisputable. There is extensive research evidence demonstrating that Māori suffer the burden of disease in a disproportionate manner. The difficulty obtaining consistent Māori specific health information is linked to the changing methods of collecting ethnicity data. However, there is increasing recognition that inequalities in health are determined largely by wider societal conditions. Economic, social, cultural, natural, environmental and political factors all influence Māori health status. Māori

understandings of health are holistic and integrative, recognising the influence of broad social determinants on the health of individuals. Te Whare Tapa Wha acknowledges the physical, mental, spiritual, and familial aspects of health and has been widely adopted as representing a Māori model of health. However, there has been criticism that the values and philosophy inherent to the model are not maintained when it is utilised outside of Māori settings.

Chapter 3: Māori and Research

Māori value and have always valued knowledge… (Cunningham 2000)
pg 62

Introduction

Māori have always appreciated the importance of knowledge, and experimentation was a valued characteristic within Māori culture. This quality is embodied in the characters celebrated in oral traditions. It is also evident from the voyages Māori made across vast expanses of ocean in search of new lands like New Zealand. The arrival of Westerners to New Zealand changed the context of research for Māori and located them as the subjects of research. This attitude prevailed in New Zealand for a number of years until Māori researchers began to challenge the appropriateness of Western research approaches and its ability to contribute to Māori development.

Māori have since reclaimed control over research processes by situating them within a Māori inquiry paradigm and developing methodologies consistent with Māori values and beliefs. Kaupapa Māori research is a uniquely Māori methodology and Māori-centred research involves the application of Western methodologies in a manner consistent with the Māori inquiry paradigm. The characteristics of Māori research have been described and are based on respect for Māori preferences, Māori control of research processes and need for benefits to be realised in the Māori community. Principles to guide researchers when working with Māori have also been described and indicate qualities valued by the Māori community.

Customary approaches

Research is about seeking out and accessing knowledge and Māori have a long tradition of research and experimentation (Mutu 1998). This is reflected in ngā kōrero tāwhito[10], historical experiences, and the creation stories. Ngā kōrero tāwhito can be interpreted literally, metaphorically or through value judgements (the promotion of certain virtues). These reflect cultural beliefs, values and norms. The creation of the world through the separation of

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[10] Oral history

Ranginui (Sky-father) and Papatūānuku (Earth-mother) by their children, who each used different methods until one, Tane[11], was successful. The forming of the first person, a Hine-ahu-one[12], by a succession of atua is another demonstration of progress via trial and error. Maui[13] is another tipuna revered for challenging the boundaries of accepted wisdom such as the shortness of the day, and the mortality of people. These are all examples of the experimental tradition that was a valued characteristic within Māori culture.

The migration from the islands of the Moana-nui-a-Kiwa[14] to Aotearoa[15] exemplifies a drive to explore and expand knowledge, qualities fundamental to research inquiry. Whare wānanga were the houses of higher learning where knowledge was debated and generated by tohunga[16]. The development of rongoā, navigation by the stars, the manufacturing of tools, utensils, art and weaponry demonstrate a commitment to knowledge and progress. According to Arohia Durie *(Durie 1998)*,

> *For iwi Māori in former times, whare wānanga, were the institutes of higher learning that carried major responsibility for the retention and transmission of knowledge, while on the marae and in the wharenui, debate would occur over particular aspects of knowledge. Research in the sense that a hypothesis, problem posing, enquiry, explanation, and problem solving existed, evolved within the bounds of particular philosophies of knowledge, of ways of knowing and accepted methodologies through which knowledge and ideas could be examined. pg 257*

Changing contexts

The arrival of Pākehā[17] to Aotearoa changed the context of research for Māori. Māori knowledge and customary research approaches were marginalised and Māori were firmly perceived as research subjects only. Research on Māori was carried out within a social

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[11] The children of Ranginui and Papatūānuku are known as atua (gods) and have dominion over different domains. Tane is known as the god of the forest.
[12] Māori are linked to the gods through their geneology. The gods collectively (up to 70 in some traditions) created Hine-ahu-one and Tane slept with her to begin the lineage of men.
[13] Maui is a revered ancestor who had supernatural powers which he used to advance the cause of men.
[14] Māori name for the Pacific Ocean.
[15] Māori name for New Zealand which means 'Land of the long white cloud'.
[16] Experts that covered a range of disciplines.
[17] Term for non-Māori usually of European origin

pathology framework that emphasised deficits and focused on Māori inability to cope in the Western world (Bishop 1998; Waitere-Ang 1998). Deficit thinking assumes that New Zealand society and systems are neutral towards Māori despite evidence to the contrary (Reid, Robson et al. 2000). The historical links between research and colonisation has led to a general feeling of apprehension amongst many Māori to any type of research (Smith 1997). Durie *(Durie 1998)* states,

> *Māori know of the essentially political nature of research from long experience as 'the researched' and that where dominant cultural norms are used as the benchmark for research, Māori difference becomes problematised. pg 258*

While there is a place for research that compares Māori and non-Māori, there have been problems with comparative studies. In particular, research that posits Western cultural preferences and values as the norm or that de-contextualises issues from their socio-economic and cultural background does not take account of the broad determinants that shape population group risk behaviours. Such deficit approaches lend themselves to victim blaming and serve to marginalise Māori and advantage the dominant population (Teariki, Spoonley et al. 1992). Specific concerns also include, who will directly benefit from the research (Bishop 1998), who controls the resources to carry out the research (Powick 2002), who determines the framework for the research, what methodologies are to be used and how are the results to be interpreted (Mutu 1998). Cunningham noted that science and the culture of science have been used as an instrument of colonisation which has limited Māori knowledge to traditional knowledge by fixing Māori development in the past (Cunningham 1998). The continuing colonisation process has seen Māori excluded from many areas of research and the corresponding benefits (Walker 1997).

Research and Māori development

Māori development aspirations provide the impetus for continuing Māori involvement in research. Research has the potential to contribute not only to Māori advancement but also advancement as Māori. Research is used to justify the allocation of resources in a variety of fields, including health. The importance of research for Māori development and to reduce

inequalities is expressed in the Health Research Council[18] guidelines for researchers on health involving Māori,

> *The continuing disparities in health between Māori and non-Māori produce a strong argument under article three for significant health research resources to be directed at resolving Māori health issues. High quality research is a key component in Māori health development, as it is essential that initiatives to resolve Māori health issues are based on a foundation of high quality information. (Health Research Council of New Zealand 1998)*

The importance of research leading to positive Māori development have been consistently emphasised by Māori academics (Durie 1994; Smith 1997; Ratima 2001). Māori development outcomes and strategic research goals were identified as themes at Te Oru Rangahau, Māori research and development conference held at Massey University in 1998.

The following table links research to Māori development and lists strategic goals for research activity that will facilitate the attainment of Māori development goals. The strategic research goals cover a broad range of activities that advocate for Māori participation in the research sector in ways that validate Māori approaches to research.

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[18] Committee that accredits health and disability and institutional ethics committees

Table 2. Te Oru Rangahau framework for Māori research and development

Māori Development Outcomes	Strategic Research Goals
T ino rangatiratanga	**R** etention, transmission & development of old and new knowledge
E quity and social well-being	**A** code of ethics
	N ational focus for Māori research and development
O utcomes linked to a secure Māori identity	**G** everation of evidence based policies and practices
R esource development and economic growth	**A** nalysis based on Māori frameworks
U niversality	**H** uman resource development
	A lliances between disciplines, sectors, & communities of interest
	U se of multiple methodologies

Ratima (2001) identified key values that underlie Māori development and their implications for Māori self-determination and advancement. The values inherent to Māori development were identified as,

- collective autonomy – recognising the autonomy of Māori collectives to control resources and be self-governing.
- Māori rights – recognises the claims to distinct sets of rights, indigenous rights, Treaty of Waitangi rights and human rights.
- being Māori – recognises that a strong sense of Māori identity is central to Māori development.
- equity – recognises that differential resource allocation can be justified on the basis of need.

- social justice – recognises that all people have the right to equal consideration in terms of development opportunities. (Ratima 2001)

These values emphasise the importance of the collective Māori identity, Māori control and fairness in the distribution of resource and opportunity. Within research, these values should be embodied if the research is to effectively contribute to Māori development aspirations.

The Māori response – new methodologies

Māori frustration with the on-going erosion of Māori language, knowledge and culture and the inability of dominant Western research paradigms to provide solutions to Māori problems led to questioning of existing research paradigms and the further development of Māori specific approaches to research. This was set in the context of vital Māori development movement that was reclaiming and legitimising Māori cultural aspirations, values and practices. Māori began to challenge the universal applicability of Western research methods and practice in a cross cultural context and argued that constructive rather than destructive methodologies were needed to promote Māori development (Stokes 1985; Te Awekotuku 1991; Smith 1997; Durie 1998). Over several decades distinct Māori research approaches re-emerged that are culturally congruent with Māori values and beliefs and ensure that Māori interests are protected in the research process.

Taxonomy of Māori research

Cunningham (Cunningham 1998) created a taxonomy for Māori research (table 3) that categorises the type of research on the degree of Māori involvement in the project and the production of Māori or mainstream knowledge for each of the following;

- Research not involving Māori (as participants)
- Research involving Māori (as participants)
- Māori-centred research
- Kaupapa Māori research

Table 3. Characteristics of four identified types of research, science and Technology

Characteristics	Research not involving Māori	Research involving Māori	Māori-centred research	Kaupapa Māori research
Description	Research where Māori participation or data is neither sought nor considered relevant; Research whose results are thought to have no impact on Māori	Research where Māori are involved as participants or subjects, or possibly as junior members of a research team; Research where Māori data is sought and analysed; Research where Māori may be trained in contemporary research methods and mainstream analysis.	Research where Māori are significant participants, and are typically senior members of research teams; Research where Māori analysis is undertaken and which produces Māori albeit knowledge measured against mainstream standards for research.	Research where Māori are significant participants and the research team is typically all Māori. Research where a Māori analysis is undertaken and which produces Māori knowledge; Research that primarily meets expectations and quality standards set by Māori.

(Cunningham 1998) pg 7

This framework recognises that Māori will continue to be participants within Western research and that non-Māori are likely to continue researching Māori or carrying out research that affects Māori. However, the development of Māori research practices based on Māori worldviews provides an opportunity for Māori to carry out research in their own terms. Ratima argued that a new Māori inquiry paradigm has emerged and that the Māori research approaches fall into two general categories;

1. Methodologies which have been developed from within a uniquely Māori inquiry paradigm and characterised by Kaupapa Māori research, and

2. Western methodologies that may be located within Western paradigms but are able to be adapted, as Māori-centred research, and applied in a way that is consistent with a Māori inquiry paradigm. (Ratima 2003)

Despite their differences Ratima notes,

> *Kaupapa Māori research and Māori-centred research share a common purpose – the generation and transmission of Māori knowledge. In terms of Māori health research there is an expectation that this knowledge will lead to positive health outcomes for Māori as Māori, and contribute to Māori advancement. (Ratima 2001) pg 155*

Characteristics of Māori research

Bevan-Brown (Bevan-Brown 1998) identified 10 characteristics of Māori research from the literature which are relevant to both Māori centred research and Kaupapa Māori research.

1. Māori research must be conducted within a Māori cultural framework. This means it must stem from a Māori world view, and incorporate Māori concepts, knowledge, skills, experiences, attitudes, processes, practices, customs, reo, values and beliefs.
2. Māori research must be conducted by people who have the necessary cultural, reo, subject and research expertise required. They must also possess a commitment to things Māori, the trust of the Māori community being researched, cross-cultural competence, personal qualities suited to doing Māori research and an understanding and commitment to the obligations, liabilities and responsibilities that are an integral part of Māori research.
3. Māori research should be focused on areas of Māori importance and concern to Māori people. It should arise out of their self-identified needs and aspirations.
4. Māori research should result in some positive outcome for Māori. This may be manifest in many different ways e.g. improved services, increased knowledge, health gains or more effective use or resources. Whatever the form, Māori research should benefit Māori in some way.
5. As much as possible, Māori research should involve the people being researched as active participants at all stages of the research process.
6. Māori research should empower those being researched. This empowerment should stem from both the research process and product.
7. Māori research should be controlled by Māori. This is to ensure that it is carried out within a Māori cultural framework and that Māori interests and integrity are protected.

The control of Māori research should extend to control in matters relating to ethical requirements, assessment, funding, intellectual property rights and ownership and dissemination of knowledge.

8. People involved in conducting Māori research should be accountable to the people they research in particular and to the Māori community in general.

9. Māori research should be of a high quality. It should be assessed by culturally appropriate methods and measured against Māori-relevant standards.

10. The methods, measures and procedures used in Māori research must take full cognisance of Māori culture and preferences. They must take into account the previous nine requirements of Māori research.

Bevan-Brown proposed that the 10 components outlined above provide a base for Māori research regardless of its area or subject of investigation. The central themes of Māori research, as proposed by Bevan-Brown, can be summarised as respect for Māori preferences, control by Māori of research processes and that Māori benefit from the research. The Māori participants or the Māori community rather than the researcher must assess benefit in this sense.

Māori-centred research

Māori-centred research involves the adaptation of Western methodologies located within Western paradigms to Māori contexts. Māori-centred research usually has Māori involvement at all levels of research activity, as participants, researchers and analysts (Powick 2002). The use of Western 'methodologies' allows researchers to use the best methods to achieve their research goals. Western 'methodologies' are usually well established and have established legitimacy within mainstream agencies which smooths the way for gaining institute approval, ethics committee approval and funding support (Cunningham 2000).

A certain level of flexibility is engendered by the ability to select from a broad range of research methods and methodologies. The use of multiple methods and methodologies, contingent on there appropriate application, was identified as one of eight strategic Māori research goals at the Te Oru Rangahau conference in 1998 (Ratima 2001). Māori-centred research often has an element of dual accountability to both mainstream and Māori

(Cunningham and Durie 1998). There is a possibility of these dual accountabilities conflicting if the expectations of the mainstream funders and reviewers are contrary to the expectations of Māori (Cunningham 2000).

Kaupapa Māori Research

Methodologies that have been developed from within a Māori inquiry paradigm and are therefore distinctly Māori are commonly referred to as Kaupapa Māori Research (Powick 2002). The term 'Kaupapa Māori' has been adopted to cover a broad range of innovative research approaches, characteristics, requirements and issues that relate to Māori (Takino 1998; Henry 1999). Kaupapa Māori Research has been defined as 'Research by Māori, for Māori and with Māori' (Smith 1995) and challenges a universal approach to address Māori needs. Rather, it gives full recognition of Māori culture and value systems (Reid 1998). Kaupapa Māori research is based on a growing consensus that research involving Māori knowledge and people needs to be conducted in culturally validating ways (Bishop 1998) that legitimise Māori knowledge and values (Walsh-Tapiata 1998) and ensure that the research benefits Māori. Henry (Henry 1999) summarises the role of Kaupapa Māori researchers as *"...to legitimise mātauranga Māori and develop kaupapa Māori, as one part of the struggle to empower and liberate Māori people and community"*. The emancipatory goal of kaupapa Māori research is one of its defining features.

Linda Smith describes a set of working principles for Kaupapa Māori research in her PhD thesis 'Ngā Aho ō te Kākahu Mātauranga' (Smith 1997). These principles derived from an educational context represent key elements that encapsulate Māori values and knowledge and which make interventions with Māori more likely to succeed. They have since been formulated as guidelines for Māori research ethics in the context of Māori research and are presented in cultural terms that reflect characteristics valued by Māori communities. They can be used to ensure that the ethics relevant to research in a Māori environment are being considered (Cram 2001).

1. *Aroha ki te tangata - A respect for people*
   Allowing people to define their own space and to meet on their own terms. Having cognisance for cultural preferences in establishing relationships.

2. *He kanohi kitea – The seen face, that is present yourself to people face to face*

   About the importance of meeting people, face to face. A process of making connections and building relationships that involves investing time in the community prior to the commencement of the research.

3. *Titiro, whakarongo…korero – Look, listen…then speak*

   About the importance of looking and listening so that you develop understandings and find a place from which to speak. Being aware of relational dynamics and open to direction from the community.

4. *Manaaki ki te tangata – Share and host people, be generous*

   About collaborative approach to research, research training, and reciprocity.

5. *Kia tūpato – Be cautious*

   About being politically astute, culturally safe and reflective about our insider/outsider status.

6. *Kaua e takahia te mana ō te tangata – Do not trample over the mana of people*

   About sounding our ideas with people, about disseminating research findings, about community feedback that keeps people informed about the research process and the findings.

7. *Kaua e mahaki – Don't flaunt your knowledge*

   About sharing knowledge and using our qualifications to benefit our community.

These principles give an indication of the types of behaviours that researchers should exhibit in their interaction with Māori. In many ways they relate to the personal qualities and characteristics that should inform the researcher's relationship with Māori communities.

Summary

Māori have a long tradition of experimentation. The arrival of pākehā changed the context of research for Māori in New Zealand. Research became linked with colonisation and many Māori became suspicious of any research. Contemporary Māori approaches to research have developed to address Māori concerns about research practices and to gain control over the processes and outcomes of research. A uniquely Māori inquiry paradigm that reflects Māori worldviews umbrellas emerging kaupapa Māori and Māori-centred research approaches.

These research approaches aim to improve the relevance and responsiveness of research to Māori. Māori centred research uses Western methodologies but applies them in a culturally appropriate manner. Kaupapa Māori research validates Māori knowledge constructs and has legitimised the application of tikanga Māori within the research environment to make research more culturally safe for Māori participants and their communities. Both these research approaches aim to produce knowledge that directly benefits Māori communities and contributes to Māori development aims.

Chapter 4: Ethics in Health Research

Introduction

Ethical principles guide the practice and behaviour of researchers to ensure that research is undertaken in ways to protect and enhance the interests of the participants (O'Brien 2001). These principles are based on western ideals of ethics and are principally informed by internationally recognised codes of medical ethics such as the Nuremburg Code (Evans and Evans 1996), the Declaration of Helsinki (The World Medical Association 1964 (revised 1975 and 1983)) and the Belmont Report (Denzin 2004). These codes adopt an ethical stance that considers principles for conducting research to be fundamental or universal in nature (Crigger, Holcomb et al. 2001). This position is premised on the assumption that research is a morally important activity because of the benefits that may arise from it and this provides a moral framework for health research (Evans and Evans 1996).

Universal ethical principles

It is widely understood that in evaluating the ethical aspects of health research, ethics committees typically apply a common set of principles to all research proposals (Goodyear-Smith, Lobb et al. 2002). These ethical principles were articulated in a framework for biomedical ethics formulised by Beauchamp and Childress (Beauchamp and Childress 1994). They proposed that the ethical principles of respect for autonomy, non-maleficence, beneficence and justice as universal in nature and applicable to any culture and society.

Autonomy

The notion of autonomy relates to the freedom of people to make intentional decisions independent from controlling influences. Within the Western ethical tradition, autonomy consists of three basic elements,

1. the ability to decide,
2. the power to act upon your decisions and,
3. a respect for the individual autonomy of others.

    (Edge and Groves 1999).

Autonomy derives its name from the Greek words *autos* 'self' and *nomos* 'rule' (Aksoy and Tenik 2002) and was originally used to describe the self-governance of independent Hellenic city-states. The concept of autonomy has since been extended to the individual and incorporates meanings such as liberty, privacy, free will, individual choice, and being oneself (Beauchamp and Childress 1994). The capacity for self-determination is one aspect of autonomy, the right to be different is another (Charlesworth 1993). Autonomy is based on the concept of the 'isolated individual', separate from everyone else and able to make independent decisions (Hinman 1998). This position forms one of the most basic elements of the Western biomedical discourse. It has been challenged by those who believe that it fails to recognise the extent to which individuals are inescapably part of a particular community and that communal values and practices largely set out our ethical goals (Charlesworth 1993). This is true of many 'traditional' societies for whom individual autonomy is a non-sense within their cultural context. Individual autonomy often has no meaning in practical life where collective structures are allocated decision-making roles (Oguz 2003).

Another difficulty that arises with the concept of individual autonomy is accounting for people who have 'diminished' autonomy or ability to make free and informed choices. This category of people can include children and people with intellectual disabilities, as well as those who are suffering from extreme pain or emotional distress. To be able to make a decision, a person must have adequate information and intellectual competence. This involves being fully aware of what the research is about as well as the possible risks or implications of participation. Another element of autonomy is the ability to act on your decision. This reflects concerns that participation should be free of coercion, duress, deceit or constraint. A respect for the autonomy of others entails a general respect for people as competent to make decisions about their own lives.

Autonomy has also been conceptualised as a quality measured by the 'ability to do'.

> *...autonomy is an intrinsic personal quality. At its most basic, to be autonomous is to be able to do – to be able to do anything rather than nothing. Autonomy, thought of in this way, is a matter of degree – the better the quality of the autonomy the more a person is able to do. (Seedhouse 1998) pg 182*

The ability to do anything rather than nothing is a quality that everyone possesses and is relative to a person's capabilities. Seedhouse makes a distinction between respecting autonomy, where a person's choice is respected, and creating autonomy, where a person's range of options and ability to do is enhanced (Seedhouse 1998).

Non-maleficence

Non-maleficence is the obligation to do no intentional harm. Its exact origin is unknown but it is closely related to the Hippocratic oath and the maxim of medical ethics, "Above all do no harm" (Beauchamp and Childress 1994). Generally speaking, we do not have an obligation to benefit other people however we have a duty not to harm them (Aksoy and Tenik 2002). In terms of health research this means minimisation of harm to research participants. While many research projects have a certain amount of risk, researchers should try to reduce the exposure of participants to harm as much as possible. The relative risk of the research procedure may be determined by comparison with the risks of current available or standard treatment. The extent and type of harm is also considered and this may include physical, psychological, social and economic factors (Ministry of Health 2002). These risks are then weighed against the benefits to either the participants or the wider community that might arise from the research project. For example, should an individual participant be at any risk of harm from their participation in the research project, then the potential good to society or future individuals with relevant needs must heavily outweigh the potential risk (Goodyear-Smith, Lobb et al. 2002).

Beneficence

Beneficence is concerned with helping others and promoting good. Beneficence the 'action' is related to benevolence the 'trait' and both of these concepts have been widely debated in philosophical circles (Beauchamp and Childress 1994). Beneficence in the health field has often been associated with the duty of care and the responsibility of health workers to take actions that positively affect their patients (Edge and Groves 1999). Its application in the context of research is linked to the likely benefits of the research for both the participants and society. In this respect it is part of the risk/benefit equation that ethics committees must assess in their evaluation of research proposals. The issue of who benefits from the research is central to many indigenous critiques of research activity (Bishop 1998; Smith 2001). Research is seen in many cases to be done for the benefit of the researcher rather than the community. The

researcher benefits directly from completing a research study and writing articles, however the community often receives little or no positive outcome from participation. The composition of ethics committees, consisting predominantly medical professionals, academics and researchers, often has a bias towards the theoretical benefits of research projects (McNeill 1996). \

Justice

Justice is the impartial, equitable and appropriate treatment of all – the fair distribution of benefits, risks and costs (Goodyear-Smith, Lobb et al. 2002). The concept of justice is informed by notions of fairness, equality or entitlement (Beauchamp and Childress 1994). The application of a particular form of justice, distributive justice is most common in health and research settings as a means of providing a moral framework for distributing scarce resources. The way in which resources are allocated is an ethical decision and arguments around justice relate to the fairness or otherwise of this process. The following principles have been proposed as determining features of distributive justice,

- To each person an equal share
- To each person according to need
- To each person according to effort
- To each person according to contribution
- To each person according to merit
- To each person according to free-market exchanges (Edge and Groves 1999)

Depending upon which of these positions informs your notion of justice, it is evident that the outcome of an ethical appeal on the basis of justice could be quite varied. The notion of justice as rights is often associated with indigenous movements and Aristotle's contention that equals must be treated equally and un-equals must be treated unequally (Edge and Groves 1999). Processes of colonisation that result in the marginalisation of indigenous values and interests have contributed to widespread inequalities and this has been challenged as unjust. The right to get equitable outcomes is central to the notion of justice as rights.

Criticism of the universal ethical principles

In theory, by adhering to the universal ethical principles stated above researchers should produce ethically sound research. Elements of each principle intertwine with the others, and the priority given to one or another of these principles is often at the heart of an ethical deliberation. The four principles approach has been criticised for not providing a reason or a theory of justification, for being open to wide interpretation, and for not providing a means of adjudicating when the principles conflict with one another (Seedhouse 1998).

> *These principles are not necessarily complimentary and may be conflicting or at times even mutually exclusive. This may require balancing of one principle against another. There is a prima facia obligation to fulfil a principle unless a stronger obligation overrides this on a particular occasion. The safety of, and benefit to, the individual is usually considered to take precedence. (Goodyear-Smith, Lobb et al. 2002)*

The cultural utility of the 'universal principles'

The four principles approach to biomedical ethics has been increasingly developed as a universal bioethics method. Despite its wide acceptance and popularity, there have been many challenges to its cross-cultural plausibility, on the basis that cultural understandings will influence the application and utility of ethical concepts (Tsai 1999). As Oguz (2003) writes,

> *Cultural interpretation of concepts is the perception of concepts effected by their cultural connections with other concepts. For example, "motherhood" as a concept has many cultural connections, so when it is used we have to consider those culturally determined contexts. pg 292*

Few studies have examined the cross cultural applicability of the 'universal' principles. Tsai (1999) compared the four principles approach to ancient Chinese medical ethics and found that the concepts of autonomy, non-maleficence, beneficence and justice were clearly identifiable. However, despite the existence of similar concepts there was a discernable difference in their practical application with a tendency towards a beneficence-oriented approach rather than the autonomy-oriented approach favoured in contemporary Western bioethics. Tsai suggested that this difference reflected the influence of socio-cultural factors (Tsai 1999).

Aksoy and Tenik (2002) also examined the cross cultural applicability of the four principles approach by determining its consistency with the principles of Islamic teachings, specifically those of Mawlana, a prominent Muslim Sufi theologian and philosopher. They were able to identify the existence of the concepts of autonomy, non-maleficence, beneficence and justice within these Islamic teachings although there were different conceptualisations of autonomy and justice. Being autonomous was dependant on knowledge and limited by the divine autonomy of the creator. Justice, in this tradition, was communitarian with a prima facia duty to defend the rights of every individual in society by protecting the benefits of the community (Aksoy and Tenik 2002).

Universality is also based on the assumption that the result of social development of all human beings will end up necessarily with characteristics of Western people (Oguz 2003). Oguz criticised the universal notions of respect for autonomy as culturally insensitive to social constructs in Turkish society, which are based on "collective autonomy". Oguz contends that fundamental differences stem from the conceptualisation of the universe (life, community, and human) so that people who exist in this cultural environment will have decision-making processes very different from that of Western people (Oguz 2003). Collective autonomy operates differently due to the blurring of individual boundaries and the nature of relationships within the collective. The propensity for misunderstanding of values and language in cross cultural studies means that the robustness of the traditional process of gaining informed consent must be questioned.

> *Accepting and imposing a Western model of autonomy as an international regulatory norm is also questionable. Modifying the methods of obtaining informed consent or the composition and content of consent forms is not adequate to overcome the respect-for-autonomy problem. It is necessary to reflect on culturally sensitive, and effective, safeguards for protecting human research subjects. Otherwise there will be significant reason to claim that the values of the developed world and methods for protecting these values are only for developed countries and they can only be practiced if the developing world will provide adequate means for scientific knowledge, which is not bound to full realization of these procedures. (Oguz 2003) pg 296*

It is possible to detect the roots of the 'Four Principles of Bioethics' in a range of cultural traditions; however, there is often a different emphasis on the individual principles as compared to Western understanding. Cultural interpretations of concepts have a significant effect on the practical application of the ethical concepts within society. This is not merely related to a difference in understanding or knowledge, but rather a fundamental difference in the conceptualisation of the universe.

Additional New Zealand ethical principles

While the universal ethical principles provide the primary framework from which ethics in health research are assessed, there are a variety of other ethical principles that inform ethical review processes in New Zealand. The following ethical principles are also considered, informed consent, privacy and confidentiality, validity of the research proposal, and compensation. Each of the additional principles has a relationship to the universal principles and supports traditional biomedical interpretations.

Informed consent

Informed consent is now considered one of the basic tenets of medical research. The way a participant makes a decision to voluntarily participate in a research project demonstrates his/her autonomy (Edge and Groves 1999; Wilkinson 2001; Oguz 2003). It is important to recognise that the process of informed consent supports the obligation to the principle of autonomy. Corrigan contends those arguments that focus on informed consent as an absolute moral principle result in a reductionist abstraction and an empty ethics that strips the principle of consent away from its social context. (Corrigan 2003)

Informed consent has its origins in the Nuremburg Code (1947), which was developed in direct response; to evidence that emerged from the Nuremburg War Crimes Trials (The Doctors Trials) about horrific medical experiments on prisoners. While the Nuremburg Code lists 10 principles, it is the concept of voluntary participation in research that has been the enduring theme (1949).

In the 1960's growing concern about the lack of ethical supervision in medical research led to the drafting of the Helsinki Declaration (The World Medical Association 1964 (revised 1975

and 1983)), a code of ethics relating to human experimentation. The Tuskegee Study played a role in the promotion of informed consent as a necessary component of ethical research. This study involved the non-treatment of black men in Tuskegee County, Alabama who had syphilis as a way to determine the natural course of the disease (Edge and Groves 1999). The study ran for about 40 years and the men were never told they had syphilis or given treatment despite symptoms of blindness, insanity and ultimately death.

In New Zealand, the Cervical Cancer Inquiry into a research study at National Women's Hospital focussed attention on ethical research practices (Coney 1988). This particular research study, which began in 1966, was designed to demonstrate that carcinoma in situ, a symptomless lesion of the cervix, was not a precursor to cancer. The study involved on-going observation of the lesion, however, the women were never informed that they were part of a research study and it led to unnecessary disease (in some cases fatal) in a number of the subjects (Campbell, Gillett et al. 1992). The findings of the Inquiry have had far-reaching effects on the way that research is administered and practiced in New Zealand (Tolich 2001). The changes include,

- Ethical approval must be gained for all human-subject research
- Ethics committees must include both lay-persons and academics
- Participants must be fully informed of the research and any risks
- Written consent must be obtained from every participant in the study (Coney 1988)

Tolich argues that the pre-occupation with informed consent in New Zealand skews the ethical debate away from other more significant ethical issues (Tolich 2001).

Privacy and confidentiality

Issues of privacy and confidentiality, particularly in the health arena, are bound by legal provisions such as the Health Information Privacy Code 1994. This code sets out the requirements that must be met regarding the collection, storage, access, use and disclosure of health information pertaining to identifiable individuals (Ministry of Health 2002). Legal codes and the ethical arguments in which they are framed are concerned with minimising the possible harm that may result from disclosure of identifiable information (Edge and Groves

1999). It requires that researchers maintain the confidentiality of information given to them and take every possible step to protect the privacy of the participants by maintaining their anonymity (O'Brien 2001). Confidentiality is the responsibility of the researcher as he/she has control over the distribution and transmission of that information. The obligation to maintain confidentiality should be weighed against the possibility of harm to others (Campbell, Gillett et al. 1992).

Validity of the research proposal

The validity of the research proposal relates to the methodological soundness of the research proposal (Ministry of Health 2002). This includes both the research design (eg methods, and analysis), the potential usefulness of the research proposal, and the experience of the researchers. Research must demonstrate that it is justifiable in terms of its potential contribution to knowledge and its relevance to current literature and previous studies. When using Kaupapa Māori or Māori-focused methodologies, researchers must demonstrate adherence to a standards set by professional peers and show that appropriate consultation has been undertaken (Ministry of Health 2002).

Compensation

Ethics committees have the responsibility of ensuring that adequate insurance cover is in place should and injury result from participation in research. Research conducted primarily for the benefit of a manufacturer or distributor of a medicine or product will be required to provide private insurance cover for the participants. Other types of research will be covered under section 32 of the Injury, Prevention, Rehabilitation, and Compensation Act 2001 (IPRAC Act) (Ministry of Health 2002).

Summary

The universal approach to ethics indicated by the four principles of autonomy, non-maleficence, beneficence and justice has been popularised throughout the developed world and has become the underpinning of international research ethics. The 'universal' principles provide the basis for other ethical principles such as informed consent and confidentiality that

have also become necessary requirements of ethical research. The universal principles are derived from Western interpretations, and the cultural utility of the four principles approach has been examined. The few studies examining the cultural utility of the universal principles have brought into question its consistency with non-Western cultural worldviews. The universal principles were discernable within other cultures however, the conceptualisation and subsequent application of those principles differed. Western application of the universal ethical favours an autonomy-oriented approach, which is inconsistent with cultures that promote beneficence-oriented assessments.

Chapter 5: Cultural Differences in Ethics

Introduction

Ethical deliberation is concerned with assessing the relative importance or priority of different values in any given context. The ability to determine what is the most ethical decision constitutes the right to be right. Cultural challenges to the universality of Western ethical frameworks supports indigenous claims to self-determination and the ability to decide what is right and true for their communities. This chapter provides an insight into cultural difference and the challenge of multiculturalism to the concept of universal ethics. It explores the notion of co-existing belief systems and the influence of different values sets on the decision-making process. Examples of indigenous ethical frameworks are then described.

Ethical deliberation

Aristotle's view was that deliberation was the essence of ethics (Seedhouse 1998). The process of contemplation aligned with a specific goal produces moral decisions based on human judgement. How people see the world is generally informed by their own experiences, values, norms and learning (National Health and Medical Research Council 2003). Values underpin what we perceive, believe, prioritise and do. There is a constant filtering of information through these value sets, and different values trigger alternative modes of decision-making. Decision making has a range of modes and while it is usually tacit and automatic, at other times it becomes either explicit and aware, or explicit, aware and deliberate (Williams 2004). Each member of an ethics committee will have their own set of values and they bring that perspective or bias to the ethical evaluation and decision making process. This will include personal values, values associated with professional bodies of knowledge, and cultural values. In order to make the ethical review process as transparent as possible committee members need to be aware of the way in which different sets of values inform and influence their decision-making. These value sets will influence the process of ethical review and the way in which 'ethical principles' are applied. Examples of the types of Western cultural bias present in research and ethics are that:

- knowledge in itself is a good thing despite what it might be used for, and research is a means to get knowledge;
- the individual's right to choose is paramount; and,
- to be valid, research must follow the rules of research (Brew 2001).

These values are inconsistent with the views of many indigenous cultures and have contributed to the feeling of mis-trust between indigenous communities and researchers. It is in the application of a given principle or the preference for one principle over another that the underlying value base is revealed. Cultural values for example have been shown to have a marked influence on the decision to give primacy to beneficence over autonomy (Tsai, 1999; Oguz, 2003). Indigenous communities continue to challenge the ethical soundness of research that marginalises their values and beliefs.

Cultural difference

That cultures differ from one another is unquestionable, however, whether this means that different cultures should be treated differently within research and the processes of ethical review is subject to on-going debate.

> *In a research context, to ignore the reality of inter-cultural difference is to live with outdated notions of scientific investigation. It is also likely to hamper the conduct of research, and limit the capacity of research to improve human development. (National Health and Medical Research Council 2003) pg 3*

The process of globalisation, which began in the West under the guise of colonialism, is based on Western notions of 'progress' and 'development' and has mainly fostered the expansion of Western ideas, values and lifestyles. Globalisation is associated with the project of modernity, which focuses on the individual and the capacity to reason in a logical linear fashion. This in turn intersects with colonisation to rename, to classify and categorise indigenous peoples, thereby imposing colonist's knowledge, discourses and ways of interpreting the world (Cannella and Viruru 2004). Through globalisation the identities of many indigenous communities were redefined as they were incorporated into a global network of complex societies comprised of different communities and different cultures (Smith, Burke et al. 2000).

The processes of colonisation have had a marked effect on the ability of indigenous peoples to control their existence within the world.

> *The whole process of colonisation can be viewed as a stripping away of mana (our standing in our own eyes) and an undermining of rangatiratanga (our ability and right to determine our destinies). Research is an important part of the colonisation process because it is concerned with defining legitimate knowledge. (Smith 1997) Pg 185*

Goldberg (1993) discussed the transformations in race relations in USA which moved from assimilation, the standard of equal treatment via the adoption of a core set of cultural and political values, to integration where minority groups are given cultural autonomy and expression at the margins of society while maintaining the hegemonic values of the dominant culture at the centre. He describes the next transformative stage as incorporation where renegotiation of the socio-cultural space results in dual transformations of the dominant values and those of the marginalised group as the latter insists on more complete incorporation into the centre and the dominant group begrudgingly gives way to produce a hybridity of new structure of authority and political initiatives (Goldberg 1993).

Multiculturalism has been advocated as a way of promoting equality and non-discrimination (Vakatale 1998). The relativist approach of multiculturalism appreciates alternative cultures rather than marginalising or condemning them. Multiculturalism accepts that ethical principles are relative and contextually bound rather than absolute. Moral multiculturalism is characterised as comprising two principles: the acceptance of moral principles as binding upon people because they are accepted by the person who holds them; and the acceptance by different cultures of different moral principles as binding because of cultural norms (Baker 1998). This contrasts with the universal approach which does not make allowances for cultural orientation and has the potential for inflexibility and disconnection from the context of the situation (Crigger, Holcomb et al. 2001).

Multiculturalism itself has also been criticised as another form of marginalisation. Indigenous views are acknowledged alongside the multitude of other cultures denying the existence of unique indigenous rights and excluding indigenous peoples from involvement in the central

dominant parts of society. It has been seen by some as a continuation of the process of colonisation as difference is applied in ways which do not support the interests and aspirations of indigenous peoples (Johnston and Pihama 1995). While explicit recognition of cultural difference, as in the case of 'apartheid'[19], can create significant barriers for indigenous peoples, ignoring difference is often more destructive for indigenous communities. The standards of the dominant culture are portrayed as 'the norm' to which other cultural groups must aspire. The inability to recognise cultural difference and its influence on the formation of knowledge is at the centre of indigenous peoples concerns with universalism in research and ethics. Interpretations of cultural diversity and multiculturalism have also been conceptualised as stages of integration that restrain resistance by playing lip service to cultural distinction. Linda Smith argues that the struggle for the validity of indigenous knowledges may no longer be over the recognition that indigenous peoples have ways of knowing the world which are unique, but over proving the authenticity and control over their forms of knowledge (Smith 1999).

Ethics is not just about following rules but also discretion and judgement. In the context of research, taking account of difference takes time, care, patience and requires building of trust and robust relationships (National Health and Medical Research Council 2003). The marginalisation of cultural values and principles is often a subtle and incremental encroachment that demeans the integrity and validity of a culture's worldview.

> *To 'misrecognise or fail to recognise [cultural difference] can inflict harm, can be a form of oppression, imprisoning someone in a false, distorted and reduced model of being'...Research cannot be 'difference blind'. Taylor cited in (National Health and Medical Research Council, 2003) pg 3*

Indigenous ethical frameworks

Indigenous worldviews, philosophy and values have applications for contemporary society. Although it is often positioned in the past, indigenous knowledge can provide frameworks for understanding current and future worlds (Durie 2003). A number of indigenous communities have expressed concerns about the types of research and research practices happening in their

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[19] South African policy of separate development for black, white and coloured peoples throughout the middle stages of the 20th century.

communities. Some indigenous peoples have carried out preliminary work to provide ethical guidance for researchers when working in their communities.

Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research

Australia has developed guidelines for health research in indigenous communities. A document titled "*Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research*"(National Health and Medical Research Council 2003) sits alongside the *National Statement on Ethical Conduct in Research Involving Humans (National Health and Medical Research Council 1999)* and provides guidance in developing ethical relationships between researchers and Aboriginal and Torres Strait Islander communities

The guidelines were developed over an extended period of time and involved significant contributions from the Aboriginal and Torres Strait Islander communities. The call for guidelines emerged from indigenous delegates at a conference in 1986 looking at research priorities for Aboriginal health. The National Health and Medical Research Council (NHMRC) who funded a 3 day national workshop on 'Ethics of Research in Aboriginal Health' the following year acknowledged these concerns. This workshop was attended by nearly 30 Aboriginal community representatives and some members of the NHMRC's Medical Research Ethics Committee (Humphery 2003). The workshop emphasised the need for consultation and negotiation by researchers that recognised the right for Aboriginal communities to self-determination and acknowledged the key co-ordinating role of Aboriginal community organisations. It also advocated the need for principles of conduct and resolved that research data should remain the property of the community being researched (Humphery 2003). The Camden Workshop, as it became known, led directly to the establishment of *Interim Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research (1991)*. The Interim Guidelines were reviewed at a workshop in Ballarat in 2002 and resulted in the endorsement of the *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research*" (Anderson, Griew et al. 2003).

The Guidelines articulate the values identified by Aboriginal and Torres Strait Islander Peoples as,

- Spirit and Integrity – The overarching values that binds the others into a coherent whole. It is concerned with the continuity of these values and ensuring that behaviour enhances rather than diminishes the values.

- Reciprocity – Creates mutual obligations to achieve equitable distribution of resources and achieve cohesion within the social order.

- Respect – Respect for human dignity as a characteristic of relationships between people based on trust and co-operation.

- Equality – Relates to the equal value of people and the right to be different which is reflected in a commitment to distributive fairness and justice.

- Survival and Protection – The importance of individual and collective culture and identity that draws strength from the values base of the culture.

- Responsibility – The recognition of core responsibilities to country, kinship bonds, caring for others and the maintenance of harmony and balance.

Each of the values is described in terms of their meaning for indigenous peoples, and their application to research. Relevant issues to be negotiated between the researcher and the community are highlighted and guidance given as to how each value would be applied. Relevant sections of the *National Standard* are listed to illustrate how each value aligns with existing mainstream ethical requirements.

The emphasis of the Guidelines is on value-based engagement rather than rule-based consultation to promote consistency with indigenous communities and their values (Anderson, Griew et al. 2003).

> *The responsibility for maintaining trust and ethical standards cannot depend solely on rules or guidelines. Trustworthiness of both research and researchers is a product of engagement between people. It is possible for researchers to 'meet' rule-based requirements without engaging fully with the implications of difference and values relevant to their research. The approach advanced in these guidelines is more*

demanding of researchers as it seeks to move from compliance to trust. (National Health and Medical Research Council 2003) pg 4

The importance of promoting ethical relationships between researchers and indigenous communities was highlighted by Anderson et al (2003) who contended that the intention of a guideline is to focus the attention of researchers on issues that require negotiation with indigenous communities.

So whilst a guideline might focus the thinking of researchers on critical issues such as the potential benefit of the research, in itself, the guideline does not resolve potential conflict. It identifies an issue that must be negotiated (Anderson, Griew et al. 2003) pg 25

Guide to ethical research practice with Aboriginal and Torres Strait Islanders

A research ethics protocol was developed by the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) to protect the rights of Aboriginal and Torres Strait Islander cultures. The principles contained in this protocol are,

i. Consultation, negotiation and free and informed consent are the foundation for research with or about indigenous peoples
ii. The responsibility for consultation and negotiation are on-going
iii. Indigenous knowledge systems and processes must be respected
iv. There must be recognition of the diversity and uniqueness of people as well as of individuals
v. The intellectual and cultural property rights of indigenous peoples should be respected and preserved
vi. Indigenous researchers, individuals and communities should be involved in research as collaborators
vii. The use of, and access to, research results should be agreed
viii. A research community should benefit from, and not be disadvantaged by, the research project

ix. The negotiation of outcomes should include results specific to the needs of the research community

x. Negotiation should result in a formal agreement for the conduct of a research project, based on good faith and free and informed consent

(The Australian Institute of Aboriginal and Torres Strait Islander Studies 2000)

This document provides guidelines for the implementation of the principles and reiterates the need for on-going consultation, engagement with indigenous communities and the importance of recognising and respecting cultural protocols and customs. In doing so it implies that for indigenous communities the process of development for a research project should be subject to ethical review. The emphasis on negotiation between indigenous communities and researchers across a number of levels is reinforced with a view to research contributing to the development goals or aspirations of the indigenous community.

Mi'kmaq Ethics Watch

The Mi'kmaw people of Nova Scotia, Canada developed a group called the Mi'kmaq Ethics Watch to review research and work collaboratively with researchers within their communities (Grand Council 2000). They also produced a document containing principles and guidelines to ensure that the ownership of Mi'kmaw knowledge and heritage rests with the appropriate Mi'kmaw communities. The principles are listed below,

- Mi'kmaw people are the guardians and interpreters of their culture and knowledge system – past, present and future.
- Mi'kmaw knowledge, culture and arts are inextricably connected with their traditional lands, districts, and territories.
- Mi'kmaw people have the right and obligation to exercise control to protect their cultural and intellectual properties and knowledge.
- Mi'kmaw knowledge is collectively owned, discovered, used, and taught and so also must be collectively guarded by appropriate delegated or appointed collective(s) who will oversee these guidelines and process research proposals.
- Each community shall have knowledge and control over their own community knowledge and shall negotiate locally respecting levels of authority.

- Mi'kmaw knowledge may have traditional owners involving individuals, families, clans, association and society which must be determined in accordance with these peoples own customs, laws and procedures.
- All research, study, or inquiry into Mi'kmaw knowledge, culture, traditions involving any research partners belong to the community and must be returned to that community.

(Grand Council 2000)

These principles emphasise indigenous ownership and control over their knowledge and culture. They also inform the obligations and research protocols for researchers conducting research involving Mi'kmaq people. The obligations entailed in this guideline are,

- All research is to be approached in a negotiated partnership.
- All research partners must show respect for the language and traditions of Mi'kmaw communities.
- Researchers shall assume responsibility for learning the protocols and traditions of their community partners and be sensitive to cultural practices to ensure respect.
- Consenting processes must be full and informed, written in English and Mi'kmaq and in no way coercive.
- Researchers should attempt to impart new skills into the community.
- Researchers should invite Mi'kmaw participation in the analysis of data and review of conclusions.
- Researchers should consider participatory research processes that empower the indigenous voice.

The obligations, informed by acknowledging indigenous control and ownership of intellectual property, highlight negotiation and a preference for participatory research processes that will increase the skill level and address an issue of importance for the local indigenous community.

The central themes of indigenous research ethics

The principles used in these indigenous ethical frameworks are based on three broad themes, respect, control and reciprocity. Respect is concerned with recognition of indigenous peoples as sovereign entities and respect for their cultural knowledge and traditions. Control implies indigenous peoples control over their involvement in research and relates to the ability of indigenous groups to control the extent of their participation in research processes and negotiate what is acceptable. Reciprocity means ensuring there are mutual benefits and they are realised within indigenous groups in an equitable manner.

These themes relate to three significant aspects of a research relationship, the status (recognition of parties as equal), the process (integrity of engagement) and the outcome (equity of outcomes). The parameters of the research relationship should be negotiated between the indigenous community and the researchers and will be relative to the context of the situation. The relationship evolves over time and the parameters may change however this must remain under the control of the indigenous group. Showing respect can have immediate results however, demonstrating reciprocity and ensuring equitable outcomes for the community are goals that will generally be realised over a longer period of engagement.

Summary

Universal approaches to ethics fail to recognise the impact that cultural difference has on the application of ethical principles. Ethics are implicitly related to a culture's values and beliefs and the cultural value set provides the lens through which ethical issues are viewed. Therefore, cultural values influence the process of ethical deliberation. Moral multiculturalism acknowledges the existence of culturally specific ethical principles. Indigenous peoples have criticised the inflexibility of universal ethical constructs and developed guidelines for researchers that reflect the ethical concerns and issues for indigenous communities. These guidelines are fundamentally based around the concepts of respect for the sovereign rights of indigenous groups, the maintenance of indigenous control over research that impacts on their lives, and the need for negotiation to ensure that elements of reciprocity are demonstrated and benefits are realised within indigenous communities.

Chapter 6: Ethical Review of Health Research in Aotearoa

...to talk about ethics of research is to come back to the question of who is going to enforce the rules. Questions of ethics are questions about power sharing and about who have the power to enforce what values. Ethical decision making in relation to research has become another area of contested space. (Brew, 2001) pg 103

Introduction

Ethical review is necessary in New Zealand for any research proposal involving human participants. It acts as a protective mechanism to safeguard the interests of the participants and ensure that they are not placed at risk of harm. The ability of ethics committees to effectively cope with increasing workloads has been the subject of general concerns that have been expressed about ethical review in Australia.

I therefore share Dodd's concern about the sustainability of the human research ethics committee system, which must cope with ever increasing workloads, grapple with global and corporate pressures, and serve in the dual roles of protecting subjects and shielding institutions from liability, all the while relying essentially on the best efforts of volunteers to shoulder this burden. (Tomossy 2002) pg 59

Ethical review processes have been criticised for providing a limited evaluation of the ethics of the research project and functioning to shield research institutes from liability.

... in reality IRBs [Institutional Review Boards[20]] protect institutions and not individuals. The guidelines do not stop other ethical violations, including plagiarism, falsification, fabrication, and violations of confidentiality. (Denzin 2004) pg 10

Ethical review of health research in New Zealand has followed these international trends and based its format on Western ethical principles and processes. Māori inclusion in ethical review

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[20] IRB is the name commonly used in the USA to describe committees that review research ethics

has been facilitated by policy that ensures Māori membership on ethics committees and the requirement that every research proposal has been consulted on with Māori prior to approval.

Ethical review in New Zealand

New Zealand has a national system of ethical review that coordinates the responsibility for human ethics. There are three national committees, each with their own distinct function:

- the National Advisory Committee on Health Disability and Support Services Ethics (NACHDSSE), which is also known as the National Ethics Advisory Committee (NEAC), provides advice to the Minister of Health on ethical issues of national significance in respect of any health and disability matter;
- the National Ethics Committee on Assisted Human Reproduction (NECAHR) advises the Minister of Health on ethical issues relating to assisted human reproduction; and,
- the Health Research Council Ethics Committee (HRCEC), which makes recommendations to the Health Research Council on ethical issues in relation to health research. The Committee also has responsibility for accrediting health and disability and institutional ethics committees and providing second opinions for research if researchers don't accept the findings of the primary ethics committee. (Health Research Council of New Zealand 2002)

The Health Research Council has accredited seven institutional (university and technical institute) and one corporate ethics committees. It also accredits and monitors the activities of 14 regional health and disability ethics committees. The health and disability ethics committees have primary responsibility for every health and disability research proposal in New Zealand. The Operational Standard for Ethics Committees (Ministry of Health 2002) provides guidelines for the constitution and operation of the regional ethics committees reviewing health and disability research in New Zealand. It indicates what research investigations must be submitted for ethical approval, outlines the guiding principles that govern the ethical review of proposals, provides explanations of principles and identifies legislation relevant to each of the principles. Ethics committees have a central responsibility to ensure that new and emerging areas of research and innovative practice (e.g. a new surgical procedure) occur in a safe and ethical manner (Ministry of Health 2002).

Composition of ethics committees

According to the Operational Standard (2002) committees should have a balance of experience, incorporate a variety of perspectives, reflect the skills and expertise relevant to the type of research reviewed, and the community whose interests are protected. There should be at least 10 members with at least 50% being lay members. The chairperson must be selected from the lay membership. It is stipulated that a committee shall have

> *...one member who is a lawyer and one member with expertise in ethics (for example, a teacher of ethics, philosopher, theologian, or community recognised person such as a Māori elder)...the committee should also have at least two Māori members.... (Ministry of Health 2002) pg 35*

To provide best quality ethical review the committee should have appropriate medical, scientific, clinical and research expertise and include individuals with an understanding of consumer and community issues and perspectives. The Operational Standard also states that Māori members "*...should have an awareness of te reo Māori and an understanding of tikanga Māori...*" and all members, "*...are expected to have knowledge of the Treaty of Waitangi and its application to ethical review*".

Principles of ethical review

Ethical review is governed by a number of ethical principles. The Operational Standard provides extensive explanations of each of the principles and also lists legalisation that is relevant to each principle. The guiding principles listed in the Operational Standard are;

- Respect for persons,
- Informed consent,
- Privacy and confidentiality,
- Validity of research proposal,
- Minimisation of harm,
- Justice,
- Cultural and social responsibility, and
- Compensation for research participants

Māori responsiveness

New Zealand is in a unique position in that contemporary interpretations of the Treaty of Waitangi emphasise a requirement that Māori have the opportunity for partnership and participation in the systems and structures of society and that Māori values and beliefs will be protected. The responsiveness of the system of ethical review to Māori has been brought into focus, ironically because one of its key functions is to assess the responsiveness of research proposals to Māori. The importance of the Treaty of Waitangi is affirmed in the Health Research Council of New Zealand's 'Guidelines on Ethics in Health Research', which state,

> *The Treaty of Waitangi is the founding document of New Zealand. The principles of partnership and sharing, implicit in the Treaty should be respected by all researchers and, where applicable, should be incorporated into all health research proposals. (Health Research Council of New Zealand 2002)*

The Operational Standard reiterates this position.

> *The principles of the Treaty of Waitangi must be incorporated in the proceedings and processes of ethics committees… Broad Māori cultural concepts should be respected and supported through ethical review. (Ministry of Health 2002) pg 2*

The Operational Standard gives guidance to researchers in terms of implementation of the Treaty principles of partnership, participation and protection in research with Māori.

- Partnership – working together with iwi, hapū, whānau and Māori communities to ensure Māori individual and collective rights are respected and protected.
- Participation – involving Māori in the design, governance, management, implementation and analysis of research, especially research involving Māori
- Protection – actively protecting Māori individual and collective rights, Māori data, Māori culture, cultural concepts, values, norms, practices and language in the research process. (Ministry of Health 2002)

Māori cultural concepts such as hauora, kaupapa Māori and tikanga Māori should be respected and consideration be given to the wider dimensions of Māori health (te taha tinana, te taha wairua, te taha hinengaro, te taha whānau) within ethical review. The Operational Standard also lists the issues that arise from Māori interpretations of the principles to ensure that tikanga, and cultural concepts are protected. This is central to the development of high quality research and requires consideration as part of the process of ethical review. The following table is taken from the Operational Standard.

Table 4. Ethical principles and additional Māori issues

Main principles	Additional issues for Māori
Respect for persons	Respect for Māori collectives – whānau, hapū and iwi
Informed consent	Gaining consent from collectives
Privacy and confidentiality	Collective ownership of information
Validity of the research proposal	Kaupapa Māori and Māori focused methodologies
Minimisation of harm	Minimising harm to te taha whānau (family and community), te taha hinengaro (emotional well-being and state of mind), te taha wairua (spirit), te taha tinana (the body or physical self).
Justice	
Cultural and social responsibility	Cultural diversity, koha
Compensation for research participants	

(Ministry of Health 2002)

The Operational Standard also includes in Appendix 8: Research involving Māori, an outline of the important issues for Māori research development and researcher responsiveness to the Treaty of Waitangi. Amongst issues that should be considered,

- The rights of Indigenous Peoples over their cultural and intellectual property (the Mataatua Declaration[21])
- The recognition of diverse Māori realities
- The opportunity for Māori to monitor, critique, and discuss, including in hui and public forums, all research impacting on Māori health
- The strengthening and development of Māori health researchers.

The issues noted in Appendix 8 reflect the desire of Māori to engage with research on their own terms, with adequate protection of the knowledge and customs that are important to them and the ability to develop the research capacity within their own communities.

Recent Ministerial review

The System of Ethical Review of Health and Disability Research in New Zealand has recently been considered by the NEAC. The focus of the review was to address matters arising from the Ministerial Inquiry into Under-Reporting of Cervical Smear Abnormalities in the Gisborne Region (National Ethics Advisory Committee 2004). NEAC identified overall goals, objectives and desired outcomes for an ethical review system.

The overall goals are;
- protection of participants in health and disability research and innovative treatment,
- facilitation of research and innovative practice that contributes to knowledge and improved health outcomes,
- finding a balance that minimises risks and maximises benefits arising from health and disability research, and
- ensuring consistency with the Treaty of Waitangi.

The objectives of the ethical review system state that it should be accountable, enabling, informed, responsive to Māori, fair, and efficient.

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[21] A declaration written in 1993 following the First Indigenous Conference on the Cultural and Intellectual Property Rights of Indigenous Peoples held in Whakatane, New Zealand.

In terms of responsiveness to Māori the desired outcomes for the ethical review system are listed as;

- a Māori ethical framework is developed and implemented,
- processes for consultation with Māori are clear and appropriate,
- Māori participation in the decision-making component of the system is maintained,
- iwi and regional diversity is understood and accommodated,
- Māori research capability is facilitated.

Recommendations from the NEAC review that were accepted by the Minister of Health, the Hon Annette King, are as follows;

a) that a new national ethics committee be established as the primary review body for all multi-centre and national research studies,

b) that every research proposal receives one ethical review conducted by a single ethics committee (either regional or national),

c) that, as part of review of national and multi-centre studies, there be a 'locality assessment' for each region in which the research is to be conducted and that this assessment be undertaken by the research host organisation,

d) that the 15 current regional committees be disestablished and replaced with 6 new committees covering larger geographical areas,

e) that health and disability ethics committees, and their review activities, be established on a direct statutory basis (under section 11 of the New Zealand Public Health and Disability Act 2000),

f) that a right of appeal from ethics committee decisions should be established, and that the appeal body would be a sub-committee of NEAC.

(Minister of Health 2004)

The six new regional committees will cover geographic areas that correlate with the boundaries of grouped District Health Boards (DHBs). Two northern regional ethics committees will be responsible for research projects situated within the boundaries of the Northland, Auckland, Waitemata, Counties Manukau, Waikato, Lakes and Bay of Plenty DHBs. The central regional ethics committee will cover the boundaries of the Taranaki, Whanganui, Tairawhiti, Hawkes

Bay, Mid Central, Wairarapa, Hutt and Capital and Coast DHBs. Two upper south regional ethics committees will review research from the Nelson-Malborough, West Coast and Canterbury DHBs and the lower south regional ethics committee will cover the Southland, Otago and South Canterbury DHBs. It is anticipated that these changes will be implemented by January 2005.

Impact on Māori

Issues of Māori responsiveness were raised during the consultation period of the NEAC review. Māori members of ethics committees discussed the impact of the proposed changes informally and a position statement to outline concerns to the Ministry of Health was produced (West, 2004). According to the position statement the changes place greater emphasis on facilitating the ethical review process for researchers and this has implications for Māori involvement in the process.

The composition and membership criteria were criticised for rendering some of the most capable Māori lay members ineligible through the exclusion of people who had links to a DHB or a provider of health professional education institutes. The large increase in the size of regions covered by the committees leads to increased number of iwi included within a committee's area of responsibility. This potentially creates additional tensions and responsibilities for Māori members to effectively represent iwi with whom they have no affiliation. Further concerns were expressed about the opportunity for political capture with the shift towards ministerial appointments and the possibility of parliamentary announcements.

> *The inclusion of Māori issues has been identified as problematic in terms of how to factor them into the process. Concerns, as identified in the NEAC Report to the Minister, have validity and the review would have to consider consultation, engagement and implementation tools that can render the ethical process itself both Māori and Treaty responsive. (West 2004)*

The need for Māori expertise was reiterated within the position statement, as was the importance of monitoring the appropriateness of locality assessments for Māori issues. Host organisations would need to develop robust processes that integrated Māori review into their

administrative procedures for approval of research protocols similar to the Ngā Kai Tātaki[22] process at the Waitemata District Health Board.   Ethics committees would need to ensure a high standard of compliance in this area. It was also suggested that a generic training package be developed and include the Treaty of Waitangi and issues of Māori responsiveness. The committees themselves should also have Treaty and Māori components as an audit requirement of their reporting. The statement also suggested that a Māori ethical framework would need to be developed and aligned to the overall ethical review process.

The position statement made the following recommendations to improve the responsiveness of the proposed changes to Māori.

a) That a roopu of former Māori researchers, lay members and/or Māori Treaty trainers be established to train all regional and multi-centre ethics committee members.

b) That there is a programme for ethical review training that is resourced by the Ministry of Health as a staff professional development programme.

c) That the Māori lay member criteria are expanded due to human resource constraints, expertise retention and mātauranga Māori.

d) That Māori lay member candidates be required to give evidence of tautoko (support) from Māori tribal and Māori taurahere[23] constructs and have the ability to demonstrate proven and established networks.

e) That the number of Māori lay members be increased to three (iwi, hapū member or taurahere Māori member).

While these recommendations illustrate the most recent formal criticism by Māori of ethical review, this follows a number of reports that have suggested mechanisms to improve the responsiveness of the process of ethical review to Māori.

Ngā Tikanga Pono Wāhanga Hauora

Ethical issues regarding Māori have been identified in literature for a number of years. The need for Māori to be more involved in the ethical review process in the health sector was stated

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[22] Māori research review committee with community representation that provides Māori consultation for research projects within Waitemata District Health Board
[23] Generic name for Māori community group or network not based on genealogical links

in the discussion document 'Ngā Tikanga Pono Wāhanga Hauora: Health Sector Ethics, Mechanisms for Māori into Ethical Review' (Te Puni Kokiri 1994). This document was developed by a Māori working group as part of an overall review of the process and structure of ethical review in the Health sector. One of the aims of the review was to examine how the community's values were incorporated in health sector decision-making.

> *Ethics is about values, and ethical behaviour reflects values held by people at large. For Māori, ethics is about 'tikanga'- for Tikanga reflects our values, our beliefs and the way we view the world. Our 'kawa' is the process by which we promote, protect and develop our tikanga. (Te Puni Kokiri 1994) pg 9*

To determine how 'tikanga' and 'kawa' might be incorporated in the process of ethical review the Māori working group identified the Treaty of Waitangi as a possible framework suggesting that the Treaty itself was an ethical structure as it *"establishes the relationship between Māori and the Crown"*. The document notes the importance of Māori involvement in discussion of all ethical issues to ensure that tikanga is preserved and protected, health issues of sensitivity to Māori are acknowledged, medical practices are monitored, and Māori take up their rights and responsibilities under the Treaty of Waitangi to be involved throughout the health system in the process of policy-making, purchasing and provision of health services.

The Working Party stressed the importance of local Māori control over their health and involvement in research, acknowledgement of Māori intellectual property and clearly identifying the responsibility of the Crown in supporting these aims. The following principles were suggested to guide the development of an ethical review system responsive to Māori:

- health is a taonga to protect and enhance;
- the Treaty of Waitangi is the basis for the ethical framework;
- Māori and Crown share responsibility for ethical structures;
- a Treaty of Waitangi framework is necessary to protect, guide, and support Māori;
- a Treaty of Waitangi framework is necessary to protect and promote the well-being of Māori and of all New Zealanders as a taonga; and,
- equitable resources should be allocated to Māori members and research participants.

The main concerns articulated in the Report are the protection of Māori values and intellectual property rights, maintaining the involvement of Māori throughout all aspects of research and ethical review, and the practical implications of the knowledge derived from the research project and its likely use.

Preliminary discussions with Māori key informants: National Ethics Advisory Committee

Issues surrounding Māori involvement in ethical review and the development of a Māori ethical framework were recently summarised in a preliminary report released by the National Ethics Advisory Committee (Cram 2003). Key informants, who could speak to issues in Māori health and disability research ethics, were asked to discuss their views on what they thought were the main ethical issues for Māori. This document written by Dr Fiona Cram, a member of NEAC and leading Māori academic, identified the following issues.

- Treaty of Waitangi

  The Treaty of Waitangi was seen as an integral part of a Māori research ethic and it also provided the basis for Māori rights to carry out their own research. Health inequalities could be viewed as unethical within the boundaries of Treaty responsibilities.

- Universal ethics

  The universality of the western model of ethics was challenged as being unresponsive to local and Māori issues, and the recognition of Māori research ethics is necessary to gain 'equality'.

- Māori research ethics

  The need for a Māori set of ethics that would reflect Māori ideas and accountabilities was stressed. The process for developing a Māori research ethic would have to involve Māori researchers, kaumātua, and other key people with a view to integrating tikanga Māori and linking ethical review across all sectors. Informants suggested a number of

principles that might underpin a Māori research ethic. They include; manaakitanga[24], kaitiakitanga[25], wairuatanga[26], respect for participants, research for the wider human good, mentoring, and partnering the academy and the community in research. There was also discussion about how intracultural diversity could be accommodated under universal Māori principles and whether Māori research ethics should only apply to Māori researchers.

- Ethics for non-Māori researchers
  It was suggested that Māori research ethics should be applicable to non-Māori researchers for research in a Māori setting, with Māori participants or on a topic of importance to Māori. Non-Māori researching in these areas would need additional guidance to ensure they acted within appropriate ethical and cultural parameters. This was particularly important in the area of qualitative research where subjective interpretations could be involved. Learning the 'rules of engagement' and undertaking consultation at the initial stages of the research assists non- Māori researchers to understand these parameters.

- Implications for Regional Ethics Committees
  It was suggested that the development of Māori research ethics would provide a theoretical base to support both Māori and non-Māori members of ethics committees. Currently, guidance for regional ethics committee members comes from the Operational Standard and the HRC Guidelines on research with Māori. It was also suggested that Māori research ethics could inform debate around the ethicality of new areas of research, such as genetic engineering.

Guidelines for research with Māori: Health Research Council

The Health Research Council of New Zealand (HRC) published 'Guidelines for Research with Māori' to provide some clarification around issues of consultation and negotiation with Māori (Health Research Council of New Zealand 1998). The Māori Health Committee, an advisory

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[24] Caring
[25] Guardianship
[26] Spirituality

committee to the HRC, was responsible for producing these guidelines and they have been adopted widely by Māori researchers (Powick 2002). The guidelines aim to develop research partnerships between health researchers and Māori communities or groups on issues important to Māori health. They also promote research practices which ensure that biomedical, clinical and public health research effectively contributes to Māori health development whenever possible. The main issues that are discussed in these guidelines relate to why Māori should be involved in health research, and how consultation with Māori about proposed research projects should occur.

Why involve Māori in health research?

Inequalities in health and the Treaty of Waitangi provide the justification for the HRC's encouragement of increased Māori involvement in health research. This is reflected in the following statement,

> *The continuing disparities in standards of health between Māori and non-Māori produce a strong argument under Article Three for significant health research resources to be directed at resolving Māori health issues. High quality research is a key component in Māori health development, as it is essential that initiatives to resolve Māori health issues are based on a foundation of high quality information (Health Research Council of New Zealand 1998).*

The HRC also has a responsibility for addressing the lack of Māori participation as researchers in the area of health. It promotes collaborative research between non-Māori researchers and Māori communities as a way to accelerate the development of the Māori health research workforce. Collaborative research approaches establish a sense of partnership and co-operation between researchers and the Māori community. Sporle and Koea (2004) suggest that the responsiveness of the intended project to Māori is measured by;

- the importance of the health issue for Māori,
- ensuring the project can realise potential contributions,
- identification of end-user organisations, and
- compliance with institutional codes of practice.

HRC's Consultation with Māori

Consultation with Māori is not only an integral part of the process of ethical review in New Zealand it is also necessary for developing sustainable relationships with Māori communities to facilitate high quality research. Consultation is defined as,

> ... *a two way communication process for presenting and receiving information before final decisions are made, in order to influence those decisions". (Health Research Council of New Zealand 1998)*

Consultation provides one of the few opportunities for Māori communities to influence the research agenda and areas of inquiry in New Zealand. The HRC guidelines provide a comprehensive explanation of the need for and nature of effective consultation as a way of developing a working relationship between the researcher and the Māori community. This process allows any issues or concerns that either party has relating to the research to be brought forward and discussed.

> *Initial and ongoing consultation can prevent problems from arising in the research process which may be unforeseen by researchers working alone. It can also provide mechanisms for overcoming any problems that may develop. Issues such as intellectual property rights, access to data, publication processes, accountability, authorship, storage of information and allocation of research funding can all be resolved in this manner. (Health Research Council of New Zealand 1998)*

Consultation will also contribute to maximising the benefits of research for both the researcher and the Māori community. Researchers, through a process of 'mutual mentoring' can acquire cross-cultural skills and experience while Māori included in the research team can benefit from the development of practical research skills. The HRC guidelines suggest that consultation should begin early in the research design, prior to finalisation of the research topic. Consultation should be seen as an on-going activity throughout as many facets of the research process as possible, and take place prior to the publishing of results to identify ways in which the outcomes can be utilised. The nature and extent of the consultation required between researchers and Māori communities is determined by the following factors:

- the intended research project's relevance to Māori health issues;

- the intended research project's degree of involvement of Māori participants;

- the research methodologies to be utilised;

- the size of the intended project;

- the intended research project's location; and,

- any existing relationship with the Māori community involved.

These factors also impact on which Māori organisations are consulted within the community. The Guidelines offer useful advice on who it is appropriate to consult with and offer suggestions of external agencies that may be able to assist researchers to make contact with Māori groups (e.g. Te Puni Kōkiri, HRC Māori Health Manager). Ethics applications were amended so that all research applicants are required to indicate if they had read the guidelines and to specify what consultation had been undertaken in developing the research (Sporle and Koea 2004).

Māori responsiveness in health and medical research

The requirement for Māori consultation has led some organisations to develop Māori research review committees with the specific role of reviewing research proposals for Māori responsiveness, giving advice and feedback to researchers, and providing a letter of support for the ethics application. Examples of this type of structure are the Māori Research Review Committee of the Auckland DHB, Ngā Kai Tātaki of the Waitemata DHB and the Māori Research Review Committee of the Counties-Manukau DHB. Two recently published papers highlighted key areas that are commonly discussed with researchers in these forum to improve the responsiveness of research proposals to Māori (Sporle and Koea 2004; Sporle and Koea 2004).

- **Utility**

  Health research on a health issue relevant to Māori should have clear benefits for Māori health. These benefits need to be clearly articulated, and the research process must be designed to realise those benefits.

- **Defining and identifying Māori**

  The use of standardised definitions and processes for determining ethnicity allows for

ethnic specific and comparative analyses to highlight outcome differences between population groups.

- **Informed consent**

  Collective approaches to gaining consent that allows potential Māori participants to discuss their involvement in the research project with whānau.

- **Confidentiality**

  The difficulty of maintaining confidentiality for Māori participants in smaller or regional studies due to extensive social networks and small eligible population groups. Alternatively, Māori participants may want to disclose their involvement in research projects to facilitate a wider understanding of the research within the community.

- **Handling and disposal of tissue**

  The respectful collection, handling and disposal of tissue samples given by Māori for the purposes of research and evidence of processes to ensure that samples are only used for the purposes which are provided for in the consent process.

- **Genetic information**

  The general reluctance of Māori to be involved in genetic research and the need for extensive consultation with Māori if they are to be included.

- **Intellectual property**

  The need for Māori to retain control over those things that are viewed as being owned by them through mechanisms such as co-authorship or joint ownership of intellectual property.

- **Koha**

  The recognition of the contribution that participants have made to the research process can be signalled through the giving of a small gift or koha (book voucher, petrol voucher, food).

- **Involvement of regional Māori health services**

  Māori health services have established networks and expertise and should be included in the discussions as part of the consultation process. They may be able to provide valuable support and on going assistance throughout the research process.

The development of Māori research review committees indicates that the host organisation is taking responsibility for ensuring that the research conducted within their domain has

considered the responsiveness of the project to Māori. Sporle and Koea have developed a framework outlining inter-relationships between host organisations, researchers, Māori end-users, ethics committees and mana whenua when developing a research proposal that is responsive to Māori (Sporle and Koea 2004). The key aspects of this model are the development of a Treaty relationship between the host organisation and mana whenua, and the development of an institutional policy statement that clarifies consultation mechanisms, issues for consultation and local research priorities for Māori well-being. This approach would provide a structure for the ongoing involvement of Māori, guidance for researchers and a mechanism for host organisations, ethics committees and funding organisations to assess the Māori responsiveness of an intended research project (Sporle and Koea 2004).

Summary

The system of ethical review in New Zealand is organised to protect the safety of participants involved in research projects and has developed specific functions to ensure research occurs in an ethical manner. Regional health and disability ethics committees have the primary function of reviewing research that uses health resources or includes as participants, person utilising the health service. Māori have consistently expressed concern that the processes of ethical review do not adequately address their concerns and ensure that research is responsive to Māori. The Health Research Council has provided guidance around appropriate consultation requirements for research. Māori academics have also indicated what issues should be addressed when Māori are consulted over research protocols. Despite reviews and changes to the system, Māori continue to have their values and views marginalised and have called for changes to make ethical review more responsive to Māori.

Chapter 7: Māori Ethics

For Māori, ethics is about tikanga (Te Puni Kokiri 1994).

Kaore rātou i mahi ture ai, ēngari, i mahi tika ai. (Kaumatua)

Introduction

Kaupapa Māori and Māori-centred researchers have expressed frustration at the application of mainstream ethical frameworks in the ethical critique of their research. There have been consistent calls for the articulation of a distinctly Māori ethical framework which is consistent with kaupapa Māori and Māori centred approaches and is able to determine the ethical robustness of research in Māori terms. The development of Kaupapa Māori research approaches has in many ways instigated the examination of Māori ethics. Calls for a Māori ethical framework emerged from the frustration of Māori researchers having kaupapa Māori research judged against Western ethical frameworks. It has been suggested that tikanga Māori is an integral part of Māori ethics however the relationship between the two has yet to be fully clarified. Confusion arises when the term Māori ethics is variously used to;

a) provide a translation of tikanga Māori,

b) describe aspects of tikanga Māori, and

c) describe the ethical issues that arise at the interface between research processes and tikanga Māori.

For the purposes of this research tikanga Māori is considered to operate on two levels, as values and as ethics. In terms of values it is concerned with what is good, that is, aspects of being that Māori value and believe to be good. These values correlate with Māori philosophy and knowledge about the nature of the universe. On the level of ethics tikanga Māori applies to the expression of those values in specific principles or behaviours, which are applied in the context of particular situations, in ethical review of health research. Therefore, tikanga provides the cultural link between philosophy and action. I will refer to tikanga-based values and tikanga based ethics throughout this chapter. Research that involves Māori inevitably

leads to tikanga-based values and ethics interfacing with research values and ethics. The issues and concerns that arise at this interface have generally been articulated in the literature as Māori ethics. To avoid confusion I refer to these 'Maori ethics" which are usually framed in Western terminology as Māori ethical issues.

The Marginalisation of Māori values

There are a number of environmental factors that contribute to the marginalisation of Māori values within New Zealand society. Graham Smith writes about a range of factors that should be considered within the New Zealand context. He notes that they are individually distinctive but may also overlap;

1. **Historical Dimension**: encapsulated in the term tangata whenua (indigenous people, people of the land)
2. **Treaty of Waitangi Dimension**: based on notions of partnership and tino rangatiratanga (self-determination).
3. **Colonisation Dimension**: with implications of assimilation, acculturation and domination by invading cultures
4. **Political Dimension**: control and domination, which has been effected through 'legislation, Acts of Parliament', co-opted democracy, and through hegemony (false consciousness) on the part of Māori, for example hegemonic understandings about the neutrality of the Westminster form of 'democracy' as constructed in New Zealand.
5. **Social Control Dimension**: implemented through at least two major levels,
   - Overt coercion: laws, legislation, courts, police, army etc
   - Covert coercion: through ideologies and hegemony, broken promises (Treaty) etc
6. **Power Relations Dimension**: reflected in the fact of being a numerical minority within the total population, of being underrepresented in the key power broking positions and in fewer numbers when representation does occur
7. **Socio-economic Dimension:** whereby Māori are disproportionately excluded from the wealth of the country; this is manifest in high levels of unemployment, poor access, participation and achievement in schooling etc
   (Smith 1997)

These dimensions impact on the level and extent of Māori participation within the structures of society and this includes the processes of ethical review.

Tikanga Māori

Māori, as an organised society have always had their own moral framework that has governed the way in which they live their everyday lives and determined their relationships with each other. Tikanga reflect Māori values and are embedded in Māori culture and mātauranga Māori. Mātauranga Māori is the intellectual property and knowledge accumulated by generations of Māori, which includes both Māori philosophy and Māori knowledge. Mātauranga Māori has become a 'political' symbol of self-determination and a reclaiming of the validity of Māori knowledge (Smith 1997). That mātauranga Māori has relevance, to decision-making for contemporary ethical issues, has been acknowledged by the Health Research Council.

> *Within mātauranga Māori there is a rich source of knowledge related to ethics and knowledge generation.* (Health Research Council of New Zealand 2004). *Pg 22*

Tikanga are practical expressions of mātauranga Māori and Māori understandings about people's relationships with each other and the wider environment. Tikanga was used in Māori society for social, economic and political dealings, to provide prohibitory controls and a framework for the legal system (Durie 1998). Tikanga is based on values, and being a values-based system Māori adhered to principles rather than rules (Ministry of Justice 2001). This system has an inherently dynamic nature, as the adherence to principles, not rules, enables change while maintaining cultural integrity. Local variation is encapsulated in the different kawa (protocols) that each marae, hapu and iwi use to ensure that tikanga is upheld.

Māori words often have multiple meanings and tikanga is no exception. Tikanga can be used to mean a rule, a plan, a method, a custom, a habit, a reason, a meaning, an authority or control, correct or right (Williams 1997). It is often described as Māori practices and protocols and is concerned with what is right for Māori.

> *The word 'tikanga' itself provides a clue that Tikanga deals with right and wrong. 'Tika' means 'to be right' and thus Tikanga Māori focuses on the correct way of doing*

something. This involves moral judgements about appropriate ways of behaving and acting in everyday life. (Mead 2003) pg 6

For Māori, any ethical decision has to be culturally processed and philosophically reconciled with tikanga Māori (Mead, 2003). It has been suggested that tikanga provides a framework through which Māori can actively engage with issues and develop relationships for research into new technologies and the ability of tikanga to inform decision-making processes in contemporary situations was reiterated in a report on Māori and Genetic Engineering which states,

There are clear indicators available to Māori within tikanga that may support decision-making processes and which also provide guidelines for ethical frameworks for research generally and genetic engineering research in particular. (Cram, Pihama et al. 2000) pg 70

The nature of tikanga Māori deliberation

Eddie Durie has written about the Māori philosophy of law. He contends that it was based on broad values (tikanga) rather than prescriptive rules. The customary process was directed at examining the justice of the case without reference to specific canons or evidential tests (Durie 1998). This concept is supported by Patterson who also noted that in Māori society there was no need to formulate law into an explicit code of rules (Patterson 1992). Rules can be inflexible while principles require a search for the justice of a case (Durie 1998). The Māori legal system was essentially an ethics based model and similarities have been drawn between the Māori concept of tikanga and the virtue ethics model associated with the philosopher Aristotle (Patterson 1992). Aristotle thought that deliberation was the essence of ethics, a process of contemplation aligned with a specific goal that produces moral decisions based on human judgement rather than rule (Seedhouse 1998). Virtue ethics and tikanga Māori are both agent centred and concerned with the cultivation of an excellence of character or mana. Mana is an essential part of the Māori way of creating and maintaining relationships through generosity and honour. It creates obligations for people to act with equal or greater kindness at an appropriate time (Durie 1998). These values can be expressed in collaborative research

approaches where the researcher becomes accountable to the study participants and their community.

Precedents within Tikanga Māori

Tikanga Māori is largely informed by examples of similar issues from the past and these are used to guide future decision-making. Māori will often look for precedents to assist the decision making process when confronted with new challenges (Mead 2003). Knowledge of mātauranga Māori also supports the development of Māori positions on contemporary issues by providing a rich background of historical and philosophical references. It has been suggested that in order to arrive at a 'Māori' position the debate should be confined to those who understand mātauranga Māori and tikanga Māori (Mead, 2003). This may limit some debates to speakers of te reo Māori as,

> *...ones understanding of tikanga Māori is informed and mediated by the language of communication. Ones understanding through te reo Māori is different from one obtained through the English language. (Mead 2003) pg 2*

Tikanga frameworks use a variety of terms such as beliefs, values, ethics, aspects and principles to interpret tikanga. Tikanga frameworks have been constructed to provide guidance for the application of tikanga as decision-making tools in a number of areas including research and ethical review. The various concepts identified within tikanga frameworks, in the context of ethical review of research, have been summarised in the table below and grouped into either values-based tikanga or ethics-based tikanga. The distinction being that the values-based tikanga represent constructs of the belief system related to the nature of the universe. Whereas, the ethics-based tikanga are the principles that are followed to ensure that the values are upheld. For example, a person's mauri (a life force) can be protected through appropriate manaakitanga (caring) and kaitiakitanga (guardianship).

Table 5: Values-based and ethics-based tikanga

Values-based tikanga	Ethics-based tikanga
Io / Whakapapa	Whanaungatanga
Mauri	Manaakitanga
Tapu and Noa	Kaitiakitanga
Mana	Mana
Wairua / Hau	Wairuatanga
	Kotahitanga
	Take-utu-ea

The tikanga encompassed in this table, which are described further below, emphasise connection with the spiritual realm, respect for all things and the significance of reciprocity in human relations. It also demonstrates how Māori values and philosophies are still evident and applicable today. As Henry writes,

> *...traces of the traditional culture resonate in contemporary Māori beliefs and practices. The resilience that this culture manifests is evidence of its on-going relevance and importance for Māori. (Henry 1999) pg 8*

Value-based tikanga

Io, in Māori philosophy is the origin of all life, from which came Papatūānuku, the earth mother, and Ranginui, the sky father. Their offspring, or atua, are guardians of every aspect of like, the sea, forests, winds, and other aspects of the human environment (Henry 1999). From the atua came people and hence the belief that we are connected through whakapapa (genealogy) with every living thing on this earth. The importance of whakapapa can be highlighted in spiritual, cultural and physical terms (Dyall 1999; Cram, Pihama et al. 2000). Io, as a value construct, emphasises interconnectedness and situates the person as an integral part of nature's eco-system.

Tapu is that which is sacred and sacrosanct in all things, the intrinsic power imbued at the moment of a thing or person's creation. Tapu refers to the spiritual attributes that a person inherits from their parents through their genes and also provides their connection to the gods. Tapu is closely linked with an individuals well being and is also reflected in their mana (Mead

2003). Protecting one's personal tapu is akin to looking after their physical, social, psychological and spiritual well-being. Tapu is often referred to in association with its oppositional element noa, which implies a state of neutrality.

Mana relates to the spiritual power and authority that can be applied to people, their words, and acts. Tapu is closely linked to mana (Henry 1999).

Mauri is the life force or the intrinsic essence of a person or object.   Mauri is the spark of life that indicates that a person or thing is alive. Like tapu it is a measure of the wellbeing of the individual and refers to the active component of life (Mead 2003). Mauri is considered to encompass the relationships between all living things and also our connection with the land (Cram, Pihama et al. 2000).

Wairua / Hau – The spirit power and vital essence embodied in a person and transmitted to their gifts or anything they consider valuable. The concept of wairua is central to Māori concerns about many areas of contemporary research particularly genetic engineering (Cram, Pihama et al. 2000). Wairua is associated with other values such as mauri and whakapapa.

These value-based tikanga are holistic in nature and inform the ethics-based tikanga, which Māori promote as ideals. The ethics-based tikanga inform behaviours which ensure that the appropriate values are respected and maintained as important tenets of Māori society.

Ethics-based tikanga

Manaakitanga can be translated as hospitality. As part of an ethical evaluation it is concerned with ensuring that no harm arises from the process or assessing whether any breach of tapu is outweighed by the benefits likely to accrue to the people. (not the researcher).

Mana can also be expressed as an ethical principle to ensure that mana Māori or the prestige and dignity of Māori is upheld at all times by the researcher (Mead 2003). This may involve ensuring that appropriate aspects of tikanga Māori are understood, acknowledged and upheld.

The researcher must be aware of the protocols of the local marae and iwi, te kawa ō te marae[27], and ensure that they are respected (Powick 2002).

Whanaungatanga is the ethic of belonging and is based on the knowledge that the whānau or extended family is the foundation of Māori society (Henry 1999). Whanaungatanga may be related to actual genealogical links through whakapapa, or it may be based on collegial links established through working together on a particular project or kaupapa. In the research context whanaungatanga relates to the ongoing process of forming and maintaining relationships between the researcher and participants must run throughout the project (Powick 2002).

Wairuatanga relates to the spiritual aspect inherent to people and Māori philosophy. It acknowledges the existence and influence of spiritual dimensions within our lives.

Kotahitanga implies solidarity, recognition of and connection to the dignity and worth of all things and people (Henry 1999). In this sense it is important that the researcher acts with integrity so that the worth of each person is respected and relationships maintain a healthy balance.

Kaitiakitanga is the obligation of guardianship to maintain the balance between all the resources available to people. The dynamic interplay between people and the environment is integrated through understanding that everything exists within a single holistic system. Within this system, people have the responsibility to act as kaitiaki.

Take-utu-ea is concerned with restoring the balance of life. The values above are inter-related and reflect the holistic nature and interconnectedness of Māori understandings of the world. Maintaining balance between different individuals, groups and systems is an integral part of this philosophy and take-utu-ea refers to the need to resolve conflicts and/or breaches of tikanga. *Take* is concerned with identifying and mutual recognition of the issue that requires resolution. *Utu* is the mutually agreed upon action that will restore balance to the relationship and allow each party to state '*kua ea*', the matter is resolved (Mead 2003).

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[27] Use to denote local variation between protocols from marae to marae or iwi to iwi.

The ethics-based tikanga ensure that Māori values are respected and remain consistent with the mātauranga from which they are derived. The distinction between values-based tikanga and ethics-based tikanga is an artificial one used to clarify and explain different facets of tikanga and provide a contrast with Western constructs of ethics. In practice, tikanga is tikanga and incorporates both Māori values and ethics consistent with mātauranga Māori.

Māori ethical issues

Writing about Māori ethics has focused on the issues and concerns that Māori have with research. This often involves the interface between researchers and the Māori community as participants, co-researchers, researchers or interest groups (Te Awekotuku 1991). Discussions around Māori ethics are concerned with protecting Māori interests and ensuring that Māori have control over activities that affect their development. While Māori have a history of continual use of their own ethical principles in their own society, its application within the wider mainstream society, and the area of research in particular, has only recently been examined. In this sense, issues of ethicality for Māori have always been closely linked with Māori development and the integration of Māori values into mainstream organisations/structures.

> *Ethics as a concept and as a science of a body of knowledge is constantly being tested and changed. Similarly, ethical values are changing and we live in a dynamic world in which our past guides the present and the future (Te Puni Kokiri 1994). Pg 13*

The appropriateness for Māori has been the focus of Māori critiques of research practice and ethics. The evolution of Māori paradigms challenged the universal applicability of ethical principles drawn from specific cultural bases (Durie 1998). Research processes were seen to be ethical in them-selves as they were derived from specific value bases. The right to develop Māori research approaches and ethics was argued by Moana Jackson at the Hui Whakapiripiri at Hongoeka marae in 1996. He stated that the Treaty affirms the right of Māori to develop processes of research and ethics appropriate for our people (Jackson 1996).

Māori researchers have identified issues of concern for Māori and advocated for consultation and research processes that ensure proper regard is given to Māori values, Māori participants

and Māori communities (Powick 2002). Discussions have centred on four key themes, respect, control, researcher ethics and accountability as essential elements of ethical research practice.

Respect

Respect for the rights and sensitivities of Māori are fundamental components of ethical research practice (Te Awekotuku 1991). Being treated with dignity involves respect for cultural identity and regard for physical, mental, personal and social well-being (Durie 1998). This can be achieved by ensuring that Māori are involved in all research concerning Māori and consent from iwi is gained through a process of consultation (Te Awekotuku 1991). Māori should fully understand the expected aims and outcomes of the project and its relevance. The responsibility to include Māori in research is based primarily on constitutional guarantees as tangata whenua (indigenous people) under the Treaty of Waitangi and not only on need (Durie 1994).   Respect for different ways of knowing allows for care and consideration of individuals and groups and acknowledgement of intellectual property rights (Durie 1998).

Control

This area highlights a number of factors for consideration to ensure that issues of authority and control over the direction, process and outcomes of the research remain with Māori. The requirement for control of research processes involving Māori to remain with Māori has resulted from concerns about who benefits from research involving Māori and a broader concern for self-determination. Inappropriate motivations and difficulties with the cross-cultural communication of values have resulted in Māori challenging the research findings non-Māori researchers (Te Awekotuku 1991). Research should be negotiated with the Māori community and collaborative projects undertaken that allow Māori the right to control all information. This implies the ability to withhold sensitive information from the project and requires gaining additional consent to make it available to the public (Durie 1998). These processes ensure that the dignity of the participants and their hapū or iwi is maintained. Māori should benefit through inclusiveness in the core activities of the research rather than just making the interface Māori friendly (e.g. use of karakia or whānau support) (Durie 1994).

The issue of intellectual and cultural property rights is of particular concern to Māori. It has been argued that the ultimate intellectual property was the ability to define what the property

was, and to protect those things important enough to protect (Jackson 1993). The protection of intellectual and cultural property rights was the basis of the Mataatua Declaration in 1993 which declared that indigenous peoples of the world have the right to self-determination and in exercising that right must be recognised as the exclusive owners of their cultural and intellectual property. It also takes the position that the first beneficiaries of indigenous knowledge must be descendents of those communities (Smith 1999). The intellectual property rights derived from research commonly reside with the either the funder of the research, or the research institute, however, some guidelines suggest that ownership of the results of the research should also be shared with the Māori community (Powick 2002; Sporle and Koea 2004).

Researcher ethics

The responsibility of the researcher to act with honesty and integrity has been brought into focus through Māori concerns about research. The latest discussion document released by NEAC on the 'Ethics of Observational Research, Audit and Related Activities' lists integrity as an underlying ethical consideration and states,

> *The investigators commitment to the advancement of knowledge implies a duty to conduct honest and thoughtful inquiry and rigorous analysis, and to be accountable for her or his activities. (National Ethics Advisory Committee 2004) pg 16*

Māori have a history of being analysed under the ontology and epistemology of the dominant culture and all research is coloured in the sense that the researcher draws their conclusion through a Western interpretive lens (Te Awekotuku 1991). Including Māori in the analysis phase of the research is a way to ensure the integrity of the research. It is important to treat all members of the research community with respect and sensitivity and always be honest in dealing with the Māori community. This includes honesty from the researcher in relation to their qualifications and capabilities to appropriately conduct a project within the Māori community (Bevan-Brown 1998).

Accountability

The accountability of the researcher to the Māori community is an important consideration and includes ensuring that there is evidence of benefit to Māori or potential contribution to Māori progress and development. There should be mutual, but not necessarily identical benefit to participants, co-researchers and researchers (Durie 1998). Māori generally recognise that research is a necessary step to address Māori development however differences exist between Māori views of what that entails and that of mainstream institutes (Durie 1994). The difficulty arises when research is funded by an agency distinct from the iwi or population under the research. This creates dual accountabilities to both the Māori community and the funder and the possibility of a conflict of interest as maintaining a primary responsibility to the iwi could be pressured by the demands of the funding agency (Te Awekotuku 1991).

The themes of Māori ethics outlined above are primarily concerned with ensuring that research is responsive and relevant to Māori. These issues are of particular importance to non-Māori researchers carrying out research among Māori. It is only by deliberate reflection on these types of issues that researchers will be able approach research with Māori in a way that enhances the mana of all parties. A researcher, who is comfortable in both cultures and can evaluate the perspectives of both sets of cultural values and the potential conflicts, will be well placed to evaluate Māori research needs (Stokes 1985). Significantly, Māori ethical issues have been articulated in English to provide an explanation of Maori concerns at the interface between research processes and tikanga Māori. The contemporary Māori term for ethics is 'matatika' and maybe this term best describes the issues arising from the bicultural interface. The word 'matatika' traditionally meant right or straight but has been adapted for use in the context of ethical discussions (Williams 1997). It has a relationship with tikanga in the sense that they both have associations with the word tika, which means just, fair, right or correct. Mata means face and therefore matatika a literal translation might be, 'What is right, at face value'.

Tikanga Māori and he matatika Māori (Māori research ethics)

Ethics committees are a site for cultural negotiation (Durie 1998). It is also important to recognise and reduce the potential conflicts of interest for Māori working within a system that may not operate in the best interests of Māori. Inevitably, researchers who situate their

research within a Māori paradigm will find that aspects of their research will be incongruent with the principles of ethics committees, which are essentially based on western ethical values. The process of gaining ethical approval from a university ethics committee and a Māori body was compared by Walsh-Tapiata, who noted,

> *...there are areas of overlap but there are also huge cultural chasms. Neither is any less valid but represents two different knowledge bases, or qualities that a person may need to be aware of when undertaking research. (Walsh-Tapiata 1998) pg 254*

Tikanga Māori and he matatika Māori exist in different spaces.   Tikanga Māori is uniquely Māori, consistent with mātauranga Māori and situated within Te Ao Māori.   He matatika Māori arise at the interface between tikanga Māori and research processes, a site of contest between differing values, and an integral part of the bicultural reality for Māori researchers and researchers working with Māori.

Summary

Māori ethics are often associated with tikanga Māori however there is a distinct difference. Tikanga Māori has a base in mātauranga Māori and is consistent with all aspects of Te Ao Māori, the distinctly Māori paradigm. Tikanga Māori operate on two levels that refer to Māori values, or what is good, and Māori ethics in terms of what is right.   Values-based tikanga include Io, tapu, mauri, mana, hau and take-utu-ea. Ethics-based tikanga expressed by these values are whanaungatanga, manaakitanga, kaitiakitanga, mana, wairuatanga and kotahitanga. Tikanga frameworks have been described, however, they have yet to be applied clearly to the ethical review of research. However, the ability for tikanga to inform research practice and the development of Māori positions for contemporary issues is evident in the literature. Māori research ethics, which could be called 'he matatika', have been discussed in the literature in terms of differences between tikanga Māori and the values and ethics of contemporary research. The central themes that arise from this contested space in terms of Māori issues are respect, control, researcher's ethics and accountability. These are primarily concerned with addressing concerns with non-Māori researchers working with Māori communities. Māori researchers are more likely to have difficulty structuring research to address the different requirements of ethics committees and Māori communities. The lack of a clear Māori ethical

framework that combines tikanga Māori with contemporary ethical issues that concern Māori is a barrier to Māori involvement in research and ethical review.

Chapter 8: Research Approach and Methods

Introduction

This chapter outlines the research approaches and methods used in this study. It begins with a discussion of inquiry paradigms and the location of this study within a distinctive Māori inquiry paradigm that informs a kaupapa Māori methodology. This study utilises a qualitative descriptive format and the research methods are described. Specific ethical and Māori process issues are also discussed in relation to this study.

Inquiry paradigms

A paradigm is a worldview and provides a framework for breaking down the complexity of the real world (Patton 1990). An articulated paradigm makes explicit the particular values and assumptions concerning what is real (ontology – the nature of reality), true (epistemology – the ways of knowing that reality) and good (axiology – elements of right and wrong) (Scheurich 1997). As Ratima states,

> *It is the paradigm that defines acceptable methodologies, research priorities, conceptualisation of problems, appropriate methods and the standards by which the quality of the research is assessed (Ratima 2001) pg 140*

Grant and Giddings (2002) describe the difference between a range of research paradigms including the relationship of the researcher to the researched, and how this influences the methodologies and methods that can used. The positioning of the researcher and the epistemology and ontology of the particular paradigm will inform the type of question asked and the type of information collected. There are a range of Western inquiry paradigms that umbrella the various research methodologies. Grant and Giddings (2002) also note that an indigenous approach is appearing and reflects emerging indigenous research practices that cross Western paradigm boundaries. Kaupapa Māori research is one such methodology that draws on elements of critical theory but situates them within a distinctly Māori worldview.

Māori inquiry paradigm

Ratima (2003) questions whether Māori research can occur within a Western paradigm and suggests that Māori have their own unique inquiry paradigm, which reflects their unique ontological and epistemological positions and worldview. She notes that the articulation of a Māori inquiry paradigm is in its developmental stages. Bevan-Brown (1998) highlights the importance of situating Māori research within a Māori cultural framework.

> *This means it must stem from a* Māori *worldview, be based in* Māori *epistemology and incorporate* Māori *concepts, knowledge, skills, experiences, attitudes, processes, practices, customs, reo, values and beliefs. (Bevan-Brown 1998)*
> *pg 231*

The primary characteristics of the Māori inquiry paradigm are the integrative nature of Māori worldviews and the recognition that what can be known is dependent on cultural values Ratima (2003). Ratima identified five key themes of a Māori inquiry paradigm that articulate its essential features and implications for Māori health research.

Table 6. Themes of a Māori Inquiry Paradigm and their implications for Māori health research

Themes	Implications for Māori health research
Interconnectedness	Māori understand the world in holistic terms, recognising connections between times, realms, and situations. Therefore, the links between health and historical, cultural, spiritual, social, economic and political factors should be emphasised.
Māori potential	Research should lead to positive health outcomes for Māori, and greater opportunities for Māori to fulfil there own potential.
Māori control	Control of Māori health research should rest with Māori. Issues of intellectual property rights should be considered in relation to this theme.
Collectivity	Māori collectives will be a legitimate focus for Māori health research, and research should lead to positive outcomes for Māori collectives (e.g. iwi, hapū, whānau). Further, Māori health research should be accountable to Māori collectives.

Māori identity	Māori cultural heritage, Māori institutions, and links to the environment are central to the Māori worldview and, therefore, need to be taken into consideration when practising Māori health research. Research should endorse Māori identity.

(Ratima, 2001)

The key themes described here are drawn from concepts within mātauranga Māori and validate Māori constructions of the world. They emphasize the importance of Māori control over the processes of knowledge production, determination of values and prioritisation of research needs.

Methodology

Qualitative methodologies reflect a philosophical and political orientation to the world which contend that meaning is only possible when it is shared (Krefting 1991; Smythe 2000). Methodology refers to a process of inquiry that determines the methods used (Cram, Pihama et al. 2000). Māori health research utilises a range of methodologies that can separated into two categories, those derived from a uniquely Māori inquiry paradigm, and those adapted from other paradigms to be consistent with a Māori inquiry paradigm (Ratima, 2001). This study is situated within a Māori inquiry paradigm and adopts a kaupapa Māori methodology which provides both a cultural and critical analysis in the context of research involving Māori (Smith 1996). Kaupapa Māori methodologies also inform research processes that legitimise and validate Māori language, culture and knowledge (Johnston 1998).

Cunningham (2000) indicates that 'the degree of Māori control' over the project distinguishes kaupapa Māori research from other research approaches that focus on Māori issues. Kaupapa Māori research is typically undertaken by a Māori research team with predominantly or exclusively Māori participants and uses Māori analysis to produce Māori knowledge which meets the quality standards set by Māori (Cunningham 2000).

Research methods

The use of kaupapa Māori methodology requires the use of methods that are culturally safe and culturally affirming. A range of methods can be incorporated within a kaupapa Māori approach that can be drawn from both mainstream and kaupapa Māori research approaches however they will firstly be assessed in terms of cultural sensitivity, cross-cultural reliability and whether they can generate useful outcomes for Māori (Smith and Cram 1997). This study follows the format of a qualitative descriptive study and provides a Māori specific critique of the process of ethical review in New Zealand. It is consistent with the characteristics of kaupapa Māori research in that it is conducted within a Māori cultural framework, it is conducted by people with the necessary cultural expertise, it is focussed on an area of importance for Māori and it will involve Māori at all stages of the research.

Relevance to Māori

Māori research should be focused on areas of importance and arise from self-identified needs and aspirations (Bevan-Brown, 1998). This study emerged from repeated calls by Māori academics for ethical review to be more responsive to the needs of Māori. Jones (2000) observed that Māori should have control over research that involves Māori at all levels including research policy, goal setting, funding and ethical guidelines. The need for Māori to become more involved in the process of ethical review was highlighted in the Te Puni Kokiri (1994) report 'Ngā Tikanga Pono Wahanga Hauora'. Arohia Durie (1998) also noted that Māori concepts of ethicality must be taken into account especially for research conducted in a Māori context. These views were further reiterated at a National hui for Māori members of regional ethics committees at Ngā Herenga Waka Marae in November 2002. Māori research ethics was also identified at as a key theme in a preliminary discussion document released by the National Ethics Advisory Committee (2003).

Sampling strategy

The participants for this study were drawn from present and past Māori members of various ethics committees who were currently living or working in Auckland. The sampling strategy consisted of both purposeful sampling and snowball sampling. Purposeful sampling was chosen as a means to maximise variation with respect to the following characteristics; the type of ethics committee (institute, regional or national), the length of time as a member and the

ability to speak te reo Māori. Snowball sampling was used led to other potential subjects being recommended by study participants based on their knowledge of the potential subjects particular expertise or unique perspective (Patton 1990). Participants were recruited until no further new information emerged from the interviews. The size of the sample (7) was determined by researcher judgement and guided by informational considerations.

Interview procedure

Qualitative data is typically derived from three main sources, open-ended interviews, direct observation and written documents. The primary sources of data for this study were the literature review and interviews with Māori members of ethics committees. In-depth open-ended interviews were used as the primary data collection method as it allows for gathering of direct quotes about people's experiences, knowledge, feelings and opinions (Patton, 1990). The advantage of this type of data collection is that it can focus on the topic of the study and provides insights into participants' perceptions of ethical review in New Zealand. Face to face interviews were selected to provide an opportunity for meeting with the participants in person as 'kanohi ki te kanohi' is an important concept in Māori culture (Smith 1996).

The researcher developed an interview schedule with input from Māori members of ethics committees, some of who participated in this study, as a key source of expertise in relation to the topic. The interview schedule focused on the responsiveness of the ethical review system to Māori and its consistency with Māori concepts of ethics and tikanga (appendix 1). The advantage of an interview schedule is that it reduces variation in the depth and breadth of information collected from the participants (Patton 1990). The interview schedule was prepared in both te reo Māori and English.
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Participants were contacted by the researcher and asked if they would like to be a part of this study. A formal invitation consisting of an information sheet and the consent form (in both te reo Māori and English) was then sent to the potential participants (Appendix 2). Interviews were conducted with each of the participants at their choice of location in either te reo Māori or English. Three participants chose to be interviewed almost exclusively in te reo Māori. Information was gathered in the form of written notes and, with permission of the participants, tape recordings of the interviews were made. The tapes were used to review and check the

consistency of the written interview notes but were not transcribed. The interviews lasted between 1-2 hours.

Analysis

Data analysis is a process by which collected data is categorised in order to address the research question/s (Ratima, 2001). The written notes for each interview were collated in a computerised database of discussion notes, and summaries for each interview were then prepared. A copy of the summary was then given to the participant to review and make any corrections or alterations. Thematic analysis was carried out whereby key themes were identified (Patton, 1990). This was done by reading and re-reading, the interviews and summary database. A summary of the key themes was developed and reviewed by the participants. A separate analysis was conducted to determine the similarities and differences between the participants who interviewed in te reo Māori and those who did not. The key findings were then discussed individually with participants to seek their agreement as to the way in which their views had been interpreted, to provide an opportunity for further input, and to facilitate a consensus approach to this study.

Māori process issues

Consultation with Māori is a requirement of ethical review and this study was designed to ensure Māori involvement at all stages of the research process to ensure cultural integrity and address any Māori ethical issues. As Cram, Pihama and Barbara write,

> *Operating in a Kaupapa Māori framework necessitates a research process that affirmed Kaupapa Māori ethics. These ethics are informed by tikanga Māori ...*
> *(Cram, Pihama et al. 2000)*
> *pg 54*

The researcher discussed the topic with a range of Māori academics and Māori members of ethics committees as part of developing the research topic. The participant's views were canvassed at all stages of the research process from the interviews, to analysis and final reporting to ensure that their views were interpreted correctly and to establish trust that the study has integrity. An important consideration when conducting Māori research is cultural

competency. The trust of the participant community will only be engendered by meeting their cultural expectations. Researchers should have the necessary cultural, reo, subject and research expertise (Bevan-Brown 1998). Also, a recognition that the researcher is engaging in a process to develop relationships that may continue beyond the parameters of the study is an essential part of ensuring that respectful processes are incorporated into all facets of the study. This can be facilitated through the use of inclusive collaborative approaches to research that foster participant involvement throughout the entire project.

The researcher, as a Māori member of an ethics committee, comes from the same community as the participants. He has background understanding and practical experience of the issues associated with ethical review in New Zealand. He is also a competent speaker of te reo Māori and gave the participants the option of conducting the interview in te reo Māori, English or both languages. Participants were given the opportunity to choose the location of the interview and the researcher ensured that appropriate protocols were followed with regard to tikanga Māori (e.g. mihimihi and koha). The primary supervisor for this thesis was also Māori which allowed conclusions drawn from the analysis to be debated against a backdrop of shared understanding.

This study also had to be consistent with the ethical principles as stated in the Operational Standard (2002) and address issues such as informed consent and confidentiality. An application for ethical approval for the project was sought and gained from the Auckland University of Technology Ethics Committee (AUTEC).

An issue of interest relating to the ethics of this study was the request that the participants be named. To address any ethical concerns with the naming of participants, full informed consent was gained and participants had the opportunity to withdraw at any time during the study. The rationale for wanting to name participants in this study is twofold. First, the participants continue to own the information they have shared with the researcher. Participants may be approached directly by people wanting to query their views or the outcomes of the project. This was not meant to absolve the researcher of any responsibility for the analysis or the conclusions of the research however it addresses the issue of the researcher becoming a gatekeeper to the information and it also increases the accountability of the researcher back to

the community. Second, the mana of the participants will add to the mana of the statements that they make and ultimately to the mana of the project. This is an important aspect to consider for Māori in terms of kanohi kitea. Kanohi kitea refers to concepts like transparency, fronting up, and standing by your words and in doing so it engenders respect.

Summary

This research study is positioned within a Māori inquiry paradigm and utilises kaupapa Māori methodology to ensure a culturally affirming research process that is congruent with a Māori worldview. The participants for the study were purposefully sampled from a population of past and present Māori members of ethics committees. They were interviewed in either te reo Māori or English using a semi-structured format. The data was analysed thematically to determine key themes. Given the nature of the study, particular attention was given to carrying out an ethically robust project using research approaches that are relevant to Māori and address Māori process issues.

Chapter 9: Participant Profiles

Introduction

Seven Māori members of New Zealand ethics committees were interviewed as part of this research study. The range of ethics committees has been described in Chapter Six. All the participants agreed to being named and this section provides a background to each of the participants in their own words.

Kay Worrall

I'm Tuhoe from Waimana. I am married with three children and have lived in Devonport for forty years. A friend in a health service asked me to apply as a member of the Regional Health and Disability Ethics Committee as a Māori lay member. I served six years on that committee, four of which were as chairperson. I have been a member of the Auckland District Health Board's Māori Research Review Committee and subsequently, the Chairperson for two years of the inaugural Waitemata District Health Board's Māori Research Advisory Group, Ngā Kai Tātaki. I am also a member of the University of Auckland's Human Participants Ethics Committee as a lay Māori member.

Nicole Presland

I am Ngā Puhi from Whirinaki but was brought up in Auckland in a whānau of six. I became aware of the role of ethics committees through my mother who was on a regional ethics committee. I responded to an advertisement in the Herald and have been on the committee now for about six years as the Northland representative one of the Auckland Regional Ethics Committees. I have been the Chairperson for the last three years. I have degree in accountancy and business from Auckland University of Technology and a diploma in Public Health from Auckland University. I am on the Council of Auckland University of Technology and have been involved with New Zealand Women's Rugby League and the National Māori Smokefree Coalition. Taking regular holidays and watching my beautiful children grow up help to bring perspective to my life.

Helene Leaf

I am from Ngā Puhi, Te Aupouri and Te Rarawa on my father's side and Danish, Jewish, English on my mother's side. My hapū is Te Hikutu. I have six adult tamariki and two whāngai tamariki. At this time I have 11 mokopuna with a further two due late in 2004 or early 2005. My passion throughout my life has been working with tamariki, wāhine and whānau. My career has evolved through this work, in empowering whānau. Tamariki and wāhine health was a motivating influence to get involved in the health arena as well as the need to help victims of violence (who sometimes became childless as a result). I was nominated to the Northern Health & Disability Ethics Committee as the Māori health and disability representative from Northland, by several Ngā Puhi health/community organisations. I served for six years until 2001 and was Chair of this committee during the last year of my term.

I trained as school dental nurse and graduated in 1965 and worked in rural locations in Hokianga, the Bay of Islands as well as Auckland. I worked on the health/social service/education and housing portfolios during the setting up of Te Rūnunga ā Iwi ō Ngapuhi in 1985-1993 and was part of the working party that set up Te Ohu Whakatipu, the Māori partner of the Ministry of Women's Affairs. I was also involved with the cervical screening pilot project in Northland for the MOH in 1986/87, and part of the working party that set up the Women's Refuge in the Mid-North, around 1984/86. This structure has a Pākehā collective and Māori collective, which allows for a dual development model. I am still actively involved with the Māori collective. This project was also the catalyst to support men to deal with violence in the community and uses a hands-off approach to allow them to deal with their own issues in their own way but still supports the process to help maintain accountability. The Mid-North Women's Refuge became the first Māori women's refuge in the country and the model for the present development of Māori women's refuges throughout Aotearoa.

I wish to acknowledge those wonderful women who initiated this development, those whom are still with us and those who have passed on. I am currently a lay Māori member on the National Ethics Committee for Assisted Human Reproduction however I am about to be replaced now that I have a new job in health, as an advisor in Family Violence Prevention Māori with the Auckland Regional Public Health Service. The Terms of Reference for the Ethics Committee exclude anyone employed in health.

Jane West

My first delve into social science research was during my midyears at college 1975-1976. I was the nominated student worker with Associate Professor John Raeburn for his Health Research Council (HRC) project developing community cohesion through the People's System attached to a community house. I attended several public and group meetings and found the approach often aligned to the previous teachings in tikanga Māori from my nanny in Kaipara, te rohe ō Ngati Whatua.

The old saying of "be away from home to learn about home" rang true when I spent over ten years away from my tribal rohe and resided in the Whakatū, Motueka area. Here I worked for Maiawhitia Ngai Tahu Whānau Trust doing research on mechanisms to integrate several community groups. Using a paihere structure, the co-venturing roopu won a social delivery contract from the Ministries of Health and Education. This facilitated the introduction of the HIPPY programme to Motueka under the concept of a family/whānau service centre. It is still operating and rates as a high achievement in my mahi away from home.

Back in Auckland, some twenty-five years later, three children and having completed tertiary study in environmental health, human ecology and developing papers of ethics, I found myself working with John again as action researcher on a two-year project called The Other Way. This project, also funded by the HRC, was with the School of Population Health, Medical and Health Sciences, University of Auckland in collaboration with Health Canada.

My interest was peaked again and I agreed to nomination as an inaugural member on the Albany Campus, Massey University Human Ethics Committee. I remained there until 2002 when I arrived at Waitemata District Health Board. I maintain the Māori Research Advisor position attached to Ngā Kai Tātaki roopu, Mo Wai Te Ora Māori Health. Included in this position, I guest lecture to tertiary institutes on how to make your ethics application Treaty and Māori responsive. In 2003 I accepted nomination onto the Auckland Regional Ethics Committee Y and have been involved in the collaborative consultation process with NEAC on the potential of a Māori framework following a hui on the new terms of reference criteria for ethics committees.

I firmly believe that while kaupapa Māori research is attaining maturity in terms of Māori for Māori from within the Māori worldview, there is also a place for sharing the 'things Māori that make us unique. In those terms, ngā hapū, iwi Māori o te motu act as kaitiaki of our collective indigenous ancestral practices and our cultural property rights within the modern day context. We can help to identify any potential risk within the research environment to our uniqueness as the indigenous culture of Aotearoa.

Kura Taumaunu

Ko Hikurangi te maunga,

Ko Waiapu te awa,

Ko Nukutaimemeha te waka.

I ako ahau i te taha o ngā tamariki i roto i te kohanga, i te taha o oku hoa i te Ataarangi, kātahi ka whai atu i te tohu ki te whakaako tamaariki. I tohungia ahau e te Kura Takiura o Tamaaki Makaurau te tohu o te kaiako mō ngā Kura Kaupapa Māori i te 1994. I hoki atu ki te hapai i te kaupapa ra i te taha o oku whanaunga i roto i nga kura. Ka tutuki noa taku tohu mātauranga, ara te BEd, mai i te Whare Wānanga o Tamaaki Makaurau i te tau 2001. I te kohanga o tērā tau i riro mai tētahi turunga hou, ara ko te Kaiwhakahaere Tikanga Ako i roto i te Pokapu Ako Tauira o Te Wānanga Takiura o Manukau. I te tau 2002 i tū ki runga i te Komiti Tangata Whenua, hei wherawhera, hei tohutohu ki te poari o Te Wānanga Takiura o Manukau ki ngā kaupapa ako. I uru hoki ki te Poari matatika mō Te Wānanga Takiura o Manukau, hei māngai Māori mō kotahi tau. Kātahi ano ahau i heke mai i te poari ki te whai i te Post-graduate Diploma in Education.

Moe Milne

Ko Hine a Maru te tupuna, ko Ngati Hine te hapū, Ko Ngapuhi nui tonu te iwi. Ko Te Kau i mua te hapū ririki i roto i a Matawaia- taku kainga.

Ko taku pakihi ko "Te Moemoea". Ko taku mahi, toku wawata, he mahi tahi ki te iwi Māori ki te whakatutuki i o rātou moemoea.

I au e mahi ana mō te poari o Te Taitokerau i uru atu au ki runga i te komiti Matatika. No reira noa atu ka kite au he take nui tēnei mō te Māori. Heoi ano, mai i tērā wā, tae noa mai ki tēnei rā, horekau ano kia tino mana tā te Māori whakaaro ki wēnei kaupapa. Me te whakapono he

mātauranga Māori kei kona hei arataki atu i a tātou mō te matatika. Ko toku tūmanako, kia whakatuhia he wānanga hei whiriwhiri ake i o tātou matatika, o tātou ake philosophy ano hoki. Kia tu motuhake tētahi komiti Māori ki te rangahau i nga tono o te Māori. Kei roto i o tātou tikanga ngā āhuatanga tōtika ka puta ai ko te oranga.

Shane Ruwhiu

Ko Hikurangi te maunga, ko Waiapu te awa, ko Ngāti Porou te iwi. I tipu ai toku papa i te whanga o Waipiro. No Hinetamatea me te Aitanga a Hauiti ngā marae o toku mama, e mihi atu ki te wāhi o Whangara hoki, te wāhi tipu o toku tipuna a Porourangi, ara, ko au he uri, he heke o Ngāti Porou. Kei te noho au ki te Rakipaewhenua mo nga tau 17. Ko Laureen toku hoa rangatira, nō te Tai Tokerau a ia. Ko Hemi taku tama, ka 21 a ia i tēnei tau. I te tau 1997 i hoki ahau ki te Whare Wānanga o Tamaki Makaurau ki te whai mai te tohu paetahi mō te mātauranga. E whā ngā tau ki reira i roto i te wāhanga Māori. I te tau 2000 i tono mai a Waitemata kia uru mai ahau ki te hohipera. Kei konei tonu au. Akuanei ka timata tētahi mahi hou hei Pou Manaaki mō te kāinga o Wilson Home.

Ko taku nei mahi,

1. hei awhina i a rātou ki te mau ai ngā āhuatanga e pā ana ki te ao Māori.
2. ki te awhina ki tētahi tangata ki te tuhi i ngā kaupapa here.
3. kia kite ai nga whānau i ngā tukanga mō ngā kaupapa here.

I roto i ēra kaupapa here kaore he ora , mena kaore he aroha i roto. Kia puta ko te mauri (te tipu, te ha, me te ora o te kaupapa) ki roto i te mahi. E toru aku tau ki runga i te komiti mō te matatika mai i te tau 2000.

Chapter 10: Results

Introduction

The findings have been structured into the following sections;

- the ethical review process and Māori,
- ethical issues of concern for Māori,
- differences between Māori and Western ethics,
- enhancing the responsiveness of the system of ethical review,
- the usefulness of tikanga Māori and mātauranga Māori, and,
- consultation with Māori.

The ethical review process and Māori

Research was seen as potentially beneficial for Māori if it addressed Māori health issues. The potential benefits for Māori include developing awareness of research processes, health issues, and providing evidence for funding and policy decisions.

> *Māori involvement in research is important as a way to get knowledge that is relevant to Māori, as a basis for change and advancement. It is important not to exclude ourselves from research, as research is the basis for funding and policies decisions in the health arena. The benefits for Māori include learning about the process of research, more people taking responsibility for health, for themselves and their whānau, the ripple effect of awareness which is necessary for Māori to allay any fear of research from previous experience. Kay*

Research outcomes should provide some tangible benefits to the community. This may require continued involvement with the kaupapa after the completion of the research report.

> *If we are going to do research then we have to be able to do something with the results, not just a baseline for more research. Helene*

The main criticism was that most research failed to engage with Māori communities and frame research questions around their needs.

We need to have appropriate research done on Māori, this means getting involved with setting the research agenda, and challenging how researchers are doing research that impacts on Māori or why they are choosing topics that don't reflect Māori issues.
Nicole

Ethical review was considered an important process to monitor research activity. Māori involvement in ethical review in New Zealand was recognised as being subject to political influences at a societal level (the status of the Treaty) and an individual level (personal assumptions and agendas).

The current political environment is a major barrier to Māori having any real placement in regulatory and compliance processes. Ethical review is about ensuring that the researcher has the capacity to comply and that compliance occurs. Already there are people are asking why Māori are there? And if because of the Treaty, why the Treaty? This is not just a health or research issue, politics plays a part. At an individual level people's assumptions and agendas, those of both the researchers and committee members plays a part in denying Māori expression on these committees.
Jane

Responsiveness to Māori

There was consensus amongst all of the participants that the current system of ethical review could be more consistent with Māori worldviews.

On a scale of 1-10, about 5/10. It doesn't take a Māori worldview into account, it is basically a mainstream approach based on Western ethical review with Māori considerations added on. It does not consider issues from a Māori point of view, or take into account Māori ethical positions. Nicole

Māori worldviews and conceptual frameworks have yet to be incorporated within research and ethical processes.

> *No reira, i tēnei wā tonu horekau anō ēra mana whakahaere i tūturu whakaae he āhuatanga Māori hei tirotiro, hei whakatakato, he aha ngā mea me rangahaua, he aha ngā tikanga, he aha ngā tika i roto i te rangahau Māori. Moe*

Kaupapa Māori research engages with Māori and is consistent with Māori worldviews however its rigour is often questioned during ethical review.

> *Kaupapa Māori research development has increased significantly over the past decade. There has been some scepticism from general members about the rigour of the research, also holistic representations and spirituality are difficult to reconcile in scientific frameworks. Kay*

The attention given to Māori and Māori issues was deemed tokenistic and tended to marginalise Māori input to the question related to the Treaty of Waitangi.

> *He 'tokenistic' kē te whakaaro ki te Māori. I roto i te puka tono ko te 'question 14' anake te wāhanga e whai whakaaro ki te Māori. Shane*

Respondents emphasised that Māori needed to be a part of ethical review to ensure that Māori issues were considered as part of the process.

> *Ina kore te Māori i uru ki roto tēnei mahi, ka raru tātou. Ka taea te wero atu e ngai tātou ki ngā pākehā mō ngā whainga, me ngā kaupapa o ngā rangahau. Kei reira he hua mā te Māori i roto i tēnei rangahau. Mena kei reira tātou, ka taea te tohutohu ki ngā mema ake ki ngā whakaaro rereke ahakoa Māori mai, Pākehā mai, nō iwi kē. Kura*

Māori involvement in ethical review was important to ensure that the process had integrity and Māori processes would benefit all participants in research.

Ensuring the integrity of the process, the mana of the process is important to Māori. All issues should have Māori involvement. Māori processes enhance the wellbeing of people in research. Jane

Establishing common Māori positions amongst increasingly diverse Māori individuals was identified as an issue. Contemporary Māori realities will have a significant impact on the acceptance of 'Māori' ethical positions. Māori values are changing and are increasingly influenced by outside forces so that identifying values that are reflective of Māori requires wide discussion.

New Zealand is a changing world, Brash, the foreshore, contemporary society, more Māori professionals developing their own sets of values different from parents and grandparents, so that means the collective set of Māori values may be changing. What is different and what has informed it, Māori views or worldviews. The discussion needs to involve all ages and stages of Māori. Kay

Māori membership on ethics committees

Māori membership on ethics committees is designed to ensure that Māori views are included in the ethical review process. Despite the consensus mode of operation on ethics committees, it is often difficult for a Māori view to be accepted particularly if it is in opposition to traditional Western ethical views. Identifying as Māori in this type of forum and promoting Māori views is a political act as Māori members are acutely aware of inequalities and the marginalised position of Māori within society. An issue of power, as reflected by the generally unquestioned acceptance of Western research and ethical constructs, underlies all deliberations.

In its present form they have tried to incorporate it (Treaty of Waitangi) by having Māori members and by having information in the guidelines. However the real issue is the inequality of power in this forum, which is skewed towards mainstream views. Helene

Within the system of ethical review, Māori views have yet to be given the same validity as these scientific or legal views.

> *Ko tona tikanga, he tū kotahi te komiti i runga i te whiriwhiri o ngā take. Mehemea e tika ka kōrero ngā experts, medical experts, legal experts, public health experts me ngā Māori experts. Koare anō kia tino mana te Māori expert, horekau anō hoki te mātauranga Māori motuhake kia mana kia orite ki te mātauranga Pākehā. Moe*

As such, to make an effective contribution in these forums Māori members require sound grounding in Māori issues and research issues and has the confidence to express these views to researchers and other members of the ethics committees.

> *Ko te āhua o te poari, mā ia mema e wherawhera mai i ona whakaaro. No reira, me maia, me kaika, me paakiwaha, me wahanui te mema Māori i ona whakaaro kei rumaki ki raro i ngā whakaaro ā ngā pūkenga mātauranga e whakahihi nei. Kura*

The participants suggested that Māori members often had dual roles and needed a range of skills to be effective. Alongside the skill set that is normally required of ethics committee members, Māori members must also have an understanding of te reo Māori, tikanga Māori, mātauranga Māori and the Treaty of Waitangi. Māori members are most frequently brought onto the ethics committee as lay members and can struggle with the scientific language and academic discourse. Formal training sessions are held infrequently and members are often left to feel their way into the process. This has implications for both the general members and the Māori members of the committee. As members bring their own backgrounds and understandings to the deliberation there is ample space for misunderstanding. Formal training or orientation would ensure that everyone has the opportunity to communicate from a similar base level of understanding. The areas that should be included in the orientation process for all members include; research methods, research ethics, the Treaty of Waitangi, and Māori ethics.

> *The current system relies on what people bring to the committee from their own backgrounds. There is a really loose process for selecting new members and providing any type of orientation to the ethical review process. There is also no review of new*

members or existing members so how do you know that people know about ethics.
There is also no requirement for other members to know about Māori.   Jane

Māori members of ethics committees have indicated a desire to have additional opportunities to develop their understandings of Māori ethics, the Treaty of Waitangi, mātauranga Māori and Te Reo Māori and ability to communicate and justify Māori ethical positions. Training of this type would have dual purposes. First, it would provide an opportunity for the training of new Māori members and a more consistent application of Māori perspectives within ethical review. Second, it would assist in the development of Māori ethical positions on particular issues.

Māori members may have difficulty articulating Māori spiritual concepts to other
members however if we must be involved in particular issues or hold particular
positions then we must know why. Jane

Me mohio te mema Māori ki te reo, ki tona turangawaewae ki ngā tikanga hoki me te
mātauranga o te whare wānanga me te noho ki te taha o te whānau, o te hapū.   Kura

Māori members considered themselves to be representing their respective Māori communities within ethical review. They considered that it is impossible to distance themselves from their responsibilities to Māori whānau and communities.

Ko te mema Māori te pou manaaki, te kaitiaki, e kawe nei i te mana, te mauri, te
tikanga o ona tipuna o tona whānau hoki. Koina te haepapa o te mema Māori. Shane

Respondents indicated that the process of selection for Māori members to ethics committees is limited and the system of ethical review has not engaged effectively with Māori communities. While ethics committees are situated within tribal or waka (confederation) boundaries there are no formal structures to ensure local Māori representation. Mana whenua[28], as kaitiaki[29], should be represented within ethics committees as they have a responsibility for the safety of the land and the people within their area.

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[28] Iwi with connections to a particular area
[29] Guardians

...ethics committees sit inside particular tribal areas. There should be recognition of Mana whenua and notification to Mana whenua (as to who is on the committee) and what processes are in place. Jane

The recent changes to ethical review, which reduce the number of ethics committees and thereby increase the area an individual ethics committee covers, will create further difficulty in ensuring mana whenua representation. It is appropriate for Māori representation on ethics committees (and institutional research review committees) to reflect the local Māori communities they represent.

Treaty of Waitangi

According to respondents the Treaty of Waitangi has an important place in ethical review of research. It has implications for both researchers and ethics committees. However, there are often misunderstandings between researchers and communities about how the Treaty is implemented in research.

Misunderstandings about how the Treaty of Waitangi should be implemented are evident and the level of expectation differs between iwi, ethics members and researchers. Nicole

Ethical review processes were not thought to adequately reflect Treaty responsiveness despite their role in evaluating the Treaty responsiveness of research protocols.

Only by having the Māori seat. The actual process within the Ministry (as in the Ministry taking responsibility for ensuring adequate resourcing and recognition) and the ethical review is nil despite us reviewing the responsiveness of researchers to the Treaty of Waitangi. Jane

The responses to the Treaty question in the ethics application were often stock phrases rather than a genuine attempt to consult with Māori.

Ko oku wheako, kaore te nuinga o ngā kairangahau i marama ki te Tiriti o Waitangi. I haere rātou ki te rapu i ngā kōrero mai i te ipurangi. He tāhae kōrero noa iho, kaore he mauri i roto i ngā kōrero hei whakamana, hei whakatinana i ngā kōrero. Shane

Participants recognised that the status of the Treaty and its application within ethical review was subject to political influences.

Legal recognition of the Treaty has influenced development over the past 20 years. The politics of the day is an important factor in setting the climate and also whether you can develop any momentum, determining what is practical possible. This is always a problem of being a minority group. Kay

There also exists a need for clarification of the difference between Treaty rights and indigenous rights.

The difference between and implications of indigenous rights versus Treaty rights are also something that needs to be clarified. Kay

The ethical issues for Māori in research

A number of ethical issues for Māori were not currently assessed within the ethical review process in New Zealand. The participants identified a number of issues that they thought should be considered in addition to the areas currently viewed as important to Māori. The allocation of adequate levels of research resource is an ethical issue for Māori on the basis of inequalities in health between Māori and non-Māori and the protections afforded by the Treaty of Waitangi.

We should be able to establish a Māori review process due to the lack of consideration and lack of Māori health gain. The Treaty would be the base for our argument to gain resources. Māori health is the priority for health research. Kay

Participants noted that Māori were often excluded from research designed without consideration of how it may contribute to Māori health or development goals.

> *A lot of research is designed in a way that excludes Māori, inclusion is important. Kay*

The participants also recognised the need to influence the research agenda to ensure that research contributes to wider Māori development goals.

> *We need to have appropriate research done on Māori, this means getting involved with setting the research agenda, and challenging how researchers are doing research that impacts on Māori or why they are choosing topics that don't reflect Māori issues. Nicole*

Māori research workforce development was seen as a significant ethical issue and relevant to increasing the capacity of the Māori community to address areas of health disparity.

> *Māori need to be up skilled and involved in research, Māori need to be empowered to be part of research, and this is an ethical issue. Māori workforce development is an ethical issue as they are often excluded from involvement. Nicole*

The importance of respecting Māori cultural practices was highlighted to improve the communication and relationship between researchers and the Māori community.

> *He kōrero rangatira kia puta mai ko te whakaaro ā te iwi Māori me te whai anō i ngā tikanga Māori, te mihi, te hongi me te harirū, me ētahi atu tikanga ki te tangohia ngā hū, ko ēnei āhuatanga kia whakatau ai i te wairua ō te tangata. Shane*

The incorporation of Māori values into both research and ethical review can ensure that research is appropriate, cognisant of Māori perspectives and beneficial for future generations.

> *Me pehea o tātou whakamahi i ngā tāonga i tēnei wā? Pēnei i te mana, pēnei i te rangatiratanga, pēnei i te mātiro whakamua, pēnei i te oritenga. E mohio ana koe ko*

ngā mahi e mahi ana i tēnei rā mō au tamariki, mō au mokopuna. Nā runga i tēnei ka kaha ki te whiriwhiri he aha ngā mea e tika ana. Moe

Participants commented on issues of intellectual property rights and the difficulties with maintaining control over indigenous DNA.

Māori have particular concerns, protection of our information is a big issue, family's DNA, it is being ripped off, used and commercialised. DNA represents our whakapapa that is unique to this region of the world and it has specific physical traits. Nicole

Participants noted that the control and validation of knowledge was dominated by Western frameworks however there were opportunities for Māori frameworks to contribute to Māori development and that researchers needed to be aware of and contribute to both knowledge frameworks.

The process of validation, i ēnei wā kei ngā Pākehā te mana mō tēnei. Ēngari me hoki anō ki a tātou te mana ki te whai mātauranga hei whakatau i tēnei ao. Me te mōhio anō he expert tātou ki te ao kei roto i te ao Māori. Me whai ngā kairangahau i te ao mātauranga Māori me te ao Pākehā. Moe

Differences between Māori and Western ethics

One of the strongest themes that emerged from the interviews was that differences exist between Māori understandings of ethics and the Western understandings of ethics that underpin ethical review in New Zealand. The interviews provided an insight into these differences and some of the tensions that exist for Māori members of ethics committees.

At a philosophical level, Māori holistic understandings of the world are not consistent with the individualised conceptualisations of ethical principles used in ethical review. While it is accepted that individual representations should be maintained, this does not exclude the application of collective understandings of these principles.

Kaore e taea ēnei tikanga ki te nohotahi ki ngā mea Pākehā. Kei a ia tona ake mana, kaupapa, ora. I ēnei rā e taea te mirimiri kia hanga tika tētahi wāhanga ki a tātou. Moe

Māori understandings of ethical principles

There were differences in the way that Māori members of ethics committees framed and applied the ethical principles used in ethical review in New Zealand to make them more consistent with a Māori worldview. This often created a tension for Māori members in terms of getting researchers and other members of ethics committees to accept these views and collective expressions of ethical principles.

> *... te rerekē o te whakaaro o te Pākehā ki te tangata me ona ake, me te whakaaro e Māori nei ki te tangata me ona katoa. Shane*

Alongside the English language ethical principles used in the sub-headings below are Māori concepts that participants used to express an alignment to Māori principles.

Respect for persons: Manaaki[30], ngākau mahaki[31], te mana me to whakaae[32]

Respect for individuals is maintained through recognising the autonomy of the individual and respecting their personal beliefs. Respect may be demonstrated by the use of lay explanations and making provision for whānau support. Respect for persons should also acknowledge the Māori collectives or communities that participants belong to.

> *Is this respect for the individual or respect for the iwi? The individual has the rights in the current context; however benefits often go to the group. Kay*

This principle can be applied in a research context to Māori collectives. Consultation with Māori provides a mechanism to acknowledge Māori communities and demonstrate respect for

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[30] To show respect or kindness
[31] To act with a benevolent heart
[32] To have control over the agreement

these collectives. Consultation has a dual function, it informs Māori communities about research activities happening in their area and it also provides researchers with feedback to improve the responsiveness of the study to Māori. Respect for Māori collectives can also be demonstrated in the way the results of the study are communicated back to the community. It is preferable that this occurs kanohi ki te kanohi (face to face), in an appropriate place and in an appropriate format.

> *Kia ngākau mahaki, ehara mā te pepa noa iho hei whakamarama atu, me mahi ngātahi te kairangahau ki ngā tāngata kia kite atu ai i te mata o te ngākau. Kura*

If you know that the recipient of the report is unable to understand highly academic or scientific language, its use in the report shows a lack of respect for the recipients. Just as a lay explanation of the research is required for the information sheet, a lay explanation of the results may be a more appropriate way to disseminate the research outcomes to the community.

Informed consent: Ko te whakaaetahi[33]

For Māori, this is intimately related to respect. While individualised consenting processes are important there is recognition that both the participant's level of understanding and interpersonal power dynamics affects the decision-making process. Participants can be influenced by significant others such as the researcher, a doctor, a kaumatua or another person. This may be related to a lack of understanding, a cultural preference, or an attitude of trust.

> *It is important to have the individual choice but culturally the decision-making roles (traditionally) were often located with people other than the individual such as the tribal leader. A similar situation often occurs in contemporary society with people deferring power to doctors or others in positions of authority. Kay*

Ethics committees themselves are a form of collective consent as they collectively agree that a research study, on balance, is safe for participants. It could be said that research already has a

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[33] To consent together

process for collective consent and that all Māori are asking is that this respect is extended to their communities.

> *It should not be solely an individual process as there are other ways to gain consent. Māori prefer communal methods. Often researchers don't want to deal with the perceived hassle of Māori consultation, however in working towards the manageability of the project, the researcher should have a process in place to allow for different types of consent. The researcher needs to know what the implications of consent are, so that they can give recognition to whānau, hapū and iwi consent. If the particular clinical condition is specific to a whānau then whānau consent is needed. The researcher facilitates the process but the direction and control of it should remain with the whānau. Jane*

Consultation again provides the mechanism for collective consent to occur. However, consultation should not be regarded as a one off meeting but as a process of relationship building, which allows benefits to be reciprocated over the term of the relationship. A relationship is not built on a piece of paper (letter of support) but by time spent together talking, discussing and sharing ideas and views about research needs and opportunities before, during and after the research project.

> *Horekau koe e riro i te whakaae mā te pepa anake, ēngari mā te roanga ō te wā e whakaritetahi ana koutou ko te iwi, ka whiwhi i tēnei. Moe*

The impact of gaining consent from Māori collectives through meaningful engagement has flow on effects for the research project such as improved co-operation and opportunities for future collaboration.

> *Whakawhanaungatanga, he maha ngā hua me ngā tikanga hoki mō tēnei āhuatanga. Ara, te hononga, te kōrero whakapai me te kōrero i kahore i whakapai. Ka noho te whānau ki te kōrerotahi kanohi ki te kanohi kia pai te haere, ara, kia whakatau i te wairua ō te kaupapa katoa, a wairua, a tinana, a hinengaro, a whānau hoki mō te rangahau. Shane*

A relationship built on mutual trust and respect allows whānau and researchers to communicate effectively and negotiate the appropriate level and extent of participation.

Privacy and confidentiality: Kōrero muna[34], ka noho tapu ngā kōrero[35]

Issues of confidentiality and privacy, particularly in terms of health information, are governed by a number of statutes. There is also an ethical imperative that supports the notion that information should remain confidential on the grounds of participant safety. However, this approach facilitates the ability of the researcher to claim ownership over the intellectual property of the research. Of all of the ethical principles, privacy and confidentiality were the least consistent with the views of Māori members.

> *Ko tētahi mea e rarua nei ngā Māori ko te tikanga ō te muna, me noho muna ngā kōrero. Kaore te Māori i tino whakaae ki tēnā. Ka pīrangi mātou ki te kite nō wai te kōrero. Kaua e huna atu. Kura*

While there was recognition that privacy and confidentiality were appropriate in some situations to safeguard any harmful effects from disclosure of information, the level of confidentiality could be negotiated with communities and participants in most circumstances. This may simply involve participants consenting to be named as part of the study and giving them the opportunity to remove or de-identify particular comments from the final report.

Concepts of privacy and confidentiality are altered when the individualised notion of autonomy is removed. Information is shared to provide support and increase the transparency and accountability between members of the community.

> *There is not enough understanding of how the concept of privacy relates to Māori. If you do research at a hui with everyone putting their information out there, nothing is private; historically people knew what was going on. That's how you kept everything*

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[34] To speak privately
[35] To be under restriction

together, and ensured that support was available and that we resourced each other. People would go away with their basket fuller than when they arrived. This was a way of sharing information and resources, a form of manaaki. We would put information on the table, address it and move on. An example of how privacy can hinder action is that in reviews of deaths of women and children, organizations have had the relevant information but haven't shared it, so inevitably those women & children are still at risk. Helene

For Māori, the mana of the speaker is also an important factor. This has particular relevance for qualitative studies as the reader is then able to determine the appropriateness of the participants as well as the researchers of the study. A process that allows participants to be named leads to greater transparency and increases the accountability of the researcher to the participants

> *For Māori it is important to know who said what, the mana of the speaker should be recognized. This happens to some extent when the researcher references other people's publications, however it may be appropriate for it to extend to the participants as well. Nicole*

Validity of research proposal: Ko te whakamana i te tono ō te rangahau[36], tika[37]

Research relevance is an integral part of Māori assessments of research validity. Research should be related to an existing community need and the outcomes should result in some tangible benefits to that community.

> *Is the research necessary in the first place? Will the research be good for Māori, not, is this good research on Māori. Helene*

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[36] To validate the research proposal
[37] To be right and just

I te mutunga ō te rā kia whai hua, kia whakatika i tētahi āhuatanga, tētahi raruraru e pā kino nei ki te iwi. Ki te Māori, ka whai mana ki runga i aua hua, ehara mā te whakaputanga ō ngā tuhinga noa. Kaua e haere pērā ana ki te kuri, ka kai, ka tiko, kātahi ka wehe. Kura

The validity of Māori research approaches, in particular kaupapa Māori research, should be supported within the process of ethical review. Kaupapa Māori research is designed to address Māori cultural preferences and has developed processes to ensure appropriate consultation strategies are implemented to address many of the ethical concerns that Māori have with research.

I kaha te komiti Māori ō te HRC ki te whakarereke i ngā criteria, i kaha ki te whakamana i ngā rangahau Māori i raro i te kaupapa ō te HRC kia rite anō te criteria Māori ki tā te criteria scientific nei. Moe

Minimisation of harm: Kia aroha ki te tangata[38], te aroha ki te whānau[39]

Minimisation of harm is usually framed in Western ethics in terms of safety of the research participants within the study processes. Māori members are also concerned about the harm that might eventuate from the study outcomes.

The harm often comes not during the research but after it finishes, in the way the results are used. Jane

Māori have been the subject of a significant amount of research however in many cases this has not translated to positive outcomes for communities. According to some participants this is 'over-researching' and is a source of frustration to Māori, as Māori communities continue to live with inequitable health outcomes. There was also some concern expressed in relation to research that gathered baseline data or was descriptive in nature but did not lead to interventions to address the health issue.

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[38] To have regard for people
[39] To have regard for families

Participants indicated that risk aversion, as opposed to minimisation of harm has often tended to be the focus for ethics committees. For example, ethics committees may be more concerned with sighting a letter of Māori support, which protects institutional liability rather than checking the appropriateness of the consultation process that safeguards the Māori community.

> *Ko te nuinga ō ngā komiti ka aro ki te 'risk aversion' mō te hapori rather than the 'minimisation of harm' mō te tangata. Horekau ngā hapori i pīrangi ki te rongo ki tētahi e whakahē ana i a rātou mahi. Ēngari, kei roto i te hui Māori ka rangona te pai me te kino, a tae noa ake te wā ka tau te take. I roto i te 'risk aversion' kaore i tau te take, i tārewa kē. Moe*

Discussion of possible harm and negotiation of management strategies should occur between researchers and Māori communities as part of the consultation process.

> *Ko te tikanga Pākehā ka kaha rawa atu te whakaritenga mō te rangahau kia ngāwari te haere. Ēngari, ki tō te Māori ehara mā te whakaritenga noa iho me aroha ki te tangata. Me whiriwhiritahi te kairangahau rāua ko te tangata ō roto i te rangahau i ngā pātai me ngā tukanga ki te whakatinana i te rangahau, kei tū te kairangahau i runga i tona ake whakaritenga, kei hāunga noa atu ngā whakaritenga ō te tangata ō roto i te rangahau. Kura*

Justice: Whai utu[40], kia tika[41], kia pono[42]

According to respondents, justice as an ethical principle, is rarely applied within ethical review in a way that represents Māori concerns. The principle of justice is fundamental to the Treaty of Waitangi and addressing the inequalities in health that exist between Māori and non-Māori in New Zealand.

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[40] To act with reciprocity
[41] To be just
[42] To be true

The concept of justice has been constructed in a different way in recent times in terms of radical or Māori rights issues. We want justice now and it is related to our rights as people, under the Treaty. Kay

Concerns about the justness of a research proposal can be addressed by engagement with Māori communities to align the research project with issues that concern them.

He pai ake te pātata atu, te piri atu kia whai hua tahi ai, ko te whānau me te kai rangahau. Kei takahia te mana ō te whānau e ngā tukanga rangahau ō te whare wānanga. Kura

Cultural and social responsibility

While cultural and social responsibility are bracketed together as a principle within ethical review processes, the participants considered that being socially responsible was quite different to being culturally responsible. Part of being socially responsible is recognising that differences exist within society and accepting that all groups have an equal place in society. The expression of social responsibility also related to addressing inequalities within the community and ensuring that communities were properly informed.

The disparities in education, health etc mean often participants have no idea of what they have engaged in. In this light we neglect our social responsibilities. Helene

Ensuring that the research project has relevance to the Māori community also demonstrates social responsibility.

Mā tēnei rangahau ka aha? Ka tiaki te oranga ō te iwi Māori e ngā hua ō te rangahau nei. Mena ka puta ngā hua ki ngā uri kei te heke mai, he rawe tēnei. Shane

Cultural responsibility implies that the researcher has an understanding of a particular culture and can modify his/her behaviour to accommodate the particular cultural preferences in a respectful manner. As an individual's background and values are likely to significantly

influence their notions of cultural and social responsibility, there is a wide range of inter-cultural and intra-cultural differences. Addressing Treaty of Waitangi issues within research acknowledges Māori difference as a priority.

> *Mā te Tiriti e whakawātea mai kia ae ki te Māori. Koinei te tino nui ō te Tiriti. Moe*

Compensation: Kia whai koha[43]

Compensation recognises the contribution of the participants to the research project. While Māori members expressed concerns that some Māori participants are easily influenced by offers of compensation generally it caused few concerns. Māori notions of koha, which are similar to the concept of compensation, have broader parameters and can be shown by how respectful the researcher is of Māori protocols.

> *He koha anō te mihimihi, te pōwhiri, kaore e whai tēnei koha ā putea anake. Ko te tino taonga te kaupapa ō te rangahau, me tiaki i te putanga ō te rangahau, te tiaki i te mauri ō tērā kaupapa. Shane*

Koha also demonstrates the respect that the researcher has for their relationship with the Māori community. It is not necessarily monetary and is also reflected by other benefits that are realised within that community. Returning to the community at the end of the study and sharing the results in an easily understandable format is one way of acknowledging the participants contributions. Maintaining contact after the research finishes indicates that the researcher has regard for the community at a personal level.

> *Ae me whai koha, a muri i te koha me hoki te kairangahau kia whakamahana ai te whanaungatanga i waenganui i a rāua tahi. Kura*

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[43] To give respect, regard or a gift

Enhancing the responsiveness of the system of ethical review

Participants had a number of suggestions for improving the responsiveness of the current system of ethical review in New Zealand to Māori. The need for more Māori representation on ethics committees was expressed.

> *More Māori members would be a good start. Nicole*

Training for all members of ethics committees was another suggestion. Basic level training in ethics would provide a consistent foundation of understanding for ethical review. The Treaty of Waitangi was also identified as a necessary training component for all members of ethics committees.

> *Every member should do a Treaty of Waitangi workshop. The Ministry of Health should fund basic ethics qualifications or training. What is required is a bit of ethical professionalism. This might involve funding of Māori issues like a hui for Māori members. Jane*

Participants also identified the need for training for Māori members in Māori ethics. Māori members may not have a strong background in Te Ao Māori despite being expected to represent Māori views on the committee.

> *Ahakoa kua tū mai he Māori ki runga i ngā komiti whakahaere, ko te nuinga he iti noa iho te wāhanga e pā mai ana ki te Ao Māori, he iti kua mana ki tā te Māori titiro. Moe*

A Māori ethical framework

Participants also expressed a need for a separate system of Māori ethical review or a Māori ethical framework to ensure that Māori values were properly considered.

> *Essentially we need to review the whole ethical review process so that it will better reflect a bicultural approach. Ideally, a form of separate Māori review prior to an ethical review that also has Māori members. Nicole*

If we can't have a separate system then at the very least a Māori centred framework should be developed and applied by existing members. Kay

The idea of a distinct Māori ethical framework was strongly supported by the participants. However, there was a cautionary note.

My view is that having a Māori framework will result in a separatist position, creating them and us and allowing Pākehā to abdicate responsibility for learning about Māori views. Alternatively we could try to make sure that Māori values and issues become a core part of general ethical review. Jane

Participants suggested a range of key elements that would contribute to the development of a Māori ethical framework. The primary feature was that it should be developed by Māori.

Heoi anō, me kawe atu te take ki te iwi, kātahi ka whakahokia mai ki te whare wānanga. Mena ehara te hanganga i te hanganga Māori ka raru. Kura

It was recognised that a Māori ethical framework would be based on applying tikanga Māori in the context of research ethics. A Māori ethical framework should be consistent with Māori values and processes.

It would articulate general communal Māori values. You could describe them or you could describe the process to ensure they are given due consideration or most likely both. At the extreme end you might say every research project must have Māori reference group as well as a Māori review. Alternatively you might describe the process, every project that includes Māori as participants must have Māori analysis, Māori involvement in design, execution and inclusion of Māori research members. Kay

Me hapai nei ngā uara o te iwi, ngā tumanako, te pono, te aroha, te mana, te mauri, te ihi, te wehi, ka puta te ora o ngā mano o to tātou tīpuna Māori. Shane

It was also suggested that a Māori ethical framework could apply to all research.

> *Me arotake i ngā rangahau katoa, Māori mai, Pākehā mai. Ko te tino kaupapa kia whiwhi te iwi Māori i ngā hua o te rangahau. Shane*

Whanaungatanga and aroha were suggested as principles to encourage more participatory approaches to research to ensure that the community was included in the research process from its inception.

> *Aroha, a more participatory approach with the community under research, it should be less clinical and removed from the participants. Whānau benefits aren't often considered as the proposals are written in an individualistic mode. Nicole*

> *Ko te whānaungatanga he tikanga Māori hei urutomo ki roto i ngā arotake matatika. Me haere te komiti ki te kite a kanohi i te kaupapa o te rangahau. Kei kore te kaupapa o te rangahau e whai hua. Kura*

The usefulness of Tikanga Māori and Mātauranga Māori

Māori, like all cultures, have a diverse range of realities and experiences that contribute to their ideas and views. There was recognition that understanding te reo Māori and tikanga Māori gave a person a different outlook on the world.

> *Anei toku ake tū i tēnei ao, ko toku ao he ao Māori. Horekau he mea Pākehā, he mea Māori, ahakoa he aha te mea. Me kī ko te rorohiko he mea Māori i te mea he Māori toku titiro. Moe*

Participants were adept at framing ethical issues and responses in Māori terms. That is, using Māori concepts and historical or philosophical references to describe the ethical issue. This demonstrated the integration of the ethical issue within a Māori worldview and provided culturally based explanations that are likely to be better understood by the Māori community.

Kaua e huna atu, me mōhio ko wai te kai kōrero, kei mea mai tētahi nō Tangaroa whakapiri noa iho aua kōrero. Kura

He mauri ki roto i te kaupapa, nō koro ma, nō kuia ma, tērā mauri. Shane

While tikanga Māori had been acknowledged within ethical review its validity has not been recognised to the same extent as Western ethical concepts.

Horekau anō, ahakoa ka whakaurungia atu ngā tikanga Māori ki roto i ngā arotake ō te kaupapa nei ka whakaitingia tona mana. Moe

Participants were strong advocates for increasing recognition and awareness of mātauranga Māori by both Māori researchers and Māori members of ethics committees. Mātauranga Māori is the way of making sense of reality. It provides the primary foundation of explanatory reasoning, which other ideas and concepts are either excluded, integrated or incorporated. Mātauranga Māori and tikanga Māori provide the philosophical framework for Māori ethical positions that integrate with all aspects of Māori reality and are not merely confined to research ethics. Pākehā knowledge constructs reality in a different form, consistent with their own values and beliefs.

Ko tā te mātauranga Māori e whakatau i te Ao Māori. Ko tā te mātauranga Pākehā e whakatau i te Ao Pākehā. Tuarua, e tiaki ana i ngā mea katoa, to tū tangata, to Ao taiao, ao hurihuri, ao wairua, ao ātea. Mena ka whakamana au i a koe, ka whakamana au i ō tupuna, i ō awa, i ō maunga, i ō mauri, ērā āhuatanga katoa. Moe

However, Western thought and contemporary development are increasingly influencing Māori perspectives.

Ko te mātauranga he mea kia tika ai to tātou tū ki roto i tēnei ao. Kia whakaae i tēnei mātauranga, i tēnā mātauranga, me mohio i anga kē mai i hea. Ko te nuinga o ngā mātauranga i anga mai i te ao Pākehā. Moe

Academic constructions of mātauranga Māori and tikanga Māori have often been interpreted within Western frameworks and differ from the understanding of the Māori community.

> *He rerekē i te tirohanga ō te hunga mātauranga ki tō te iwi. Mena kua whakangungu a ia ki ro kura noa iho, ka whakamārama taua hunga i ngā tikanga Māori ki tā te tirohanga ā te Pākehā. He kama kē atu rātou ki te tukuna ngā whakaaro e Māori nei, ahakoa kua weherua ērā whakaaro i ngā whakaaro ā ngā iwi kainga. Kura*

It is important that researchers do not reinterpret Māori views into academic jargon that is unrecognisable to the people who initially provided the data.

> *Ka ako hoki ngā kairangahau kei raro i te Pākehā paradigm no reira ka haere te kairangahau ki tona kaumatua, ka hoatu te kaumatua i ana kōrero e Māori nei engari kei te whakarongo te kairangahau me te whakapākehā anō i ngā kōrero. Ka mahi te kairangahau i ana mahi, ka whakahokia ngā kōrero ki te kaumatua, kaore te kaumatua e mohio ki te kōrero ahakoa nōna i te tuatahi. Moe*

Developing the skills of an expert within mātauranga Māori requires the same type of skills relevant to ethical deliberation. Discussion is needed to ensure that Māori ethical positions are congruent with tikanga Māori and mātauranga Māori.

> *Mehemea ātanoho ki te wānanga, kei reira tonu ngā whakautu. Ki au ko te tohungatanga he tangata mōhio, ka whiriwhiri ki runga i te māramatanga, ka taea te tātari i ngā kōrero, ka mōhio te noho wahangū, e mōhio ki te inoi ki te ao wairua mō tētahi māramatanga, e mōhio ki te ātanoho ki te whiriwhiri kōrero. He take tino nui, i roto i tēnei āhuatanga ka pupū ake te whakaaetanga ki te tikanga, ki te kawa. Moe*

Māori researchers need to look to mātauranga Māori and validate this knowledge system as a cornerstone of te Ao Māori.

> *Kua mataku kē tātou te Māori ki te ao o te tohunga meinga kōrero mai ngā Pākehā, ngā Māori, ngā ture rānei. Ēngari nā rātou te wānanga, me taku whakapae me taku*

whakaae he tohunga kei waenganui i a tātou i ēnei rā. Kua riro ngā whakaaro kia PhD rā anō tātou kātahi ka tohunga. Me maumahara ake ki te mau ake ki te mātauranga Māori. Moe

Researchers need to improve the level of accountability back to Māori communities as research is often just a component of a wider kaupapa (purpose) and it is important that researchers ensure that the research project meets the community aims.

Anei te pātai ki ngā kairangahau, i rapu haere i ngā pūtaketanga ō ngā kaupapa, e pēhea ana ā koutou whakahoki i te kaupapa kia noho tika ai ki runga i tona ora? I te mutunga ō te rangahau me hoki atu anō ki ngā tāngata kia whakahokia te kaupapa me tona mana ki te ora. Moe

In this sense, Māori community support is conditional and constantly re-evaluating the integrity of the researcher and the usefulness of the research against wider community goals.

Ina whakahaere a Māori nei ka haere to rangahau i runga i taku whakapae, ehara i te tautoko, kia mutu noa kātahi ka arotake, e pehea ra te rangahau a te kairangahau. E tika ana āna kōrero i roto i te rangahau, kaore rānei. Moe

Consultation with Māori

As members of ethics committees, the participants of this study were uniquely placed to see the range of research projects that are being undertaken and comment on whether health sector research resources are being allocated towards Māori health and development issues in an equitable manner. The utility of any particular research project to contribute towards Māori health and development will be dependent to some extent on how the research question is framed and developed. The main criticism was that most research failed to engage with Māori communities and frame research questions around their needs.

We need to have appropriate research done on Māori, this means getting involved with setting the research agenda, and challenging how researchers are doing research that

impacts on Māori or why they are choosing topics that don't reflect Māori issues. Nicole

Māori members of ethics committees saw the process of consulting with Māori in the development of research projects as a significant activity. Consultation with Māori communities was intended to create the opportunity for dialogue between Māori and researchers so that research projects could be focused on areas that would be of direct relevance to Māori and carried out in a way that would optimise the benefits for Māori.

Mena ka haere te kairangahau ki te kōrero ki te iwi, ki te hapū, ki te whānau hoki, mā te kōrero e hāpai i ngā tikanga ō te whakawhanaungatanga. He maha ngā hua ka puta. Shane

The importance of appropriate consultation was expressed with preference given to consultation with people who were representatives of relevant Māori groups.

Around consultation - who has been consulted? Are they an individual or a representative of a group? Nicole

Māori research review committees contribute to this process however in some respects they hinder the development of relationships between researchers and Māori communities by providing a Māori consultative structure removed from the participant community.

It has started to address this through Māori research review committees to get more meaningful consultation. However this is still an external process aimed at improving Māori responsiveness. Nicole

The process of consultation should allow enough time and discussion to address any possible ethical issues for the researcher and the Māori community at a strategic level and an operational level prior to ethical review. This process of consultation should be reflected in the letter of support not indicated by it. Effective consultation with Māori is therefore dependent on researchers, ethics committees and Māori recognising the importance of this process.

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If Māori are always approached as the last part of the process it will never address Māori concerns adequately. Jane

Perceived barriers to effective consultation include;

- consultation is seen by researchers as an imposed process,
- researchers lack Māori networks,
- researchers are unsure who it is appropriate to consult with,
- consultation impacts on research timeframes and funding deadlines
- equity issues are not considered to be the responsibility of researchers
- minimal standards of consultation required by ethics committees, and
- equity issues aren't the responsibility of ethics committees

Often researchers don't want to deal with the perceived hassle of Māori consultation. Jane

Despite these perceptions, the process of consultation is actually undertaken by researchers on a regular basis. For any proposed research project there will be a period of discussion where the researcher talks informally and formally to colleagues, supervisors, funders and providers to develop some form of consensus as to the nature and purpose of the research project. This process can be likened to gaining the collective consent of interested parties to the research project. If Māori were included as part of this early development process then consultation with Māori can also positively inform the project. Initially, consultation with Māori may be a more formal proposition however as time and the relationship develops it is likely to become less formal and more collegial.

During this process a number of other principles are addressed (privacy, confidentiality, minimisation of harm, respect). A natural reflection of this process is the reciprocity that flows from the relationship that develops. Jane

The approach of many researchers and ethics committees to consultation with Māori is as a check off process to meet the requirements for ethical approval. Ethics committee should be clear about what counts as appropriate Māori consultation and whether researchers need to

improve upon the level of consultation undertaken prior to granting ethical approval for the study. This may also involve taking the position that protocols will not be reviewed until the Māori consultation process has been undertaken and Māori support is provided in writing. The rationale for this position is that evidence of prior Māori consultation is necessary to ensure that any Māori concerns have been made explicit.

> *Māori should be involved throughout right from study design. Current members need to be up front about retrospective submission of Māori consultation. Māori consultation should be viewed as an integral part of the whole application however in the current operations is seems that Question 14 [Question regarding the Treaty of Waitangi] is not viewed to be as important as other sections. Jane*

Summary

The interviews yielded a wealth of information reflecting the participant's knowledge and experience within the system of ethical review in New Zealand. According to participants there is much scope for improving the responsiveness to Māori of ethical review in New Zealand. They identified significant differences in the way that Māori interpret ethical principles, and, that there are a number of ethical issues of concern for Māori that are not adequately assessed by the current processes of ethical review. The participants also suggested a number of mechanisms, ranging from the development of a Māori ethical framework to improving consultation processes, to improve the responsiveness of ethical review to Māori.

Chapter 11: Discussion

Introduction

The research questions for this study asked whether the system of ethical review in New Zealand was responsive to Māori and how tikanga Māori might inform Māori research ethics. It was evident from the responses of the participants that the system of ethical review could be more responsive to Māori. The primary concern of Māori members of ethics committees, who participated in this research study, was that the system of ethical review in New Zealand is based on Western models of research and ethics and does not effectively incorporate Māori ethical concepts. Participants also indicated that tikanga Māori can inform Māori ethical positions however their application within the context of research needs to be clarified.

This chapter in addressing the research questions explores the marginalisation of Māori values within ethical review. It examines the issues of importance to Māori, which are generally excluded from ethical review, and discusses the mechanisms through which Western values are maintained. The need to broaden the parameters to ethical review, to include Māori ethical issues and researcher ethics is considered

Māori responsiveness in ethical review

Ethical issues for Māori have always been closely linked with Māori development and the advancement of Māori aspirations. For Māori, the ethical evaluation of research occurs within a Māori development framework. The implication is that links between ethical review and the goals of Māori society are more strongly emphasised by Māori as research provides a mechanism to identify and address inequalities in health.

Māori involvement in ethical review is underpinned by the Treaty of Waitangi, which has provided one source of justification for the inclusion of Māori members on ethics committees and the expansion of current ethical principles to incorporate Maori ethical issues. However the extent to which Māori values are taken into account has been restricted by maintaining the minority position of Māori within this forum. Two Māori members in a committee of 12 is the

current acceptable ratio and Māori values and Māori ethics continue to be pushed to the periphery. The integrative tendencies of the dominant culture not only marginalise Māori values but also inform the policies and processes that entrench those positions within the structures of ethical review. Consultation processes designed to increase Māori input into research design and usefulness have also been marginalised by the lack of rigour shown in evaluating this aspect of the research proposal.

The Treaty principles of partnership, participation and protection are of particular relevance to ethical review of health research and underpin Māori claims for increased involvement in the ethical review process. The Treaty of Waitangi is a unique document in that it enshrines indigenous rights as part of the New Zealand's constitution[44]. Within the health sector the relevance of the Treaty is widely acknowledged in key documents. Application of the Treaty has been problematic, and there continues to be dispute as to its significance to contemporary structures. In particular, the current interpretations of the Treaty principles of partnership, participation and protection are limited in the context of health research and do not encompass the ethical issues identified in this chapter as important to Māori.

The latest re-organisation of the system of ethical review in New Zealand is likely to further restrict Māori input into the processes of ethical review, both on the committees and through research consultation. The decrease in the number of committees reduces the amount of Māori representation and in most cases alienates local iwi representation as each committees region now crosses multiple iwi and waka boundaries. Local consultation becomes the responsibility of the host research organisations yet few of them have established structures that recognise mana whenua groupings. The lack of monitoring in this area means that it may be subject to abuse and inhibit local Māori community involvement in research conducted within their boundaries. Of course, the utilisation of universal ethical principles supports the view that only one ethical review is necessary and this should be consistent and reliable regardless of which ethics committee is responsible for the evaluation. However, the Māori members of ethics committees have made it very clear that Māori communities should be represented and Māori values should be incorporated within ethical review in New Zealand. Māori members also

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[44] The Treaty of Waitangi is not a written constitution but within constitutional law it is one of the core documents.

expressed the need to increase the Māori membership on ethics committees to ensure that Māori views can be safely articulated and included within ethical deliberations.

This research indicates that Māori values are marginalised within ethical review in two distinct ways by;

- the objectification of Western values into value-neutral ethics, and
- excluding ethical issues of concern to Māori.

Western domination of knowledge validation

Ethical review has developed as a mechanism to facilitate the research process and the production of knowledge. It is part of a coherent system based on legitimating the Western tradition of inquiry and reinforcing Western assumptions about the nature of reality (ontology) and the nature of knowledge (epistemology). Over the last 150 years Māori have been encouraged to participate within Western systems of education and actively discouraged from engaging with traditional Māori structures. Despite increasing acknowledgement of the Treaty of Waitangi and Māori rights to fully participate within the structures of society, Māori expertise and Māori knowledge have not yet been recognised as having the same validity and legitimacy as Western knowledge. Māori knowledge has been integrated but only into the margins of society. This also describes the situation of ethical review in New Zealand where Māori values are acknowledged but not considered to have equal weight within ethical deliberations. As one participant stated,

> *Kaore anō kia tino mana te Māori expert, korekau anō hoki te mātauranga Māori motuhake kia mana kia orite ki te mātauranga Pākehā.*

Figure 1. The integration of Māori values into the margins of society

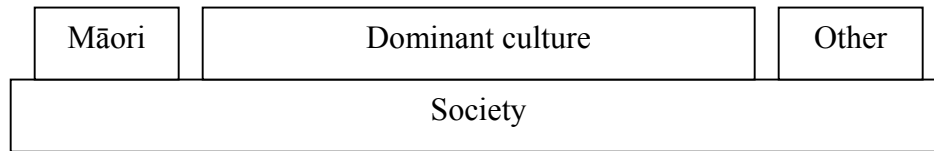| Māori	Dominant culture	Other
Society		

Figure 1 provides a visual representation of how Māori values are permitted to exist within the margins of New Zealand society, tolerated yet not fully accepted. The exclusion of the minority results from failing to resolve conflict that arises when the dominant party to the relationship has different core cultural values.

> *Such exclusion limits the potential of the minority, and undermines their dignity and worth. As such it is unethical. (Anderson, Griew et al. 2003) pg 26*

Māori members expressed the need to incorporate Māori values and knowledge into a central position within ethical review in New Zealand to increase the level of Māori involvement and control over the review of research protocols.

Dominant values

Values underpin what we perceive, believe and do and they also inform decision-making processes of which ethical deliberation is a part. How people view the world is informed by their personal values and experiences and these are affected by cultural, social and professional influences. Globalisation and increasingly multi-ethnic societies have resulted in a vast milieu of values that individuals may choose to adopt. However, choice is influenced by the propagation of dominant culture values through the social, education, legal, political and economic structures of society, which in turn informs the development of culturally congruent professional values. The vast majority adopt as personal values, those that are constantly reinforced within society and consistent with the dominant culture. This provides a mechanism for justifying individual positioning and reinforcing dominant perspectives that exist only as one possibility within the range of worldviews. Māori, in a position where the values of their profession are inconsistent with their cultural values, either find ways of reconciling the difference or develop a sympatric understanding that each set of values can co-exist in their own space. The importance of exposing the values that underpin positions or arguments

through critical analysis is that it challenges the dominant positioning of Western values. This is especially relevant for Māori as it is possible for them to contribute to the continued marginalisation of Māori cultural values by adopting those of the dominant culture. This is what theorists have termed 'hegemony' or false consciousness.

Figure 2. Reinforcement of Western value systems within Society

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                    ┌─────────────────────────────┐
                    │   Core Professional Values  │
          ┌─────────┼─────────────────────────────┼──────────┐
          │ Māori   │  Dominant Cultural Values   │  Other   │
          │ Values  │                             │          │
      ┌───┴─────────┴─────────────────────────────┴──────────┴───┐
      │              Range of Societal Values                     │
      └───────────────────────────────────────────────────────────┘
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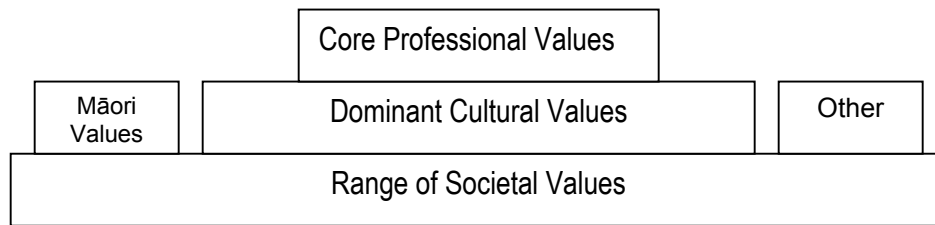
Figure 2 illustrates the marginalisation of Māori values and the congruence of various sets of Western values that serve to strengthen the dominant Western position. Some of the Māori members indicated that it was important to know whose knowledge or values were informing a 'Māori' position.

> *Ko te mātauranga he mea kia tika ai to tātou tū ki roto i tēnei ao. Kia whakaae i tēnei mātauranga, i tēnā mātauranga, me mohio i anga kē mai i hea. Ko te nuinga o ngā mātauranga i anga mai i te ao Pākehā.*

'Māori' positions should ideally be informed and situated within a Māori worldview. From this viewpoint, everything in the world can be interpreted in a manner consistent with Māori values and beliefs. Māori, who have a lived experience of Māori culture, can move in and out of the dominant culture and apply a Māori lens to any situation. Māori whose background was more congruent with the dominant culture tended to view Māori values as relevant to the Māori world and were often unsure how to integrate Māori values in a meaningful way into situations outside of a Māori context.

Objectifying values

Values can be thought of as belonging to an individual or group. Values are subjectively experienced and valued by an individual or group that maintains those values in common. Acknowledging cultural diversity and cultural values is becoming more prevalent however there are limits to their inclusion. The maintenance of dominant cultural values within ethical review has been facilitated by the objectification of Western values into universal ethics. There are two key features to this pr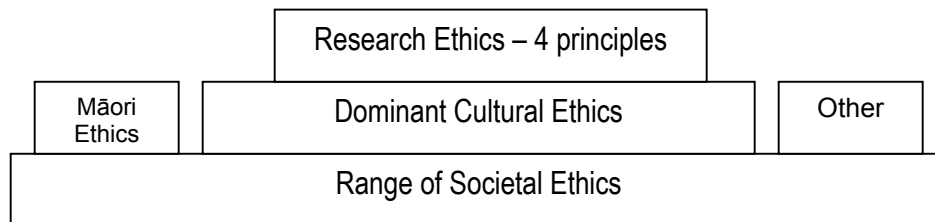ocess. First, the change in terminology from values to ethics. Seedhouse (1998) makes no distinction between 'ethics' and 'morality' (values) and uses the terms interchangeably. Ethics is derived from the Latin word 'ethos' and morality from the Greek word 'mores', however both apply to the concept of custom. This implies that they are either the same thing or different expressions of the same thing. Ethics, as a deliberation, is concerned with making value judgements, whether on the basis of perceived duties (deontology), perceived consequences (utilitarianism) or virtues. There seem to be two main reasons for separating the terms values and ethics.

First, it is inherently difficult to justify forcing personal values on to another individual particularly if you prescribe to the notion of autonomy and free will. However, the concept of ethics conjures up a more objective positioning with the personal ethic not belonging to oneself but externally mandated by a greater collective. As a collectively held set of principles, ethics can legitimately be imposed on others in a way that values can't, despite the subjective positioning of their underlying value base. It changes the perception of a review process from a value based judgement to a value-neutral one, obscuring the subjective position of the evaluator behind an objective façade and creating a hegemonic understanding about the neutrality of ethical concepts and the system of ethical review.

Second, the 'universal' ethical principles claim this objective positioning and contribute to the unilateral application of Western ethical constructs within the New Zealand system of ethical review. The four principles approach is claimed to "…encompass most if not all of the moral issues that arise in health care (and may) be seen to encompass all moral issues…" (Gillon 1994). However it has been criticised for lacking a theory or justification to support its moral conclusions (Seedhouse 1998). The simplicity of the framework allows various cultures to recognise elements of their own beliefs and integrate it within their own philosophies. This has

been perceived as cross cultural utility and acceptance of the principles of a Western interpretation of ethics. Despite the many limitations of the universal 'four principles' approach to ethics and the existence of various alternatives (Seedhouse 1998), it continues to be advanced as the dominant ethical framework. Figure 3 illustrates how dominant values systems (figure 2) are reinforced by objectification into ethical constructs.

Figure 3. The values/ethics switch

Research Ethics – 4 principles		
Māori Ethics	Dominant Cultural Ethics	Other
Range of Societal Ethics		

The participants in this study attributed the lack of responsiveness to Māori of ethical review in New Zealand to the adoption of Western values and ethics as its central component. The lack of consideration of tikanga Māori resulted in the exclusion of ethical issues of concern for Māori from the process of ethical review of health research.

Māori ethical issues

The Māori members of ethics committees highlighted a number of issues that they considered are relevant to ethical review in New Zealand but are not appropriately addressed in the existing ethical review processes. The issues identified by the participants that arise at the interface between tikanga Māori and Western research ethics and impact on the responsiveness of ethical review to Māori are;

- resource allocation,
- exclusion of Māori,
- alignment to Māori development goals,
- Māori research workforce development,
- respect for Māori cultural practices,
- incorporating Māori values,

- intellectual property, and
- developing mātauranga Māori.

Resource allocation

Research is an instrument of power; in that research provides the foundation for evidence-based practice, service planning and resource allocation. The Treaty of Waitangi and the wide ethnic inequalities in health provide compelling arguments for directing substantial research resources specifically to areas or questions relevant to Māori health. Māori members have a particular responsibility to evaluate how research projects might contribute to Māori development and a reduction in disparities. This is essentially an issue of justice as the existence of ethnic inequalities in health within New Zealand is unjust. As such, the ethic of justice encompasses resource allocation. The allocation of funding is a political act through the channelling of resources towards particular research interests. If research resources are not specifically allocated towards areas that contribute to Māori health then Māori will become further disadvantaged in an increasingly competitive research environment.

Exclusion of Māori

Research projects often exclude Māori as participants, often through the focus of the research, sometimes because of a perception that consultation with Māori is too difficult and many times because Māori participation has not been considered. These positions are unacceptable as they lead to further inequality within our society and contribute to increasing disparities in health. Government funded research is obliged to address the needs of all New Zealanders including Māori. It is therefore unethical to exclude Māori from involvement in the development of the research agenda as research will not benefit Māori in an equitable manner. This extends to the formation of research questions and the framing of the methodology for the research project.

Alignment to Māori development goals

One of the most significant and consistent messages from the participants was that research needed to be relevant to Māori needs and aspirations and this was a significant ethical issue in terms of addressing inequalities in health between Māori and non-Māori. This was best achieved by meaningful engagement with the Māori community. The ability of any particular

research project to contribute towards Māori health and development will be dependent to some extent on how the research question is framed and developed.

> *Whenever possible, health research on a health issue relevant to Māori should have clear benefits for Māori health. Such benefits need to be clearly articulated, and the research process must be designed to realise those benefits. (Sporle and Koea 2004) pg 2*

While the primary outcome of a research project may not have any direct relevance to Māori, the collection of ethnicity data may provide useful secondary outcomes that may be of benefit. This may require over-sampling the Māori population of the study so that statistically relevant data can be obtained to provide results that have equal explanatory power. Research has an important contribution to make to the achievement of broader Māori development goals. It is important that Māori continue to drive the research agenda to focus research into areas that will contribute to those goals. Many agencies have developed research plans in consultation with Māori, which identify priority areas that can act as a starting point for the development of research questions. Co-ordination in planning and inclusion of Māori in the process of research consultation and ethical review ensure that the research is aligned to Māori development goals.

Māori research workforce development

Increasing and strengthening the Māori health research workforce is one of the HRC's strategic goals. Māori health workforce development is an ethical issue as equitable representation of Māori at all levels of society is necessary for a fair and just society. Māori researchers bring cultural competencies alongside technical skills to work more effectively on Māori issues and link to Māori communities. There will however always be a role for non-Māori researchers in contributing to Māori health goals given that the full range of expertise and skill is required for quality research to address the breadth of Māori concerns. This can be argued as a Treaty responsibility or as an ethical responsibility to address the principles of justice and social responsibility. Even if a research project has no direct obvious relevance to Māori health priorities, developing Māori research capacity is one way that non-Māori researchers can assist the realisation of Māori development goals.

Respect for Māori cultural practices

Respect for persons is one of the principles of ethical review in New Zealand. Respect for Māori culture is one way in which respect for a Māori person can be demonstrated. The use of Māori protocols and simple courtesies, such as the correct pronunciation of names, helps to engender trust and respect from the participants and Māori communities. Tikanga best practice guidelines have been developed in a number of organisations such as the Auckland DHB and guidance is also available from Māori units associated with these organisations. These documents cover areas such as the handling and disposal of tissue and body fluids. The recently legislated Health Practitioners Competency Assurance Act 2004 requires health professionals to maintain certain levels of competence, including cultural competence. This does not require all researchers to become experts in aspects of Māori culture, but rather to recognise cultural difference and take into account Māori cultural preferences by seeking Māori cultural advice when working with Māori communities.

Incorporating Māori values

A step beyond respecting Māori cultural practices is the incorporation of Māori values into the research process. While it may be thought that this is only necessary for Māori centred research or Kaupapa Māori research, other research may also benefit from the consideration of Māori values. Māori values may compliment mainstream research values and be relevant to other population groups. For example, Māori processes require on-going relationships between researchers and participants to better ensure that researcher responsibilities are met. Incorporating Māori values into a research study acknowledges their ability to sit alongside other research values with mutually beneficial effects.

Intellectual property

The issue of intellectual property rights is central to research activity. Ownership of the research and subsequent rights to any commercial benefit from it usually reside with the researcher and the research institute. Participants are expected to be motivated by a social conscience to take part as their participation in the research project may benefit wider society and future generations. However, research institutes retain the right to commercialise the information derived from research studies and therefore receive direct benefits should a viable commercial project eventuate. Current laws and practices do not protect Māori intellectual

property as only "new" knowledge can be protected through patents. This is a significant issue for Māori. Māori have had particular concerns about the patenting of genes. Conceptually, Māori disagree that one person/company can legitimately own genetic information passed down through generations and shared by a wider grouping, just because they have described its function and given it a name. At a practical level, Māori realise that this type of activity will continue and in some cases Māori whānau are active supporters of genetic studies particularly when it is likely there will be a direct benefit to their health. The process of support is facilitated by arrangements for sharing intellectual property rights. This provides a mechanism for whānau to continue to share in the benefits of the research that are based on their genetic resource.

Developing mātauranga Māori

Mātauranga Māori is the intellectual property and knowledge accumulated by generations of Māori and includes both Māori philosophy and Māori knowledge. While Māori support drawing on the widest possible knowledge base to inform Māori health development, there is a clear view that mātauranga Māori is of particular value in addressing Māori issues. This is particularly relevant in the health sector where approaches to addressing Māori health based on Western frameworks have done little to address inequalities in health. The allocation of resources to research activity should include the further development of mātauranga Māori.

The Māori ethical issues identified above reflect the concerns expressed by the participants in this study. This does not imply that these are the only ethical issues for Māori, rather key issues that are not currently incorporated within ethical review.

Incorporating Māori ethical issues within ethical review

The four principles approach to medical ethics is presented as a universal framework and provides the basis for ethical review in New Zealand. Research ethics is becoming increasingly codified with an emphasis on the consistent application of ethical rules. This creates inflexibility and removes the evaluation of research from its context within individual communities. For Māori, ethical review cannot be removed from people's lives and existence within families, communities, cultures and society as this distances decision-making from the ecosystem of real life. Acknowledging that researchers, ethics committee members and

community members have personal, professional, and cultural values that influence their decision-making processes within research and ethical review would make the evaluation of research a more transparent process. These values inform the following sets of ethics, researcher ethics, research ethics, and he matatika (Māori ethical issues), all of which should be evaluated within ethical review in New Zealand.

Researcher's ethics

It has been suggested that ethics in research has two main components - research ethics and the researcher's ethics (i.e. the scientist's personal honesty)(Aagaard-Hansen, Vang Johansen et al. 2004). Issues relating to the researcher's ethics are not specifically discussed within the current system of ethical review. However, researcher's ethics may be demonstrated through appropriate consultation with Māori, and the use of collaborative or participatory research approaches. Māori researchers have given anecdotal accounts of situations where their names have been included under Māori consultation on ethics applications, for research studies that gained ethical approval, without their knowledge or consent. The honesty and integrity of a researcher must surely impact on whether they adhere to accepted standards of research ethics upon which they gained ethical approval.

Members of ethics committees have discussed the possibility of monitoring research to check that it has progressed ethically in accordance with their submission. The lack of a monitoring function means the after ethical approval has been given, the researcher and the institute have responsibility for monitoring the ethical soundness of the research. Kaupapa Māori research has developed guidelines for Māori Research Ethics that specifically address 'researcher's ethics' and behaviour in cultural terms. For Māori, the researcher's ethics are an integral part of the ethics of research, especially as Māori prefer collaborative approaches that include the community. Utilising collaborative research approaches makes the researcher responsible, not to a removed discipline (or institution) but rather to those studied. Consultation with Māori is a requirement of ethical review (Ministry of Health 2002). However, Māori expect a greater level of engagement and involvement in the research process. A high degree of personal integrity and commitment is required to meet the cultural and ethical expectations of Māori and addressing these expectations enhances researcher ethics.

Research ethics

The ethical review of research is strongly influenced by the requirements of the research profession. Research ethics are primarily concerned with the principles of informed consent, confidentiality and minimisation of harm, which along with the evaluation of the 'validity of research proposal' tend to represent the main focus of the evaluation. As individually mediated processes these concepts are easier to assess than the notions of justice and cultural and social responsibility, which must be considered from a community perspective. For ease of application it is therefore no surprise that principles oriented towards individual values have tended to become the primary focus of ethical review, while community oriented values like justice and cultural responsibility are sidelined.

The principles underpinning ethical review, as used in New Zealand can be separated into two categories. Principles that address issues of ethics and safety of the study for the participants (internal ethicality of the study) and those that relate to the ethics and safety of the study for the wider community (external ethicality of the study) (Table 7). The preferential application of internal or external ethicality factors relates to the value a culture places on the underlying principle of autonomy and beneficence. Māori members demonstrated that their interpretation of ethical principles was oriented towards beneficence rather than autonomy. This highlights the importance for Māori of external ethicality factors and the role of research in contributing to Māori development aims.

Table 7. Internal and external ethicality factors in research

Internal ethicality – Safety of research for participants	*External ethicality – Safety of research for communities*
Informed Consent	Justice
Confidentiality	Cultural responsibility
Research validity	Social responsibility
Respect for participants	Respect for communities
Minimise harm (to participants)	Minimise harm (to communities)
Compensation for participants	

Research ethics have traditionally focussed more on issues that relate to the internal ethicality of research in terms of participant safety and there is a wealth of information about the processes of informed consent and confidentiality designed to minimise harm to individual research participants. Internal ethicality can be demonstrated at an individual level by respecting the autonomy (freedom of choice) of each of the participants and giving due consideration their safety.

Issues related to internal ethicality are dealt with extremely well within the current system of ethical review. Issues of external ethicality such as justice and social and cultural responsibility are less clearly applied in the ethical review process. External ethicality principles relate to deeper societal values such as fairness and address areas of central significance to health such as inequalities. These principles are a significant motivator for Māori researchers and Māori members of ethics committees. The external ethicality of any study could then be assessed against its ability to address inequalities. Research that failed to consider Māori issues or was likely to increase inequalities would be considered unethical. Consideration of how a research study fits within a broader social agenda is not considered to fall within the realm of deliberation for ethics committees despite this having a bearing on the potential benefits and risks of the study. While this debate takes place within moral and ethical realms, the action or inaction for that matter is often more political in nature as it essentially involves decisions about resource allocation. The field of research ethics and the ethical review process has therefore focussed on the safety of the participants and generally gives less consideration to the impact of the research on inequalities within the wider community.

He matatika Māori: Māori research ethics

Continuing disparities in health indicate that traditional research has been largely ineffective in dealing with Māori issues. The Health Research Council of New Zealand recognises the importance of Māori ethical views and issues. As part of its Health Research Strategy to Improve Māori Health and Well-being it has included a goal that specifically aims to ensure Māori health research ethical issues are considered alongside other health research ethical issues (Health Research Council of New Zealand 2004). The principle of justice implies that inequalities should be addressed and that equal consideration be given to both Māori research methods and Māori ethical constructs. It substantiates Māori claims to exist in New Zealand

and participate within contemporary structures as Māori, not just as a person who is Māori. He matatika Māori or Māori research ethics should be considered as part of the ethical review process. Respect, control and accountability have been identified as recurring themes in the literature. This research identifies a range of Māori ethical issues that are not addressed within the system of ethical review, but are consistent with tikanga Māori and considered important by Māori. The interface of Western ethics and tikanga Maori in the context of research requires a framework where discussions about these two value sets can occur.

> *If effective ethical guidelines for research in Māori contexts are to be realised, Māori concepts of ethicality must be taken into account, a stronger obligation than social or cultural responsibility. (Durie 1998) pg 257*

He matatika Māori, mātauranga Māori and tikanga Māori

The ability of 'Tikanga' to inform ethical decision-making processes was recognised by the participants. He matatika Māori should be informed by tikanga Māori and mātauranga Māori. Tikanga Māori is underpinned by mātauranga Māori, Māori philosophy and knowledge. Tikanga Māori are the uniquely Māori values and ethics that in turn inform particular kawa[45], ethical positions or practices. Therefore, Māori ethical positions on contemporary research issues should be congruent with tikanga Māori and reinforce the philosophy of mātauranga Māori. A combination of Māori knowledge and Māori values will produce distinctly Māori ethical positions. If mātauranga Māori is overlaid with Western values or Māori values applied to Western philosophy, then quite different ethical outcomes could be expected. A Māori ethical framework should be constructed within Te Ao Māori[46] to be consistent with Māori understandings of the nature of reality (ontology), and the nature of knowledge (epistemology). A Māori ethical framework will need to be consistent with mātauranga Māori and tikanga Māori if it is to be accepted by the Māori community. For Māori any ethical decision has to be culturally processed and philosophically reconciled with tikanga Māori (Mead 2003). This also implies that to develop a Māori ethical position it will be necessary to have an understanding of mātauranga Māori and tikanga Māori.

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[45] Embodied by the concept 'te kawa o te marae' which signifies the specific protocols of traditional Māori communities
[46] Māori world view

The values embodied in tikanga Māori reflect the holistic and interconnected nature of Māori understandings of the world. The expression of particular tikanga will vary depending on the context. While tikanga Māori was not developed specifically for ethical review it can be interpreted in the context of ethical review. However, this relies upon cultural skill to ensure the appropriate application of tikanga Māori and that subsequent decisions are made with care and judgement. A participant stated this point,

> *Kei te ngaro haere te āhuatanga ō te ātanoho ki te whakarongo, ki te tātari kōrero, ki te whiriwhiri i ngā painga ō te hui…nā wai i ātanoho, i ātawhakarongo ki ngā kōrero kia rongo ai ki te ia o te kōrero, te wairua o te hui. Mā tēnā ka taea te whakatau kia tau te take.*

Extending the parameters of ethical review

Sympatricity is a term for the situation where at any moment there will be competition between numbers of mutually contradictory theories. The image is of sympatric theories that operate in parallel, at the same time competing and co-existing (Stainton Rogers 1991). Within sociology, sympatricity has been used to describe competing belief systems around medical and lay representations of health. In many ways, Māori members of ethics committees demonstrate an ethical sympatricity by concurrently taking into account concepts of tikanga Māori and Western ethics, despite areas of inconsistency between the two (from which arise Māori ethical issues). The context of the situation then determines which set of ethics takes priority for any given ethical deliberation. In the case of informed consent, Māori members may be asked to decide whether oral consent is appropriate for research within a particular community. Likewise confidentiality was seen by some participants to be inconsistent with tikanga Māori as sharing information could allow the community to support its members.

Ethical review has been criticised for a failure to see human beings as social creatures located in complex historical, political and cultural spaces. Current ethical review processes that only evaluate research ethics and not the researcher's ethics or he matatika Māori will always be considered insufficient from a Māori perspective. Each of these areas is important for Māori and their inclusion will result in a more robust and inclusive ethical evaluation that is capable of addressing all ethical issues for Māori. Tikanga Māori have evolved over time to address

the needs of the Māori community. However, while Māori have begun to apply tikanga within the structures of contemporary society and the area of research, a framework of Māori research ethics suitable for ethical review has yet to be developed.

A Māori ethical framework for research

There have been repeated calls for the development of a Māori ethical framework to inform the inclusion of Māori values within ethical review (Te Puni Kokiri 1994; Cram 2003). The participants in this study reiterated the need to develop a Māori ethical framework to ensure that health research is ethically sound for Māori. A Māori ethical framework would also support the work of Māori members of ethics committees, and provide more consistent guidance to researchers. The participant's responses indicated that Māori interpretations of Western ethical principles were framed with a beneficence focus to make them more consistent with a Māori worldview. There was a strong view in the literature and among participants that mātauranga Māori and tikanga Māori can be used to inform Māori ethical evaluations within a system of ethical review.

The participants identified that differences exist between Western interpretations of ethical principles and Māori interpretations. This is illustrated both by their explanations of how they apply the existing principles used in ethical review and the inconsistency between Western interpretations and Māori values. This study has highlighted a number of factors that would contribute to the development of such a framework. The most important factors to consider in the development of a Māori ethical framework are that;

- it must be developed by Māori and be consistent with Māori values and processes, and
- it should provide a clear link between tikanga Māori and contemporary ethical issues.

Māori have always acknowledged that despite the increasing Māori social and cultural diversity there are distinctive Māori ethical viewpoints that are shared by many Māori and are grounded within a Māori worldview. Ensuring the appropriate process for developing a Māori ethical framework will be vital to establishing its validity amongst the Māori community and those who will use it. The process should be controlled by Māori, who will decide the length and breadth of consultation required, to ensure that the framework meets the expectations of

the Māori community. The acceptance of Māori values by the structures governing ethical review and an active undertaking to institute the framework will also be important.

Tikanga within a Māori research ethical framework

A Māori research ethical framework would identify tikanga Māori appropriate for evaluating research and describe their relevance and application within ethical review. Table 8 brings together the values and ethics of tikanga Māori that have been identified as relevant to research ethics in the literature.

Table 8: Values-based and ethics-based tikanga

Values	Ethics
Io / Whakapapa	Whanaungatanga
Mauri	Manaakitanga
Tapu and Noa	Kaitiakitanga
Mana	Mana
Wairua / Hau	Wairuatanga
	Kotahitanga
	Take-utu-ea

The participants referred to many of these values-based and ethics-based tikanga during the interviews. Manaaki, mana, whanaungatanga, wairua, mauri, kaitiakitanga, tika, whakapapa, tapu, noa and kawa were all specifically mentioned in the context of ethical review and the participants also suggested other Māori principles that could be a part of a Māori ethical framework such as aroha[47], nohotahi[48], rangatiratanga[49], ōritenga[50], and mātiro whakamua[51].

A Māori research ethical framework would have to provide clear links between tikanga Māori and Maori ethical issues, in order to inform Māori specific ethical positions. In Table 9 below, examples of how ethical issues identified as important to Māori can be aligned with some of the Māori values and ethics listed in tikanga frameworks are provided. The table also demonstrates that there is a relationship between tikanga Māori and existing ethical principles.

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[47] compassion
[48] to sit together
[49] Māori authority
[50] equality
[51] to look ahead

Table 9: Tikanga framing Māori ethical issues

Ethical Issues for Māori	Intellectual property	Incorporating Māori values	Resource allocation
Values	Tapu / Noa	Wairua / Hau	Tika
Ethics	Kaitiakitanga	Wairuatanga	Take-utu-ea
Ethical Principles	Minimise harm	Social and Cultural Responsibility	Justice

The issue of intellectual property can be framed by tikanga like tapu[52] and kaitiakitanga[53]. Tapu recognises that restrictions are required to protect special information and that a person, whānau or group will need to be the kaitiaki or holder of that information. The purpose of such restrictions is to minimise the harm that may come to the community by protecting special categories of knowledge that are not intended for wider dissemination, such as information relating to whakapapa[54].

Incorporating Māori values is associated with recognition of hau[55] and wairuatanga[56], the unique spiritual essence of each person, object or kaupapa[57]. Acknowledging everyone's uniqueness could be considered an element of social and cultural responsibility.

Resource allocation aligns with the value of tika[58]. Given that everyone in New Zealand must share in the resources of this country it is only fair that they are distributed in a way that is fair and just. The ethical concept of 'take-utu-ea' assists in the identification and resolution of issues to ensure that there is a balance and equity amongst community members. The ethical principle of justice can be viewed in a similar manner.

The challenges

Developing a Māori ethical framework that considers Māori ethical issues in the context of research would be a major advance. A Māori ethical framework would provide a clear direction for the inclusion of the values and ethics of tikanga Māori in the ethical review

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[52] Protection
[53] Guardianship
[54] Genealogy
[55] Essence
[56] Spirituality
[57] Purpose
[58] Just(ice)

process and could be used to support both Māori and Pākehā alike in the ethical review of research.

Tikanga Māori are yet to be given meaning in the context of ethical review. That is, little has been written about tikanga Māori, its relationship to contemporary ethical issues for Māori and how they inform ethical review in research. To apply tikanga Māori to new situations requires a level of understanding about mātauranga Māori as well as an appreciation of the context of research. To date, there have been limited opportunities for Māori to engage in this discussion within contemporary ethical review structures.

There is however the risk that Māori ethics in ethical review will become secondary to research ethics or viewed as the Māori perspective on research ethics. Jackson noted that the use of the phrase 'a Māori perspective on' often leads to the belief that Māori views are secondary or marginal to mainstream or dominant views:

> *The word perspective to me is interesting. It assumes that there is something that is given upon which Māori are expected to have a valid view. The moment you do that you situate the Pākehā model as the truth; and you ask Māori to give a view on it. I think there are Māori truths and they exist independently of whatever Pākehā view as reality or truth and to seek a Māori perspective is to legitimate the Pākehā perspective on the issue. So to ask for a Māori perspective on say the use of land is to validate the Pākehā concepts of property and to seek to fit a Māori view of that within it. Whereas what we should begin with is: What is the Māori truth on land and how does that sit alongside, rather than fit within, the Pākehā view? Moana Jackson quoted in (Cram 2002; Cram 2003) pg 82*

This was reiterated by one of the participants, who expressed concern that a Māori ethical framework might itself be marginalised and result in further inequalities for Māori. The process of integration tends to maintain the status quo and only allow cultural groups effective control of their autonomous cultural determinations at the social margins (Goldberg 1993). The utility of any Māori ethical framework will be determined to some extent by the ability of both Māori and Pākehā to understand the concepts and to apply them to the range of research

methodologies, not just kaupapa Māori research. While a Māori ethical framework would be of primary use to research within a Māori inquiry paradigm, it could equally evaluate the ethical aspects of any research protocol, as all New Zealand research is in some way relevant to Māori.

Contemporary Māori realities will have a significant impact on the acceptance of 'Māori' ethical positions. The extent of social and cultural diversity amongst Māori is greater than at any point in the past. Increasingly, Western thought influences Māori and these concepts are co-opted into Māori worldviews. Developing consensus around the 'Māori' applications of tikanga Māori in ethical review will be a challenge. Many contemporary issues, such as genetic modification, have a polarising effect on different parts of Māori communities. It is likely that there will be a diverse range of opinion amongst Māori as to what constitutes an appropriate Māori position. Over time, discussion and debate will shape the application of tikanga Māori to contemporary ethical issues. It has been suggested that to accommodate new technologies it may be necessary for Māori to change the belief and philosophical system (Mead 2003). Whether this is accepted as part of a normal cycle of development or as a challenge to the cultural integrity of Māori knowledge constructs will likely form part of these debates. Indeed, all ethical frameworks need to be sufficiently flexible to allow for the natural evolution of values within cultures and society.

Finally, a process of ethical review that includes an assessment of the ability of a research study to address inequalities in society is likely to have a significant impact on the development of research questions and the subsequent allocation of research resources. This would present a direct challenge to the intellectual independence of researchers and the academy to develop research in areas that could not demonstrate relevance to identified health inequalities within New Zealand. The Australian guidelines indicate,

> *As Indigenous Australians attempt to assert control over the processes of knowlege development they will, inevitably, at times confront the intellectual autonomy of researchers. Nevertheless, clearly articulating the Indigenous values that underlie such relationships gives researchers, both Aboriginal and non-Aboriginal, the*

possibility of developing a value based engagement through which such conflicts could

be resolved. (Anderson, Griew et al. 2003) pg 27

A Māori ethical review pathway

Participants in this study also expressed the possibility of a separate system of ethical review for Māori. The adoption of a model of ethical review that incorporates Māori ethics as a central part of the process or the development of a Māori ethical framework creates the opportunity for a specific pathway for Māori ethical review. It was suggested in 1994 by the Te Puni Kokiri review of the national system of ethical review that a national Māori ethics committee could be developed (Te Puni Kokiri 1994).

The lack of understanding of Māori paradigms, methods of inquiry and tikanga by ethics committees has been highlighted previously (Walsh-Tapiata 1998). The opportunity to gain ethical approval from a Māori committee may encourage researchers to base their research protocols within a Māori inquiry paradigm. The option of a Māori ethical pathway would be welcomed by Māori, and is supported by the principles of the Treaty of Waitangi. The rationale for the option of a parallel pathway is that a Māori ethical review process will assess research from a worldview suitable for the focus of the research. It would enable robust review of Māori specific research and be particularly concerned with the cultural appropriateness of the protocol and the broader interests of Māori. A dual pathway model of ethical review has been adopted in some universities in the USA to provide separate ethical assessments for biomedical research and social science research (Denzin 2004). The dual pathway model has been utilised under the new restructuring of the system of ethical review to allow for a single ethical review by either a regional ethics committee or the multi-centre ethics committee. Therefore, there are precedents.

Fig 4. Proposed system of ethical review in NZ
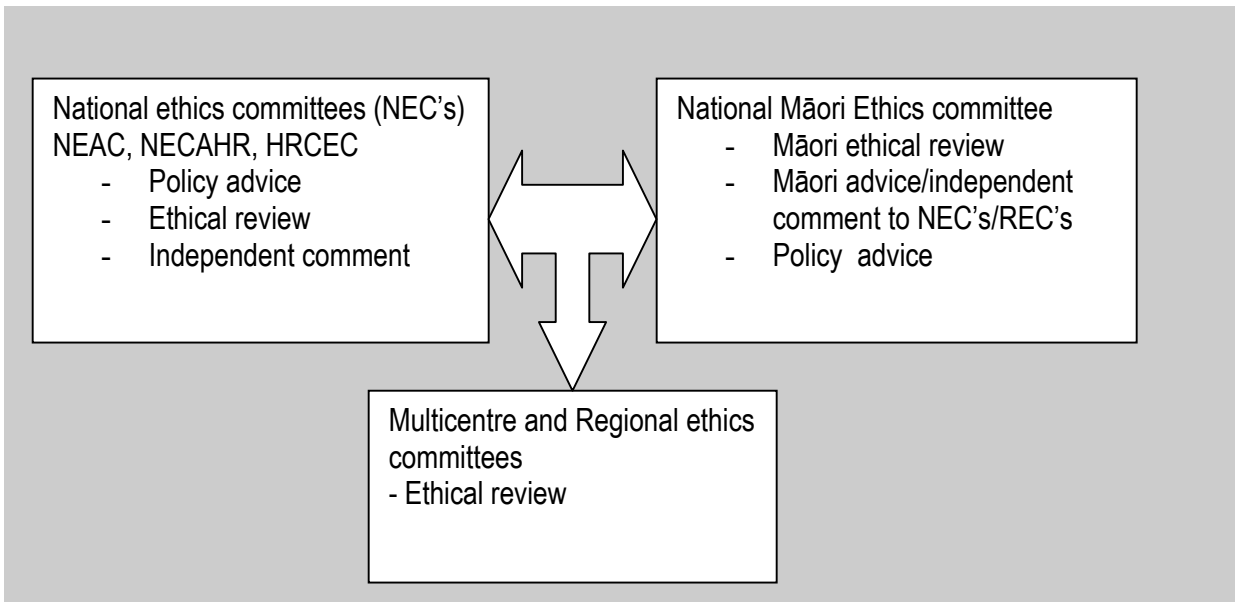
The development of a Māori ethical review pathway would involve the creation of a National Māori Ethics Committee (figure 4). This committee could have a number of functions. First, it could provide an option for researchers to have their protocols assessed by a Māori ethics committee. This would take the form of a parallel pathway and protocols could be assessed by the national Māori ethics committee rather than the Multicentre Ethics Committee or the Regional Ethics Committees, in keeping with the aim "…*that every research proposal has one ethical review by a single independent committee…*" (Minister of Health 2004).

The Māori ethical review pathway would necessarily follow best practice guidelines including the Operational Standard, though the Standard would require revision to incorporate Māori research ethics and researcher ethics. A National Māori Ethics Committee would have a greater depth of knowledge around, tikanga Māori, mātauranga Māori, their application in ethical review, and Māori research methodologies. The operation of the committee would likely follow Māori processes and be more responsive and culturally appropriate for Māori centred and kaupapa Māori research. Researchers could have the option of conducting their review in Te Reo Māori and the development of mātauranga Māori through research would be facilitated by the existence of a Māori ethics committee. Any researcher could choose to have

their protocol heard by this committee however it is likely to be used primarily by researchers operating under a Māori inquiry paradigm or with predominantly Māori participants.

Second, a National Māori Ethics Committee could be the Māori body that could provide advice and recommendations to all other ethics committees working in the health and disability sector. The National Ethics Committee on Assisted Human Reproduction (NECHAR) is currently going through a process of consulting Māori on pre-implantation genetic diagnosis and the establishment of a national Māori ethics committee could facilitate these types of consultation processes. The committee could also support the Ministry of Health's sector policy directorate on ethics and innovation to ensure policy developments were Treaty and Māori responsive.

Thirdly, it could provide Māori leadership in the area of ethics. A national Māori ethics committee would be responsible for the development of a Māori ethical framework and providing advice on its application, a responsibility currently tasked to NEAC. It could oversee the appointment processes of Māori members to all ethics committees in the health and disability sector and contribute to the development of orientation programmes for ethics committee members. A national Māori ethics committee could allow the Treaty principle of partnership to be demonstrated within the system of ethical review and provide a mechanism for enhanced Māori participation within research and the protection of Māori interests within this area.

Māori have criticised the recent changes to the system of ethical review in New Zealand as reducing Māori responsiveness. However, the development of a national Māori ethics committee to provide policy advice and independent comment to national ethics committees and create a Māori pathway for ethical review could be seen as a positive step to enhancing Māori involvement in ethical review and contributing to broader Māori development goals.

Chapter 12: Conclusion

A robust New Zealand system of ethical review has an important role in facilitating the responsiveness of research to Māori. The capacity of the ethical review system to address Māori responsiveness, the Treaty of Waitangi, and wide and increasing ethnic inequalities in health justify strong Māori involvement in ethical review at all levels. The current extent of Māori involvement is limited and Māori values are marginalised. The primary mechanisms utilised to improve responsiveness, Māori membership and research consultation, have had a limited effect on the inclusion of Māori values into the processes of ethical review or influencing the research agenda. The lack of formal support and training for members of ethics committees, particularly Māori members, was a major concern. Both researchers and ethics committees are complicit in allowing research consultation with Māori to become a superficial activity and largely ineffective in improving the relevance of research generally to Māori communities.

Western values have been recast in the form of universal ethics to maintain their dominant position in ethical review. To move beyond this situation, much work is required to ensure that Māori values are incorporated as central components of ethical review. This research has identified the limited scope of ethical review as problematic for Māori. Existing ethical principles are biased towards autonomy-based interpretations that encourage individually mediated principles rather than beneficence oriented interpretations, which would promote community-oriented principles. From a Māori perspective, the inclusion of Māori ethical issues in the process of ethical review would provide a more robust and transparent review process that would address Māori concerns and thereby facilitate responsiveness to Māori. A Māori ethical evaluation of the research proposal would thereby become part of the ethical review process. The process would more effectively assess the safety of the research for Māori individuals and Māori communities, as well as evaluate the capacity of the research to address ethnic inequalities.

A necessary step towards the incorporation of Māori values within ethical review will be the development of a Māori ethical framework. While this project has been tasked to the National Ethics Advisory Committee, it is vital that the development of a Māori ethical framework is

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controlled by Māori to ensure that the outcome is acceptable to the Māori community. The research findings suggest that it will be a value-based system that describes the expression of tikanga Māori within the context of ethical review. The tikanga based values and ethics included in this framework are likely overlap with those underpinning kaupapa Māori research and identified within existing tikanga frameworks. A number of ethical issues have been identified in this study that would need to be addressed within a Maori ethical framework. These issues are, resource allocation, intentional exclusion of Māori, alignment to Māori research goals, Māori research workforce development, respect for Māori cultural practices, incorporating Māori values, intellectual property, and developing Mātauranga Māori.

The utility of any Māori framework will be determined to some extent by the ability of both Māori and Pākehā to understand the concepts that it uses and to apply them to the range of research methodologies, not just Māori research. It will be important that opportunities are promoted for Māori participation in ethical debates and the publication of Māori positions alongside presentation at hui[59] and conferences will facilitate this debate. This will enhance the development and understanding of Māori "ethical" concepts, values and positions. The development of a Māori ethical framework as a central component of ethical review will provide the basis for a parallel Māori pathway which researchers could choose to use if appropriate for their research question, methodology or participant community. The establishment of a national Māori ethics committee would facilitate this process and could also provide Māori policy advice and independent comment to the national ethics committees. This would provide a tangible example of Treaty responsiveness within the system of ethical review in New Zealand.

The challenge for Māori across a variety of contexts in New Zealand is to affirm Māori rights to participate in a manner that enhances tikanga Māori and mātauranga Māori and leads to improved outcomes for Māori. Māori development is dependent on maintaining control of their involvement at the cross-cultural interface. In the context of a fast changing world increasingly impacted by globalisation, integrating new perspectives within a Māori worldview, while retaining our cultural integrity is the reality of modern life. A robust system of ethical review should not only accommodate but also reinforce Maori cultural integrity.

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[59] gathering

Chapter 13: Glossary of Māori Terms

Ako	learn, teach
Ako Māori	Māori teaching
Aotearoa	New Zealand
Aroha	affection, compassion, love
Atua	deities
Hapū	sub-tribe
Harakeke	flax
Hau	wind, breath
Hauora	health
Hui	gathering
Kaitiakitanga	guardianship
Karakia	prayer
Kaumātua	elders
Kaupapa Māori	Māori focussed
Kawa ō te marae	marae protocols
Kawe	carry
Ki-waha	colloquial sayings
Koha	gift, donation
Kōhanga Reo	Māori pre-school centre
Kōrero	speaking
Kotahitanga	unity
Kua ea	settled (of an issue)
Kuia	elder women
Kura Kaupapa Māori	Māori school
Mana	authority
Manaakitanga	caring
Mana whakahaere	control
Mana whenua	local dominion
Marae	traditional Māori house

Mātauranga Māori	Māori knowledge
Mātiro whakamua	to look ahead
Mauri	life source
Moana nui a Kiwa	Pacific ocean
Mōteatea	traditional lament
Muna	secret
Ngā kōrero tāwhito	oral history
Ngākau mahaki	benevolence
Noa	free from restriction
Nohotahi	to sit together
Nohotapu	remain under restriction
Ōritenga	equality
Pākehā	non-Māori New Zealanders, usually of European descent
Papatūānuku	earth-mother
Pounamu	greenstone, a precious stone
Poutama	stepped pattern on panelling
Rangatiratanga	Māori authority
Ranginui	sky-father
Rūnanga	Governance body
Take	reason, issue
Tamaki Makau Rau	Auckland
Tangata	person
Tangata whenua	people of the land, indigenous people
Taonga tuku iho	ancestral inheritance
Taurahere Māori	Māori networks or groups without genealogical links
Tautoko	support
Tapu	prohibition, restriction, protection
Te Ao hurihuri	the changing world
Te Ao marama	the world of understanding
Te Reo Māori	Māori language

Te Whare Tangata	the womb
Te Whare Tapa Wha	four walls of a house
Tiaki	look after
Tikanga Māori	Māori protocol and process
Tika	right, just
Tino rangatiratanga	absolute sovereignty
Tohu	sign
Utu	reciprocity
Wairua	spirit
Wairuatanga	spirituality
Waka	confederation of tribes
Whaikōrero	formal speech-making
Whai utu	respect
Whakaaetahi	consensus
Whakaaro Māori	Māori thought
Whakapapa	genealogy
Whakatauki	proverbs
Whānau	family
Whanaungatanga	kinship relationships
Wharenui	house
Wheke	octopus
Whenua	land

Chapter 14: References

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Apendix 1: Interview Schedule

Ethical Review of Health Research:
A Māori Perspective.

Name:
Biography:

- **How well does the current system of ethical review of health research meet the needs of Māori?**

- **How could the current system better meet the needs of Māori?**

- **What is the current role of Māori in the ethical review of health research?**
  - **- Are there particular issues that Māori members should consider? (as an individual, as part of the wider community)**
  - **- What should the role be?**

- **How does the TOW relate to the ethical review of health research?**
  - **- Implications for the role, process or composition?**

- **What aspects of ethical review of health research are of particular relevance to Māori?**
  - **- role, process, composition, topics?**

- **Do you think that the principles used in ethical review are consistent with Māori values?Which Māori values? Why?(expand)**
  - **Respect for persons**
  - **Informed consent**
  - **Privacy and confidentiality**
  - **Validity of research proposal**
  - **Minimisation of harm**
  - **Justice**
  - **Cultural and social responsibility**
  - **Compensation for research participants**

- **Are there any other Māori values that should be included in the ethical review of health research? Any other values/principles?**

- **How do you think these values should be reflected in the ethical review process?**

- **What, if any, do you think are the barriers to operationalising these values or principles in the ethical review of health research? How could they be overcome?**

- **Is there a need for a distinct Māori framework or system of ethical review? What would be the key elements of that framework or system?**

Ngaa Patai

He Matatika Māori

Ingoa:
Koorero aa tangata:

- **Ka aro raanei te arotake matatika o ngaa rangahau ki ngaa aahuatanga Māori?**

- **He aha te tūranga o te Māori i roto i ngaa arotake matatika mo ngaa rangahau hauora?**

- **Me aha te turanga o te Māori i roto i ngaa arotake matatika?**

- **He take Māori hei aro ma te mema Māori?**
  Me pehea te aro aa te mema Māori?
  Ki te tangata?
  Ki te iwi whanui?

- **He take too te Tiriti o Waitangi i roto i teenei mahi?**
  Hei turanga, tukanga, aahuatanga, take

- **Ki too whakaaro, he aha ngaa take whakahirahira mo te Māori i roto i teenei mahi?**
  Turanga, tukanga, aahuatanga, take

- **Ki too whakaaro, ka hängai ränei ngaa matatika päkehä ki ngaa tikanga Māori?**
  Ko ëhea o ngaa tikanga? He aha ai?
  - **Respect for persons**
  - **Informed consent**
  - **Privacy and confidentiality**
  - **Validity of research proposal**
  - **Minimisation of harm**
  - **Justice**
  - **Cultural and social responsibility**
  - **Compensation for research participants**

- **He tikanga Māori anoo hei urutomo ki roto i ngaa arotake matatika? He tikanga, uara anoo?**

- **Me pehea eenei tikanga e puawai i roto ngaa arotake matatika?**

- **He aha ngaa mea hei aukati i eenei ahuatanga? Ka peehea e karo atu?**

- **Me tuu ränei tätou i tetahi hanganga matatika Māori? He aha ngaa aahuatanga o te hanganga?**

Appendix 2: Invitation to Participate and Consent Form

PARTICIPANT INFORMATION SHEET

Tuia ko te Rangi e tu nei
Tuia ko te Papa e takoto nei
Tuia ko te here tangata
Ka rongo te poo
Ka rongo te ao
Tihei mauri ora

Tuatahi ka huri ra ngaa whakaaro ki a Io te puukenga, Io te waananga, Io te Matua Kore.
Tuarua ki ngaa tini mate o teenaa iwi, o teenaa iwi puta noa i te motu. Haere koutou ki te huinga o te Kahurangi. Tuatoru ki ngaa whatu morehu o raatou maa, ki ngaa mana, ki ngaa ihi, ki ngaa wehi.

Tena koutou katoa.

Title: Ethical Review of Health Research, A Māori Perspective.

An invitation to participate in this research study

To:

My name is Maui Hudson. My iwi are Whakatohea, Ngaruahine, and Te Mahurehure. I am a student at Auckland University of Technology conducting research for a Masters Degree in the Division of Public Health and Psychosocial Studies. I am conducting this research for the purpose of my thesis, and have chosen this research subject because I think it is very important for Māori development in health research.

Māori contribution to health research has been increasing over a number of years beyond that of participants. As researchers, Māori are developing methodologies that are congruent with a Māori world view and address our values and tikanga. Māori are also involved in the ethical review of health research as members of accredited ethics committees at an institutional, regional or national level. The principles that govern ethical review in New Zealand are based largely on western philosophy and western values. It has been identified by a number of Māori researchers and also at the Puu-Tai-Ora wananga, for Māori members of ethics committees, that a Māori ethical framework should be developed. This would be based in and reflect Māori values and tikanga.

The aim of this study is to determine what Māori values and/or tikanga could inform a Māori perspective on the ethical review of research. I would like to interview you, but you are under no obligation at all to agree to be interviewed. Interviews would take about one to two hours, and would be at a time and place of your choosing. You can speak in either Māori or English or both, the choice is yours. I would prefer to audio tape the interview but this would only be done with your consent and could be turned off at any time. You can withdraw information at any time.

If you decide not to be interviewed please let me know on Tel: 09 917 9999 ext 7235.

Given the nature of this study I would like to be able to name the participants either in an appendix or in a short biography as part of the study. I feel that it is important that people that read the research know who the participants were and what their background is. You may consent to this or to have your anonymity maintained. You will be given the opportunity to change, alter or delete any comments that you do not wish to include. Once again, you can withdraw information at any time.

Thank you very much for your time and help in making this study possible. If you have any queries or wish to know more please contact me at:

Division of Public Health and Psychosocial Studies
Auckland University of Technology
Private Bag 92006
Auckland.   Tel. 917 9999 extn 7235

My supervisors are is :   Dr Mihi Ratima
                                           Associate Professor of Māori Health
                                           Division of Public Health and Psychosocial Studies
                                           Auckland University of Technology
                                           Private Bag 92006
                                           Auckland.   Tel. 917 9999 extn 7234

The Head of Department is: Peter Greener
                                           Head of Division
                                           Division of Public Health and Psychosocial Studies
                                           Auckland University of Technology
                                           Private Bag 92006
                                           Auckland.   Tel. 917 9999 extn 7187

For any queries regarding ethical concerns please contact:

The Chair,
Auckland University of Technology Ethics Committee
c/- Executive Secretary
09 917 9999 extn 8044

APPROVED BY THE AUCKLAND UNIVERSITY OF TECHNOLOGY ETHICS COMMITTEE on 27/04/04

CONSENT FORM

THIS CONSENT FORM WILL BE HELD FOR A PERIOD OF FIVE YEARS

Title: Ethical Review of Health Research: A Māori Perspective

Researcher: Maui Hudson

I have been given and have understood an explanation of this research project. I have had an opportunity to ask questions and have them answered.

I understand that I may withdraw myself or any information traceable to me at any time without giving a reason.

- I agree to take part in this research.

- I agree/do not agree to the interview being audio taped.

- I agree/do not agree to being named as a participant in this research.

      Signed:

      Name:
      (please print clearly)

      Date:

Approved by the Auckland University of Technology Ethics Committee on 27/04/04 **AUTEC Reference number** 04/32

He panui whakamarama
I tënei rangahau

Tuia ko te Rangi e tu nei
Tuia ko te Papa e takoto nei
Tuia ko te here tangata
Ka rongo te poo
Ka rongo te ao
Tihei mauri ora

Tuatahi ka huri ra ngaa whakaaro ki a Io te puukenga, Io te waananga, Io te Matua Kore.
Tuarua ki ngaa tini mate o teenaa iwi, o teenaa iwi puta noa i te motu. Haere koutou ki te huinga o te Kahurangi. Tuatoru ki ngaa whatu morehu o raatou maa, ki ngaa mana, ki ngaa ihi, ki ngaa wehi.

Tena koutou katoa.

Ingoa: He Matatika Māori

He inoi ki a koe kia uru mai ki teenei rangahau

Ki a:

Ko Mataatua, ko Aotea, ko Nukutere, oku waka. Ko Whakatohea, ko Ngaruahine, ko Te Mahurehure oku iwi. Ko Maui Hudson töku ingoa. He akonga ahau I te Waananga Aronui o Tamaki Makau Rau. Ko taku nei whainga, ko te rangahau kia ekengia te taumata mo te tohu paerua. Heoi ano he painga ano mo te iwi whanui ka puta i te rangahau nei.

He maha ngai taatau e mahi ana i roto i te rangahau, hei kai rangahau, hei kaititiro, hei tauira hoki. Kua huri ke ngaa kairangahau Māori ki te hanga i ngaa momo rangahau e hangai ana ki te Ao Māori, ki ngaa tikanga Māori. He mahi hoki maa te Māori hei arotake i ngaa rangahau hauora kia pai ai nga whakaritenga mo aua mahi. Heoi ano, ko ngaa momo tikanga, ara, ngaa matatika e whakawaa ana i ngaa rangahau, he hanganga na te pakeha. He raru teenei mo ngaa kairangahau Māori e uu tonu ana ki ngaa tikanga Māori, mo ngaa kaiarotake Māori hoki. Kei a taatau o taatau ake tikanga e paa ana ki te rangahau, me te mohio ano ki te Ao e Māori nei.

Ko ngaa whainga o tenei rangahau;
- Tuatahi ko te rapu i ngaa momo tikanga e paa ana ki te rangahau, e paa ana hoki ki te hauora.
- Tuarua ki te hanga i tetahi hanganga mo ngaa matatika Māori.

Kei te hiahia ahau ki te uiui I a koe. Ka hangai ngaa patai ki ngaa tikanga e paa ana ki te rangahau me te hauora. Ko te roanga ake o ngaa whakawhitinga koorero, kaore e tua atu i te rua haora. Ka taea te koorero Māori, koorero pakeha, koorero reo rua ranei. Kei a koe tonu te tikanga kia uru mai, kia noho atu ranei i tenei rangahau. Maau e whiriwhiri te waa me te waahi mo te uiui. Ko taaku e hiahia nei ko te hopu i ngaa koorero ki te mihini, heoi ano kei a koe te tikanga whakaae, whakakaore ranei. Mena ka whakaae, ka taea te whakakore i te mihini ina kore koe e pai ki te hopunga o eetahi pitopito koorero. Ka taea hoki koe ki te whakawatea i a koe, ki te whakawatea i o korero i tenei rangahau.

Mena kaore koe e pïrangi ki te uru ki te rangahau nei, waea mai ki 09 917 9999 ext 7235.

Mena ka panui te tangata i tetahi korero e paa ana ki ngaa momo tikanga ka puta mai te patai, na wai te koorero nei? Koianei te take ka pirangi ahau ki te whakamohio atu ngaa ingoa o ngaa

taangata kua uru mai. Heoi ano, kei a koe te tikanga mo tena. Mena ka whakaae ka whakahokia o korero ki a koe, mau tonu e whakaae, e whakakaore ngaa wahanga ka uru ki te rangahau.

Mena he patai taau, waea mai, tukua mai ränei ki a:

Division of Public Health and Psychosocial Studies
Auckland University of Technology
Private Bag 92006
Auckland.   Tel. 917 9999 extn 7235

Ko töku Rangatira :   Dr Mihi Ratima
                                       Associate Professor of Māori Health
                                       Division of Public Health and Psychosocial Studies
                                       Auckland University of Technology
                                       Private Bag 92006
                                       Auckland.   Tel. 917 9999 extn 7234

Ko te Tumuaki: Peter Greener
                                       Head of Division
                                       Division of Public Health and Psychosocial Studies
                                       Auckland University of Technology
                                       Private Bag 92006
                                       Auckland.   Tel. 917 9999 extn 7187

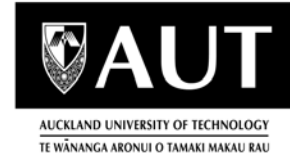Mena he patai e paa ana ki ngaa matatika, paa atu ki a:

The Chair,

For any queries regarding ethical concerns please contact:

The Chair,
Auckland University of Technology Ethics Committee
c/- Executive Secretary
09 917 9999 extn 8044

APPROVED BY THE AUCKLAND UNIVERSITY OF TECHNOLOGY ETHICS COMMITTEE on 27/04/04

Whaarangi Whakaae

KA MAU TONU TEENEI WHAARANGI WHAKAAE MO NGAA TAU E RIMA

Ingoa: He Matatika Māori

Kairangahau: Maui Hudson

Kua whakamarama mai ngaa aahuatanga o teenei rangahau. Kua whakautua aku nei paatai. E mohio ana ahau ka taea e au te whakawätea I ahau, te whakawätea I aku koorero I tënei rangahau.

- Ka whakaae ahau ki te uru ki tënei rangahau.

- Ka whakaae/whakakaore ränei ahau ki te hopu I aku koorero ki te mihini.

- Ka whakaae/whakakaore ränei ahau ki te whakaingoatia ahau ki roto I ngaa tuhinga

  mo tënei rangahau.

Na:

Ingoa:

Ra: