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***HE WHAKAMATAUTAU PI TAU A MO TE MATE PUKUPUKU:
NGA TIKANGA A TE AO MĀORI***

**DNA TESTING FOR CANCER SUSCEPTIBILITY:
THE NEEDS OF MĀORI**

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(Waiora)*

A thesis submitted in fulfilment of the requirements
for the degree of Doctor of Philosophy in
Molecular Medicine and Pathology/Maori and Pacific Health
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ABSTRACT

An inherited predisposition to cancer may result from constitutional mutations in a number of tumour suppressor genes. Knowledge of the specific mutations within a family which render the individuals susceptible to bowel, breast or stomach cancer facilitates genetic testing. Genetic testing is a relatively new technology, and New Zealand society is still coming to terms with its ethical implications and informational potential.

Maori people are the indigenous people of *Aotearoa* New Zealand. As a consequence of a colonial history that has had a major impact on *Maori* health, New Zealand is struggling to reduce significant disparities in the health status of *Maori*. With the exception of one high profile case, *Maori* people have not readily engaged in genetic testing or genetic counselling services. This thesis set out to examine *Maori* perspectives about this state. Drawing on a *Kaupapa Maori* approach to research, a group of *Maori* cultural commentators (*Pukenga*), *Maori* families (*whanau*), and health professionals who work with families (Interfacers) were interviewed for this study.

The thesis discusses the different world views that *Maori* have in regards to health, well-being and human society. These world views help explain *Maori* cultural perspectives about predictive/presymptomatic DNA testing. The thesis draws on the notion of two worlds which may stand apart in terms of world view, but which have the potential to come together at the level of individual and family health and well-being. The thesis draws on the interviews and suggests pathways forwards in the area of genetic counselling and other services. While these pathways are relevant to *Maori* and the New Zealand context, the study shows how other cultural groups with alternative world views may seek their own solutions and responses to the technologies available through predictive/presymptomatic DNA testing.

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<i>Ko Rangiheke te awa</i>	<i>Ko Kakirikura te awa</i>
<i>Ko Te One Roa a Tohe te tai</i>	<i>Ko Te One Roa a Tohe te tai</i>
<i>Ko Mamari te waka</i>	<i>Ko Ngatokimatawhaorua te waka</i>
<i>Ko Te Aupouri te iwi</i>	<i>Ko Te Rarawa te iwi</i>

Tihei Mauriora

Hutia te rito o te harakeke

Kei hea te komako e ko

Ki mai koe ki ahau

He aha te mea nui o te ao

Maku e ki atu

He tangata, He tangata He tangata

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To my *whanau whakapapa*, I thank you all, for it has been a long climb which almost did not begin when our eldest daughter died of colon cancer in 1998. To my husband Garth of almost fifty three years, thank you for journeying with me up the mountain. And now we have the journey down. As Browning wrote, ‘The best is yet to be’. A big thank you to our daughters Ruth, Anne, Gareth and Louise who have always lovingly supported and encouraged their mother the ‘chronologically endowed student’, and who, each in their own way, contributed to the completion of this thesis. To their husbands David, Dave, Russell and Andrew, your support and friendship has been appreciated. To my sister Effie who encouraged me all the way- thanks. Throughout this thesis the importance of the *mokopuna* has been articulated and discussed, always with pride and *aroha*. Therefore to Lara, Zak, *Nane*, Jade, *Anaru*, Danielle, Eve, Jordan, Levi, Samuel and Liana our *mokopuna*, thank you for being so patient, Grandma will be more available now.

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Tena ra koutou katoa; ahakoa te mamae; haere tonu koutou ki te whai nga matauranga hauora mō ā koutou mokopuna.

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Moe mai koutou i runga i te whariki a Hine nui te po. E kore koutou e warewaretia e matou

KUPU WHAKATAKI

*Whaia katoatia ngā taōnga kei roto i Te Kete Aronui, hei
aria atu i nga rauhangā ō tenei aō kikokiko, hāunga anō
kia tika ai te hauora ō te iwi mē ngā uri whakatupu, kei
te heke mai*

Pursue the corpus of *Māori* knowledge contained in *Te Kete Aronui*, to remedy the ills of the world as well as to sustain good health for the present and future generations

THE PROLOGUE

The impetus for this study was grounded in the recognition amongst biomedical scientists of the potential for of the new genetic technologies to have psychosocial impact. Such impacts were linked to the personally held perceptions of the nature of genetic inheritance and diverse views on any form of interruption to the natural process. Cultural factors were clearly implicated in this. When invited to consider this research which involved asking *Maori* their views on DNA testing and more specifically predictive/presymptomatic testing where there is a familial cancer in the family, I felt that I needed firstly to situate myself. As a mature *Maori* female researcher who had a background in Education, my entry into the health arena was through helping with research into the genetic aspects of *waehape* at the invitation of Dr. Cyril Chapman a clinical geneticist and Mr. Richard Nicoll an orthopaedic surgeon in 1992-1993. This research became the basis of my thesis written for an M.A in Education (1995). Prior to this I had been a primary school teacher with a commitment to community life, in areas other than health care promotion. Throughout my life I have been devoted to the care of *whanau*, first as the eldest with four siblings and later as mother and grandmother to our five daughters and our eleven *mokopuna*, and support to the wider *whanau*. I consider *whanau* to extend from *whanau whakapapa* to the many other *whanau kaupapa* such as *Kohanga Reo*.

While deciding how to introduce myself and my subject, I drew inspiration from Graham Smith's introductory chapter in his 1997 Ph.D thesis. He states:

This chapter makes overt all the political, social, cultural, and economic influences which accrue to the author's background and which therefore contribute to the authors' makeup, preferences and prejudices (Smith 1997:53).

This stance, he argues, does not make the work less valid than research and writing which is supposedly believed to be 'neutral' and interest free.

This prologue explains my long journey through to this research which serves as an entry point into a broader understanding of how new genetic techniques can find a comfortable place in a *Maori* world view. The research also takes note of the needs of *Maori* as they look at the services provided by the Ministry of Health through District Health Boards, so that development of services can be cognisant to their future needs and aspirations as stakeholders.

Being born of a *Māori* mother and a *Pakeha* (person of European descent) father in 1932 meant in *Aotearoa*, New Zealand, that I was registered as a *Māori*. The assimilation policy of the time successfully made me a ‘brown *Pakeha*’¹ and until I was 34 years old this state caused me only intermittent discomfort. I left the Native School in *Ahipara* in the far north when I was eight years old as my parents decided in late 1940 to seek a better life for their family in Auckland. Soldiers leaving to go overseas to fight in World War Two meant that work was more readily available in the cities. There were not many *Māori* living in Auckland at that time but they seemed to be concentrated in the slum area of the inner city among *Pakeha* working class people. The assimilationist policy imposed by the government from 1844 meant that *Māori* had to renounce their language and culture and be educated in the English traditions and language.

I was enrolled at Napier Street School in Freemans Bay, Auckland along with my younger sister. What a change it was from *Ahipara* Native School where there were few *Pakeha* children enrolled. Our new school was the opposite with very few *Maori* attending. Because our dad was *Pakeha* we had been known in *Ahipara* as

¹ This phrase describes a person born Maori but assimilated into the Pakeha way of life and usually without being able to speak Maori.

'the *Pakeha* kids'. At our new school we became 'black *Maori* kids'. We had not minded being called the *Pakeha* kids but I remember not liking being called the black *Maori* kids. Being *Maori* was not something that was valued and I was always embarrassed if a teacher asked if there were any *Maori* in the class for whatever reason. Being *Maori* was always a feeling of being judged and a lack of pride in our culture became the default position. Nonetheless, I survived and graduated to Auckland Girls' Grammar School, where I did not achieve my potential scholastically. Later I went on to Auckland Teachers' College where one *Maori* male student teacher told someone on meeting me that he had never met a more "*Pakeha*(fied) person". I did not feel comfortable with the *Maori* students, who all seemed so much better at things *Maori* than I was. I was happier with my *Pakeha* friends and so successful had my assimilation been, that I did not really think of them as *Pakeha* until I was at teachers' college where there were so many more *Maori* than at my secondary school.

I began my teaching career in Auckland in 1953, married a *Pakeha* and raised a family of five girls. As we kept our connections with my mother's *whanau* and *turangawaewae* I did not at that stage feel my life lacking in the *Maori* dimension. However the death of my mother in 1966 when I was 34 years old changed the course of my life.

After great discussion within our family and her brothers and sister coming from the North to request her body for burial it was decided to return my mother's body to our *turangawaewae* and the *urupa* where all our close *whanau* were buried. At her *tangi* I realised for the first time that my identity as a brown *Pakeha* was challenged.

Following her burial, I as the eldest child was asked by my aunt to thank everyone in the *wharenuia* for all they had done for my mother's *tangi*. My shame at not being able to do this in *Maori* was so great that I vowed to learn my mother's birth language and one day be able to stand up and speak in *Maori* in that *marae*.

That was 1966 and the *Maori* language renaissance in *Aotearoa* had not begun. However it was a good place to start because, hand in hand with *Te Reo* (the language), goes *Nga Tikanga* (cultural knowledge) - one cannot stand without the other. While it was so easy to articulate the words and the feelings about wanting to learn *Te Reo*, it transpired that it was a long hard road of 18 years to acquire fluency in what should have been my birthright. These feelings have been echoed by people of other ethnicities and cultures who have come under the influence of European colonisation and assimilation. The impact of our social experiences of being educated and socialised by others, which privileges one cultural heritage to the detriment of the other, is clearly articulated in the words of DeAnda (de Andra cited in Reason and Bradbury 2001:315).

To become bicultural an individual must engage in a dual socialisation process. One acquires values, beliefs, communication and behavioural styles from a culture of origin as well as becoming exposed to the same dynamics of a majority culture. An ethnic minority will have success in becoming bicultural to the extent that information and skills needed for negotiating the mainstream culture are provided, commensurate with receiving affirmation for the basic values, beliefs and behavioural styles of one's minority culture.

Gloria Bravette-Gordon, an African Caribbean writing of her search for 'bicultural competence', describes the struggles entailed in developing 'bicultural competence' as a 'Black British', whose unique ethnicity is subsumed within this homogenising form of identification. For Bravette-Gordon this entails:

an attempt to depict the conscious and deliberate process of becoming bicultural, rather than merely making erroneous claims of biculturalism as an automatic and defensive response to the realities of being ‘Black’ in ‘White’ society. People of African descent *do not* receive affirmation for the basic values, beliefs and behavioural styles of their minority culture in British society. As a result, and this is particularly true for the many African Caribbeans who do not even like to be identified as being related to Africans, we tend to deny that culture (Bravette-Gordon 2001:315).

A return to primary teaching in 1973 and the influence of the principal Jim Laughton at Richmond Road School in Auckland was significant in my journey to becoming a *tuturu* (genuine) *Maori*. This school had a roll with 98% Polynesian children and my reason for applying for a position there was that I felt I could empathise with these children. Although my journey from *Ahipara* to Auckland was a short distance compared with their journey from the Cook Islands, Samoa, Niue, and Tonga to *Aotearoa* New Zealand, the cultural shock was comparable, although I did however have an advantage in that I spoke the English language. Their problem was like my mother’s when she went to school when she did not understand her teacher and was made to renounce her mother tongue. Laughton’s philosophy was that children should have and retain a pride in their language and culture, but he also made provision of a place for these children where a love of learning could be nurtured.

I saw this as a ‘win win’ situation, since, while mentoring and teaching, my own search for my language and customs was nurtured and energised in the environment. Jerry Norman, an itinerant teacher of *Maori*, was also of enormous help in my language acquisition because he encouraged me to speak *Maori* with him when he visited our school. He made the rule that if I wished to converse with him then it should be in *Te Reo*. Although very reluctant at first, on a long experiential basis of having been laughed at, it was a great step and I became less shy of making a fool of myself.

In 1984 I was fortunate to attend a month-long *Maori* language course (*Te Kete Papaku*) at the *Kuratini* (Polytech) in Wellington. It had as its tutors, *Teariki Mei* and *Huirangi Kerepuru* assisted by other visiting *Maori* tutors. It was one of the most rewarding months in my life and I shall never forget how much my *reo* and *tikanga* improved, and the wonderful friendships that were forged in that time. *Huirangi Waikerepuru* and June Mead were successful in their application to the Waitangi Tribunal to have *Maori* recognised as a national language.

A survey by Richard Benton in the late 1970s had shown the *Maori* language to be in a stage of decay and many *Maori* were shocked into finding ways to keep the language from extinction. The *Kohanga Reo* movement was born out of this desire in 1982 with the opening of the first *Kohanga Reo* in *Wainuiamata*, Wellington. This language revival movement strongly supported within *Maoridom*. With the rapid spread of *Kohanga Reo* nationwide, the question arose as to what was to happen to these children when they left *Kohanga Reo*? My acquisition of *te Reo* was to be of more value because I would be able to teach it. For Jim Laughton my principal who was also *Maori*, an opportunity to provide for children something he and myself had not been offered in our education was possible.

In 1985 with support from the whole Richmond Road School *whanau* a Bi-Lingual class was opened and I taught there until enrolling at University in 1988. The school *whanau* also fought for, and established on the school grounds, a *Kohanga Reo* which opened in November, 1985.

Just before beginning my undergraduate degree majoring in *Maori* Studies and Education, I was approached to supervise the *Ritimana Kohanga Reo* following the

resignation of the previous *kaiako* (teacher). I said had always wanted to go to university and I still would, but I would give 3 days a week to the *Kohanga* for one year and enrol to do six papers at University. I taught at *Kohanga* for 4 years the time it took to complete my B.A. and I then resigned as supervisor. I had intended to be the full time post graduate student, but again this was not to be. The *Maori* Liaison officer at the University, *Taimininga Potaka* asked me if I would consider taking up a position as a research assistant in a Genetic study of Clubfoot at the School of Medicine. The two reasons for accepting this position was that at last *Maori* were being asked to interview *Maori* and secondly two of my brother's children have *waehape* (clubfoot). This was combined with post-graduate study towards an MA in Education (1995). Today I am Bi-Cultural, Bi-Lingual and proudly identify as *Maori*.

After the completion of my M.A., and some relaxation time, I had planned to continue my work with the Clubfoot Study (*waehape*), and our group made a funding application to this end. The response, however, from the *Maori* committee of the Health Research Council (HRC) and *He Kamaka Oranga*² that this was not a top priority for *Maori* research dollars (Personal communication Winship, 1996). I was invited by Winship to consider research which involved asking *Maori* their views on DNA testing and more specifically predictive/presymptomatic testing where there is a familial cancer in the family, and this has been a turning point in my life. The ability that I had acquired and the self belief and worth of

² *He Kamaka Oranga* was established in 1993 within Auckland Healthcare now known as the Auckland District Health Board (ADHB). It was established with the aim of improving the responsiveness of the organisation to *Maori* consumers and improving *Maori* health gain. HKO, *Maori* Health was the first major "mainstream enhancement" strategy of this kind nationally. It currently consists of a General Manager *Maori* Health; Chief Advisor, *Tikanga*; Senior Medical Advisor; *Maori* Public Health advisor and further designated management positions. *He Kamaka Oranga* covers the areas of health funding, planning, primary, secondary, tertiary, quaternary sectors and provider services. *Maori* Health Advisors provide strategic advice and *Kaiatawhai* staff support *Maori* consumers and their *whanau* seeking healthcare within the ADHB (Barnes, 2005 personal communication).

my culture were key factors in qualifying me to undertake such a responsible area of research for *Maoridom*.

A note about style

In her PhD thesis Linda Mead bolded and italicised *Māori* words and this appealed to me as I read it. I proceeded to do this in my work. Two academic women who read some work I had submitted for comment, expressed their dislike of this practice and asked why I had chosen to do this. My reply was simply that I liked it, but their question prompted me to find out why Linda Mead had chosen such a stylistic device. Within her thesis she explained that she bolded and italicised her *Māori* words because she wished to privilege *Māori* language by making distinctions in the text. *Māori* words, she believes, cannot be slotted into an English structure ‘without losing some of its meaning’ (Mead, 1996:31). She believes that *Māori* words get appropriated by others, who learn how to use them, in only one or two contexts.

Māori words, she argues, especially for *Māori* readers: have other meanings attached to them which connect the word itself to other contexts, to experiences and to concepts related spirituality, emotion and values. Simply at a visual level there are different textual landscapes which *Maori* words on their own and juxtaposed with English words create. I use *Maori* language because there is no alternative expression in English, which says quite what I want to say (Mead, 1996:31). I concur with her reasons and so do the same through out this thesis.

TABLE OF CONTENTS

<i>Title Page</i>	<i>i</i>
<i>Abstract</i>	<i>i</i>
<i>Acknowledgements</i>	<i>ii</i>
<i>Nga Mihi</i>	<i>ii</i>
<i>Kupu Whakataki</i>	<i>v</i>
<i>The Prologue</i>	<i>vi</i>
<i>Table of Contents</i>	<i>xiv</i>

SECTION ONE 1

INTRODUCTION	2
<i>The ethical and psychological aspects of predictive DNA testing</i>	<i>6</i>
<i>The aims</i>	<i>8</i>
<i>Lack of information</i>	<i>11</i>
<i>Thesis structure</i>	<i>12</i>
 CHAPTER ONE	 15
KAUPAPA: 'PLAN, A PHILOSOPHY AND A WAY TO PROCEED'	15
<i>Introduction</i>	<i>15</i>
<i>Rationale for the chosen methodology</i>	<i>15</i>
<i>Epistemological basis</i>	<i>16</i>
<i>Experiential basis</i>	<i>19</i>
<i>Towards a Maori methodological framework</i>	<i>21</i>
<i>Looking back in order to go forward</i>	<i>21</i>
<i>Moving forward</i>	<i>24</i>
<i>The theoretical basis of Kaupapa Maori Research</i>	<i>25</i>
<i>Kaupapa Maori theory</i>	<i>25</i>
<i>What is critical theory?</i>	<i>26</i>
<i>Kaupapa Maori methodology</i>	<i>27</i>
<i>Who then should do this research?</i>	<i>27</i>
<i>Who is the research for and why is it needed?</i>	<i>30</i>
<i>What difference will the research make?</i>	<i>31</i>
<i>Who should carry out the research?</i>	<i>31</i>
<i>How do we want the research done?</i>	<i>32</i>
<i>How will we know if it is worthwhile?</i>	<i>33</i>
<i>Who will own the research?</i>	<i>33</i>
<i>Who will benefit from the research?</i>	<i>33</i>
<i>Investigative Strategies</i>	<i>34</i>
<i>Interviewing</i>	<i>35</i>

Group One: Feasibility Study	37
Rationale	37
Ethics	38
Recruitment	38
Interviews	39
Group Two: Whakapapa Whanau	40
Rationale	40
Ethics	40
Recruitment	41
Interviews	44
Group Three: Pukenga	44
Rationale	44
Ethics	44
Recruitment	45
Interviews	45
Group Four: Interfacers	46
Rationale	46
Ethics	46
Recruitment	46
Interviews	47
Analysis of data	48
Summary	48
 SECTION TWO	 50
 CHAPTER TWO	 51
TE AO MAORI	51
Introduction	51
Cosmology	53
The creation	54
Whakapapa	57
Pukenga discuss Whakapapa	60
Karakia, Tikanga and Matauranga Maori	66
Tane the first Maori researcher	67
Wananga (Places of learning)	69
Tikanga Maori	70
Tapu	72
Noa	73
Mana	73
Mauri	74
What is spirituality?	74
Summary	75
 CHAPTER THREE	 77
WHANAU AND LEADERSHIP	77
Introduction	77
Understanding whanau	78
Whanau in Maori social organization	82
Understanding leadership within Maori social organization	84
Kaumatua	85
The role of Maori women	88
Summary	94

CHAPTER FOUR	95
HAUORA MAORI	95
<i>Introduction</i>	95
<i>Te Tiriti o Waitangi</i>	96
<i>Article I: Transfer of sovereignty</i>	97
<i>Article II: A continuation of property rights</i>	98
<i>Article III: Citizenship rights</i>	98
<i>The Treaty in regard to health</i>	98
<i>What is the Waitangi Tribunal?</i>	100
<i>Hauora Maori</i>	102
<i>Looking back to fully understand</i>	103
<i>Strategies for good health</i>	103
<i>Maori view of illness</i>	105
<i>Maori health after contact</i>	107
<i>Aotearoa</i>	109
<i>Loss of land as a health issue</i>	113
<i>How the land was lost</i>	114
<i>Maori views on Health</i>	115
<i>Te Taha Wairua</i>	116
<i>Te Taha Hinengaro</i>	117
<i>Te Tinana</i>	118
<i>Te Whanau</i>	120
<i>Te Wheke (the octopus)</i>	121
<i>Summary</i>	122
CHAPTER FIVE	124
TE AO PAKEHA	124
<i>Introduction</i>	124
<i>Genetics</i>	125
<i>Chromosomes: The packages of genes</i>	125
<i>DNA and genes</i>	126
<i>Autosomal dominant inheritance</i>	128
<i>Penetrance</i>	129
<i>A background to cancer</i>	129
<i>What is cancer</i>	131
<i>Tumours</i>	131
<i>Malignant tumours</i>	132
<i>Stomach cancer</i>	133
<i>Colorectal cancer</i>	134
<i>Breast cancer</i>	135
<i>Familial cancer</i>	136
<i>The genetics of cancer</i>	136
<i>Summary</i>	139
<i>Genetic Tests</i>	140
<i>1. Diagnostic test</i>	140
<i>2. Predictive test</i>	140
<i>3. Prenatal test</i>	141
<i>4. Predisposition testing</i>	142
<i>5. Pre-implantation genetic diagnosis (PGD)</i>	142
<i>6. Research test</i>	143
<i>7. Cancer Cytogenetics</i>	143
<i>The role of DNA testing in cancer</i>	144
<i>The HD experience</i>	145
<i>The utility of testing</i>	148
<i>Example</i>	149

<i>Gender issues in testing</i>	149
<i>Genetic counseling</i>	151
<i>Historical beginnings</i>	151
<i>Informed consent for genetic testing</i>	152
<i>The right not to know</i>	154
<i>Individual or collective autonomy</i>	154
<i>Informed consent for genetic testing of children</i>	155
<i>Insurance and discrimination</i>	157
<i>Privacy</i>	160
<i>The impact of testing on families</i>	161
<i>Rejection and isolation</i>	161
<i>Loss of future screening procedures</i>	162
<i>Summary</i>	162

SECTION THREE 163

CHAPTER SIX 164

<i>PUKENGA</i>	164
<i>Introduction</i>	164
<i>Comments on good health</i>	164
<i>Comments on predictive DNA testing</i>	168
<i>Making the decision to have or not have the DNA test</i>	174
<i>Aspirations</i>	176
<i>Consultation</i>	176
<i>Guidelines for helping whanau take advantage of technological services</i>	178
<i>Framing the health issue in a manner to which the client/whanau can relate</i>	181
<i>Partnership</i>	182
<i>Ethical issues</i>	184
<i>Need for information to be clear, simple and empowering</i>	184
<i>Summary</i>	185

CHAPTER SEVEN 186

INTERFACERS	186
<i>Introduction</i>	186
<i>The professionals and their work</i>	188
<i>What is good health?</i>	194
<i>What do Interfacers know of whakapapa?</i>	194
<i>The importance of whakapapa to the whanau</i>	196
<i>Adhering to the Treaty of Waitangi partnership</i>	198
<i>Views of DNA</i>	199
<i>Learning as a two-way process</i>	202
<i>An interchange of experience – the surgeon</i>	207
<i>Surgeon's post operative concern</i>	210
<i>An interchange of experience – the specialist nurse</i>	213
<i>Summary</i>	216

CHAPTER EIGHT	218
<i>WHANAU-WHAKAPAPA</i>	218
<i>Introducing the Whakapapa Whanau</i>	218
<i>Whanau One</i>	218
<i>Role Model Stomach Cancer Partnership Funded</i>	224
<i>Whanau Two and Three</i>	225
<i>Whanau Four</i>	230
<i>Whanau Five</i>	231
<i>Whanau Six</i>	232
<i>Summary</i>	233
SECTION FOUR	234
CHAPTER NINE	235
THEMES	235
<i>Introduction</i>	235
<i>Seeking Knowledge of Science</i>	236
<i>The need for knowledge</i>	237
<i>A collaborative project</i>	240
<i>Other sources of knowledge</i>	242
<i>Decision making</i>	243
<i>Collective decisions</i>	244
<i>Factors influencing decisions to take the test</i>	247
<i>Children</i>	248
<i>Reasons mitigating against taking the test</i>	251
<i>Feelings</i>	253
<i>Resignation</i>	254
<i>Anxiety</i>	259
<i>Loss</i>	260
<i>The value of counseling and informed consent</i>	262
<i>Anger</i>	263
<i>Gratitude</i>	264
<i>Nga Moemoea</i>	265
<i>O matau turangawaewae</i>	265
<i>O matou kaumataua</i>	269
<i>Kanohi ki te kanohi</i>	270
<i>Maori want the best</i>	271
<i>The importance of clear straightforward information</i>	272
<i>Summary</i>	273

CHAPTER TEN	275
DISCUSSION	275
<i>Introduction</i>	275
<i>The research approach</i>	276
<i>Two world views</i>	276
<i>Te Ao Maori</i>	277
<i>Whanau</i>	278
<i>Hauora</i>	279
<i>Te Ao Pakeha</i>	280
<i>Bridging Two worlds</i>	281
<i>Pukenga</i>	281
<i>Interfacers</i>	282
<i>Whanau case studies</i>	282
<i>Themes</i>	283
<i>Reflections on the research</i>	285
<i>Issues relating to ethics</i>	285
<i>Workforce development</i>	286
<i>Suggestions for the future</i>	287
<i>Provision of context sensitive options</i>	287
<i>Access to information</i>	288
<i>Partnership approaches to future practice</i>	288
<i>Future directions for study</i>	289
<i>Concluding Remarks</i>	290
<i>Te Ohonga Ake i ōku moemoea kō te puawaitanga ō te whakāro</i>	
GLOSSARY	291
REFERENCES	304
APPENDICES	323