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HE WHAKAMATAUTAU PI TAUA 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  
University of Auckland  
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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 with 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.
ACKNOWLEDGEMENTS

NGA MIHI

Ko Orowhana te Maunga
Ko Rangiheke te awa
Ko Te One Roa a Tohe te tai
Ko Mamari te waka
Ko Te Aupouri te iwi

Ko Whangatauatia te Maunga
Ko Kakirikura te awa
Ko Te One Roa a Tohe te tai
Ko Ngatokimatawhaorua te waka
Ko Te Rarawa te iwi

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
Te Aupouri

Tenei te mihi ki toku whanau whanui: he mihi tenei ki a koutou e noho mai na i te Hiku o te Ika a Maui, ki toku whanau, toku hoa rangatira, ki oku kotoro me nga mokopuna hoki, he mihi nui tenei ki a koutou. He mea nui te whanau ki ahau.


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you left the university, and for always fitting me into your busy timetable when I was in Wellington each month.

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Ritimana Kohanga Reo is another whanau which I wish to thank, and in particular Jenny Page, our administrator who, for all the years we have been associated, has listened and
supported me along with her husband Graeme. *Tena koutou oku hoa o te Kaunihera Kaumatua.*

*Tena koe e Rau Kapa, taku whanaunga nō Te Aupouri he mihi nui mō ō kupu rangatira mō tenei tuhituhi nga roa.*

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.

My most heartfelt thanks go to all those *whanau* who were participants in this research. Sharing your stories, your pain, your courage throughout has been my privilege. To the *Pukenga* and Interfacers your participation and support has added greatly to this research. There would have been no thesis without you all.

*Tena ra koutou katoa; ahakoa te mamea; haere tonu koutou ki te whai nga maturanga hauora mō ō koutou mokopuna.*

*This thesis is dedicated to our dearly loved eldest daughter Mary-Rose, wife of Fred Covich, who died on 23rd April 1998, and all those whanau members who have died of cancer since I started this thesis.*

*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 taonga kei roto i Te Kete Aronui, hei aria atu i nga rauhanga o tenei aō kikokiko, hāunga anō kia tika ai te hauora o 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 impetus for this study was grounded in the recognition amongst biomedical scientists of the potential for 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 Māori world view. The research also takes note of the needs of Māori 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’ 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 Māori attending. Because our dad was Pakeha we had been known in Ahipara as

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

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'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 wharenui 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 Anda 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 biculturality 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 Oranga² 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 Maori 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.
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