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Tuku iho, he tapu te upoko.
From our ancestors, the head is sacred.
Indigenous theory building and therapeutic framework
development for Māori children and adolescents with
traumatic brain injury.

A thesis presented in partial fulfilment of the requirements for the
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Doctor of Philosophy
in
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Abstract

International research shows ‘minority’ culture and indigeneity are risk factors for traumatic brain injury (TBI) and for differential responses by rehabilitation services. New Zealand epidemiological studies align with those findings showing that Māori tamariki (children) and taiohi (adolescents) are significantly over represented in TBI populations with poorer outcomes, including higher mortality rates.

This study asked two questions. Firstly, what do Māori people say about tamariki and taiohi TBI in the context of the Māori cultural belief that the head is the most sacred part of the body? Secondly, how could this information be used to build theory and inform a framework to address the rehabilitation needs of this group?

Eighteen marae wānanga (culture specific fora in traditional meeting houses) were held in urban, rural and remote locations. Participation in these marae wānanga established an overt collective Māori cultural orientation at the entry point of the study. This collective view meant that marae themselves were considered as respondents. Data were analysed using Rangahau Kaupapa Māori (Māori indigenous research methods) and informed by elements of grounded theory.

The central aspect of the theory proposes that TBI not only injures anatomical structures and physiology but also injures wairua. Wairua is defined here as a uniquely Māori dimension of wellbeing characterised by profound connection with all elements of the universe. The wairua injury means culturally determined interventions are both indicated and expected. The cultural knowledge required to address the wairua injury is housed within whakapapa (genealogy). This knowledge is activated by a cascade of events. The wairua theory in mokopuna TBI thereby provides a guide to intervention. The interventional framework underpinned by this theoretical position is called Te Waka Oranga. This framework uses the metaphor of a waka, a traditional Māori sailing vessel, preparing for journeys, in the process of moving across the ocean and finally arriving at it’s destination. In this way this framework provides a Māori space where both Māori and clinical world views and their respective interventions can co-exist and be jointly monitored. This framework is therefore a practical tool that clarifies the interface where the two world views of the whānau and clinicians meet, suggesting opportunity for improved outcomes.

This is the first study to propose and operationalise an indigenous theoretical construct for Māori child and adolescent TBI rehabilitation. Methods including noho puku, whanaungatanga, kaitiakitanga and centrifugal thinking were employed in novel ways. Future application of this work includes non-accidental traumatic brain injury, youth forensic populations, incarcerated groups and virtual rehabilitation.
Preface and acknowledgements:

Ko te mauri o Ngāpuhi he mea kua huna i te moana
The essence of Ngāpuhi is hidden in the ocean

I would like to preface this thesis with description of a number of events that influenced this research journey. Their linkages have become clearer to me as I progressed into the final stages of writing this report. By presenting them here I invite the reader into a more personal understanding of the lived experienced of my doctorate. I hope in this way to exemplify the unfolding of understandings and learning that I experienced along the way and to set the scene for reading this work.

As the only Māori child and adolescent psychiatrist assessing and providing assessment and treatment regarding the neuropsychiatric sequelae of traumatic brain injury (TBI) in tamariki and taiohi, including the crucial involvement of their whānau, I found that Māori cultural practices and approaches were valued and seemed to help progress better outcomes. I was intrigued by this observation and began mulling over how to find out more. This doctoral programme has been a central focus of pursuing that inquiry. I discuss the underpinnings of my world view in more detail in the methods section.

“Ko te mauri o Ngāpuhi he mea kua huna i te moana” is a whakatauki (proverbial saying) that I first heard from Shane Wikaira on Matai Ara Nui Marae in the Hokianga, Northland, Aotearoa, New Zealand on 29th November 2008. He was sharing his understanding of the Ngāpuhi classification system of the mind, passed on to him by kaumātua (elders), with a small group of whanaunga (relatives). One aspect of the whakatauki speaks about the best place to hide something being right in front of you. The whakatauki suggests that the ordinary aspects of life have imbedded within them the mauri, the life force, the essence of being. How this whakatauki would influence my doctoral journey was something I did not anticipate at that time.

Glass Murray was one of our precious Te Tai Tokerau kaumātua who strongly supported my research. He attended the hui were I sought permission from my whānau to proceed with this endeavour as well as both of the rangahau wānanga (research meetings) at Potahi marae as part of this project. Glass had been a kaihoe (paddler) on the Ngātokimatewhaorua waka, launched in 1940, at the centenary of the signing of Te Tiriti O Waitangi (The Treaty of Waitangi). I have included a photograph of the waka taken in 1940 with kind permission of The Alexander Turnbull Library on page vii. In 2010 Glass was photographed at Waitangi standing beside the waka he had paddled 70 years before (p viii). Three photos of him and the waka, taken that day at Waitangi have watched over me writing this thesis. Sadly, Glass passed away in August 2011. I took one of these photos to give to
his wife, Aunty Wini at his tangihanga (traditional Māori funeral) in Te Kao. Uncle Glass’ passing further strengthened my resolve to ensure his legacy of support was brought to fruition. These photos of Uncle Glass and the waka have been right in front of me, just as articulated in the whakatauki, and yet their significant influence evaded me until recently. As I immersed myself in my findings and wondered how to bring together the voices of my participant marae wānanga (traditional fora held on traditional meeting houses), a framework in the form of a waka began to take shape. Interestingly, as you can see in the photograph, the waka has a head at it’s prow, this is a common adornment of waka which shows another connection between the head and waka in Te Ao Māori (the Māori world). Over the last year, as I focussed more and more on writing, the idea of a waka has grown to become the framework that I present in this thesis. This framework has been constructed on the premise that it is by bringing on board all those involved in tamariki and taiohi (child and adolescent) traumatic brain injury rehabilitation in a manner that enables the active participation by whānau using culturally determined interventions which are likely to improve both the process and outcomes.

This thesis is intended for a broad audience. This is because tamariki and taiohi TBI have a wide ranging impact in our society; youth courts, prisons, alternative education, mental health services and substance abuse rehabilitation facilities all have an over representation of young Māori with a history of TBI. So I have written with a variety of readers in mind including whānau, iwi (tribal) leaders, community workers, academics, clinicians, service managers, policy makers, judges and teachers among others. It is my hope that this framework can be used to enhance opportunities for early rehabilitation of tamariki and taiohi Māori with TBI and their whānau to reduce the risk of poor outcomes for the Māori community and enhance Māori development. Importantly, this work could also be used to inform prevention strategies, an aspect central to the thinking of those of us providing specialist rehabilitation services.

I would like to acknowledge a number of people who have helped me to navigate this journey of rangahau (research). Firstly, my husband Paddy who has been a wonderful confidante, keen-eyed proof reader and who attended some of the wānanga helping me with both cultural protocols by speaking for me and with the technology of recording. My children have kept me on track with their encouragement and have buoyed me along with their humour. My dad, John has provided wise counsel and support. The Murray whānau, especially Glass, Wini, Errol and Pineaha as well as Uncle Joe and Aunty Loui have afforded me enormous support and their contribution has been invaluable. My Aunty Thelma Munro helped with organising many of the marae wānanga, thank you Aunty! My cousin Hera was always cheering me on from where ever she was in the world. And my cousin Monica whose music continued to inspire the journey. I am so grateful to you all.
I have been truly privileged with my supervisory panel. Professor Chris Cunningham, Professor Sir Mason Durie and Professor Richard Faull have been generous with their time and thoughtful feedback. A special thanks to Chris who made time for face to face meetings and responded to my many emails and texts. I have been blessed with the guidance of my Rōpū Kaitiaki which included Professor Sir Mason Durie and Professor Richard Faull as well as Naida Glavish, Amster Reedy, Dr Greg Finucane and Associate Professor Juan-Carlos Arango-Lasprilla from Virginia College University, Washington D.C. A special thanks to Rangahau Te Roro me te Hinengaro; The Centre for Brain Research staff for assisting with hosting these annual hui.

Whaea Moe Milne attended several of my rangahau wānanga and provided invaluable reflections and support, ngā mihi e te rangatira. Dr Waiora Port was able to attend the first hui in Waitara which was a wonderful gift, ngā mihi e te rangatira. I would also like to thank Professor Te Tuhi Robust and Ngā Pae o te Maramatanga for their scholarship in 2009 and Massey University for the Purehuroa Scholarship in 2011 both of which helped to support the costs of the eighteen wānanga, Rōpū Kaitiaki hui and conference travel. Kathryn McPherson, Professor of Rehabilitation (Laura Fergusson Chair), AUT University, was enthusiastic about the project from the start and generously put me in touch with Jo Fadyl, one of her doctoral students. Having Jo as a fellow research colleague was invaluable, her exacting critique thought provoking, thank you Kath and Jo! Dr. Melanie Cheung, Dr Amy Norman, Kimiora Henare and the Māori doctoral writing group in Auckland provided an enriching writing environment, providing meetings that were like coming up for air from the depths of solitary persistent writing. Ngā mihi kau atu anō kia koutou. Hohepa Renata (Ngāpuhi, Ngati Kahu) at Taurahere Marae, Te Noho Kotahitanga, UNITEC, tolerated numerous emails with my drawings of the features of Te Waka Oranga and transformed the template into a colourful and engaging taonga (treasure), sincere thanks, e hoa. Finally, I would like to acknowledge ethics approval obtained from Southern A 09/48 Massey University Human Ethics Committee.

As I come to the end of writing this thesis I am reminded that the next stage of hard work is already underway; developing pilot projects to test the findings. Writing funding proposals and fostering partnerships to ensure this work doesn’t just sit on a shelf.

This process has been hugely rewarding. I hope that other Māori clinicians consider pursuing their areas of interest in this manner. In my view, this is a valuable process for Māori clinicians to hone much needed research skills, to better question and understand the underlying drivers of our approaches, the complex situations within which we work and how to improve outcomes that have meaning for whānau.
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Hone was a 17 year old tamatane (son) when I first met him. He had sustained a severe traumatic brain injury at the age of three months and been taken to the local emergency department. He had bilateral retinal hemorrhages and other injuries consistent with non-accidental trauma. Over the years he had been cared for by several whānau (family) members including his grandmother who had recently passed away and this resulted in him moving again. When I was asked to provide psychiatric assessment and recommendations for treatment his whānau were concerned about his sleep disturbance and angry outbursts, they worried this meant he was grieving for his grandmother. Alongside a range of neurorehabilitative interventions I recommended a detailed Māori cultural rehabilitation component given his positive response to kuia and koroua (elders), karakia (prayer), waiata (song) and kapahaka (performing arts).

Introduction

Traumatic brain injury (TBI) in tamariki Māori (Māori children) has been a neglected area of Rangahau Kaupapa Māori (Māori specific research). This is surprising given pockets of knowledge pointing to the importance of greater understanding in this area informing culturally salient modes of prevention and treatment for Māori.

General public awareness of traumatic brain injury is low (Gordon, et al., 2006). Despite this, there are intermittent expressions of public outrage when a child dies following non-accidental traumatic brain injury. Statistics are published reminding us that Aotearoa New Zealand has shamefully high rates of death secondary to child abuse, often resulting from trauma to the head (Kelly, MacCormick, & Strange, 2009). In addition, experts have reported on the role of traumatic brain injury as a risk factor across a range of important domains which influence long term health and well being (Ministry of Justice, 2010; New Zealand Guidelines Group, 2006). The Māori community and Māori leadership recoil in horror, again and again, attempting within their relative spheres of influence to make a difference to preventing these forms of Māori traumatic brain injury. Unfortunately, it seems for the most part, these episodes of collective horror, and dissemination of information about the size of the problem, are soon followed by a return to a resigned nihilism. There are notable exceptions where in some communities the atrocities of abuse have enabled the garnering of both neighbourhood and national action (Ihaka, 2011). While these preventable
deaths attract media and political attention for a time many of the survivors of childhood traumatic brain injury of any cause remain relatively hidden and misunderstood. The sequelae of the brain injury are often only being recognised if these children and adolescents happen to attract attention because of changes in their behaviour, impact on learning and social interaction, or later because they have come to the attention of the law or mental health services. Even then, the degree of contribution conveyed by the traumatic brain injury to the child’s overall circumstances and the injury’s interaction with other factors, such as whānau coping, may be poorly understood. Indeed, TBI early in development, the evolving influence of the injury or injuries and their sequelae and links with difficulties many years later, prove difficult for families and professionals alike to assess. These layers of misunderstanding can lead to inconsistent access to treatment. Whānau develop their own explanatory models for young peoples’ behaviour and sometimes opportunities for education about TBI, intervention and healing are missed. For those working with mokopuna (grandchildren) and their whānau (families) who survive all types of traumatic brain injury, developing an inclusive approach with whānau can be a challenge. When working with Māori whānau key aspects of that challenge relate to the collision of two worlds; Te Ao Māori (The Māori World)¹ and the world of TBI rehabilitation. The situation where whānau have caused the injuries is even more complex.

The objective of this rangahau (research) has been to better understand how Māori whānau think about traumatic brain injuries and what preferences they have for responses to these types of injuries. In building on existing knowledge this study aimed to produce a practical tool, based on a theoretical foundation, to more effectively bring whānau and clinicians together in the shared endeavour of working with mokopuna (grandchildren) with traumatic brain injury of any cause, thereby improving outcomes.

This thesis is the first piece of Rangahau Kaupapa Māori, literally, research where the subject or agenda is Māori specific, conducted by a Māori researcher in the Māori community with methods determined by a Māori world view, deliberately aimed at improving rehabilitation for mokopuna with traumatic brain injury and their whānau. This rangahau takes a Māori belief “he tapu te upoko (the head; te upoko, is sacred; he tapu) and employs it in asking two questions. Firstly, what do Māori talk about when invited to reflect on this concept as a starting point for discussion about mokopuna traumatic brain injury in marae wānanga (traditional discussion fora in traditional meeting houses)? Secondly, how can the ideas generated inform theory building about mokopuna traumatic brain injury and using this theory building, be developed into a Māori cultural framework for intervention?

¹ Here the phrase Te Ao Māori is used to emphasise the Māori world view which encompasses recognition of Māori history, values, beliefs and practices.
Tangata Māori, Māori people

The approach taken is Kaupapa Māori; by Māori for Māori, which invites the question, who is Māori? For readers unfamiliar with this ethnic group a brief explanation is warranted. Here the term ethnic refers to the group of Māori, defined by a shared cultural heritage. Māori are the indigenous people of Aotearoa New Zealand. We are a resilient and resourceful people, descended from the ocean-going navigators of Te Moananui a Kiwa, the Pacific Ocean. The most recent New Zealand Census of Population and Dwellings was held in 2006, a further Census planned for 2011 was postponed because of the Christchurch earthquakes. The Census asks three questions about Māori ethnicity; which ethnic group do you belong to, are you descended from a Māori and do you know the name(s) of your iwi (tribe or tribes)? In 2006, 643,977 reported being of Māori ethnicity, almost 17.7% of the New Zealand population. 565,329 or 14.6% identified as Māori (Statistics New Zealand, n.d). The Census also found that Māori continue to be a young population with approximately 35% of Māori under 15 years old. These figures demonstrate that Māori are a significant proportion of the New Zealand Aotearoa population and underscore the importance of youth in considering Māori needs. There is ongoing debate about the relative heterogeneity of Māori cultural identity, and the dimension of experience of being Māori as well as the implications of being defined as Māori in research (Pomedli, 2008; Robson & Reid, 2001; Wereta, 2002). Despite this, there is a consensus in writing about and considering Māori as a group (Durie, 2011). This is reflected in a range of ways including government documents referring to Māori specific policies and a political party called ‘The Māori Party’ (Minister of Health, 2005, 2006; Ministry of Health, 2002).

As the lone identified Māori child and adolescent psychiatrist practicing in Aotearoa New Zealand, standing in both Te Ao Māori (The Māori World) and the clinical world, it was apparent from my practice that a culturally informed rehabilitation framework would support consistent application of tikanga Māori (Māori cultural lore) alongside clinical responses to mokopuna (grandchild) traumatic brain injury. The adequacy of a culturally robust response could not rely on the Māori ethnicity of the clinician advocating for the cultural needs of whānau.

A framework, which has been developed from the korero (discussion) and whakaaro (thinking) shared in wānanga (traditional fora) at participant marae (traditional meeting houses), is called Te Waka Oranga (a waka being a traditional form of ocean and river going transportation and oranga being a Māori word for wellbeing). This waka gives shape to the processes that enable transparent and shared action, roles and responsibilities for both whānau and clinical teams in the mokopuna traumatic brain injury rehabilitation journey.
Thesis structure

I have chosen to structure the thesis in a manner that resonates with the journey of a waka. This occurs in three main sections: the first three chapters Ka rewa te waka (the waka is getting under way), are about the context of the rangahau, the methodology and methods and reflect the preparation of a waka for a voyage. Ka tere te waka ki tai (the waka is moving swiftly across the water), the second section consists of two chapters. These describe the findings, in this way representing the waka in motion travelling towards the destination. The final two chapters, describe the arrival at the place of the theory building and framework development and then the conclusions of the rangahau, in the same way as a waka arrives ashore with new learnings from the journey; Ka ū te waka ki uta (the waka has arrived on land). So with this in mind, a brief description of each chapter follows.

Chapter two: Literature review

This chapter begins by defining traumatic brain injury and it’s significance as a health problem in mokopuna Māori. The local data is contextualised by the international literature which shows marked similarities between Māori, and other minority groups, in terms of patterns of injury and service responses and an absence of culturally determined interventions. This evidence points to the influence of disparate world views, that of the patient’s ethnic culture and the culture of rehabilitation services responses. A synthesis of the literature pertinent to mokopuna Māori traumatic brain injury resonates with local and international authors’ calls for research focussed on ethnic cultural issues in traumatic brain injury rehabilitation (New Zealand Guidelines Group, 2006; Uomoto, 2005). This chapter then sets the scene for the description of the approach taken in this study.

Chapter three: Methodology and Methods

This chapter describes both the process and content of the Rangahau Kaupapa Māori approach taken. A detailed discussion about the underpinnings of decisions made is included. The two questions of the study are articulated; what do Māori say in distinctively Māori settings about mokopuna traumatic brain injury and how can this discourse be used to develop a practical framework for TBI rehabilitation? Use of structured Māori specific rangahau activities called noho puku (self-reflection), whanaungatanga (relating and connecting), kaitiakitanga (guardianship), not previously described as being used in this way, are presented. These activities informed both the research design decision-making as well as ways to interact with all layers of the rangahau process including with the data. Centrifugal thinking, a concept described by an eminent Māori scholar (Durie, 2002) as a type of Māori thinking, is also employed as a novel rangahau tool. The qualitative research
practices of member checking and constant comparison were other mechanisms used in the suite of approaches enlisted to best answer the rangahau questions posed.

The next section of the thesis exemplifies the waka’s journey across the ocean: Ka tere te waka ki tai; the waka is in rapid motion.

**Chapters four and five: results and analysis, first and second layers**

This section focusses on the findings and analysis. The design of this work makes the difference between results and analysis less distinct than in other research paradigms. Levels of analysis inform the presentation of the findings and are woven into each of the results chapters. The analysis is deliberately presented as a finding itself in keeping with this type of research. Seven key ideas were identified in the first layer of findings presented in chapter four. Chapter five describes what I have called a Māori cultural formulation of traumatic brain injury in response to three pūrakau (case studies).

Ka ū te waka ki uta; the waka has arrived on the shore.

**Chapter six: Theory and Framework**

The final section of this report embodies the waka’s arrival at it’s destination. Two key outcomes of this work are presented in this chapter. A theoretical position called **The theory of wairua injury in traumatic brain injury** and the framework **Te Waka Oranga** are described.

**Chapter seven: Conclusions and recommendations**

Finally, the implications of the framework are presented including challenges to implementation and recommendations for future work. Reflections on my work with Māori whānau and their mokopuna with traumatic brain injury and how that could be influenced by Te Waka Oranga is included here. Limitations and strengths of the study are also reviewed. A summary of how this rangahau contributes new knowledge to this important area of health is the concluding synthesis.

**Other comments about this thesis**

I have given a great deal of thought to the best way to write this thesis and I have read others’ views about the optimal ways to present this kind of work (Alvermann, O’Brien, & Dillon, 1996; Sandelowski, 1998, 2002). First, I have attempted to balance the need to be transparent so the reader can engage with the methodological strengths and weakness of the approach with the risk of committing “methodolatry”\(^2\) (Janesick, 2000). Second, I have tried to match the right amount of verbatim quotes with sufficient interpretation of their

\(^2\) a preoccupation with selecting and defending methods to the exclusion of the substance.
meanings in order to reach so called “thick description” without the detail becoming unhelpfully dominant (Ponterotto, 2006) or the interpretation interrupting the flow of the participants voices.

I have included a brief vignette of a moko puna with traumatic brain injury and their situation at the beginning of each chapter. These are not real people but combine elements of moko puna with traumatic brain injury and their whānau that I have had the privilege to work with. This device has helped me to hold the reality of working clinically with whānau in the context of being in the role of researcher. My hope is that this will also help orientate the reader to the dual roles of indigenous clinician and researcher illustrating some of the key learnings of the research journey as described in the conclusion.

I have used the word patient throughout the text to describe a person who is being cared for by health services. Many words are used in such services to describe a person who accesses these types of supports; consumer, service user, tangata whaiora (literally a person who seeks well being) are preferred by some. In this context, the word patient recognises this special role this word denotes, recognising strengths and challenges and the unique and precious relationship between patients, their whānau and health care professionals. I hope this choice of words does not offend, rather can be tolerated as reasonable in this context.

Finally, many Māori words are included. I make no apology for this. Living at the interface of Te Ao Māori and Te Ao Pākehā much of my daily communication is in both languages. A great deal of the discourse from participants was in Te Reo Māori, some of that was in using Māori phrases in largely English sentences. I thought long and hard about how Māori words could look in this thesis. I decided that I did not want these words and phrases to be in a different font or italics because I did not want them to be represented as different in this way, they are part of my lexicon and part of the lexicon of my participants. However, recognising that they may not be familiar to the reader and in some cases where a particular meaning is used in a given context, I have provided explanation either in brackets or in the related text, or both. In addition, I have provided a glossary to assist the reader. I hope the brief translation after the first appearance of words reduces the need for frequent referral to the glossary. My aspiration is that in this way the thesis encourages readers in their use of Te Reo Rangatira (literally the ‘language of chiefs’, another way of describing the Māori language) and as a mechanism for better understanding of Te Ao Māori and therefore, Māori whānau, no matter what the readers’ field of endeavour. Without wanting to preempt the findings, the role of Te Reo Rangatira is an important outcome of this work. Presenting the words in this way is my attempt to honour this throughout.
Roimata was three years old when she sustained a moderately severe traumatic brain injury as an unrestrained passenger in a motor vehicle accident driven by a whānau member. I met her when she was aged 14. Neuropsychiatric assessment demonstrated significant and persistent intergenerational grief about the accident. Roimata had the occasional, but chronic experience of “seeing tupuna” (ancestors). In my opinion these were not psychotic symptoms, rather trauma related cultural phenomena. I recommended she be supported to meet with her koroua and kuia (elders) at her home marae to assist with making sense of her experiences and working to alleviate collective whānau grief. At regular follow up the experiences of seeing tupuna gradually resolved in tandem with the whānau making meaning of their grief.

Introduction

This chapter describes a pragmatic review of the local literature to describe the size and shape of Māori tamariki (child) and taiohi (adolescent) traumatic brain injury (TBI) and to highlight issues pertinent to psychiatrists and other specialists who work in this field. A review of the wider literature describing cultural aspects of international TBI research further contextualises these findings.

Literature searches of Medline, Web of Science, PsychLit and Scopus data bases using the words indigenous, ethnic, culture, native, native american, native alaskan, native hawaiian, Māori, aboriginal, traumatic brain injury, rehabilitation, pa(e)diatric, disparities and epidemiology were undertaken. References lists were also hand-sorted.

The literature is adult-centric and selected papers are summarised. Significant gaps in the literature were found, in particular an absence of research exploring indigenous pediatric traumatic brain injury. Recent local epidemiological studies describe Māori tamariki (children) and taiohi (adolescents) as being significantly over represented in TBI populations with poorer outcomes including higher mortality rates. International research shows evidence of ‘minority’ culture being a risk factor for certain causes of injury and a differential rehabilitation service response.

These findings are particularly important for psychiatrists working with Māori, and are also highly relevant for all health professionals, managers, funders and policy makers whose work impacts on tamariki Māori traumatic brain injury and their whānau. This literature review underscores not only the importance of simply asking effectively about a possible
traumatic brain injury history but also the importance of cultural factors in all aspects of the rehabilitation journey and outcomes. In addition, in identifying literature gaps this chapter highlights a role for use of Rangahau Kaupapa Māori to explore specific Māori cultural aspects of traumatic brain injury, thus laying down the platform for the research undertaken in this study.

Traumatic brain injury in children and adolescents is characterised by a number of distinct features. A central issue is that children and young people are still growing and therefore face the challenge of development in addition to recovery. Another is that children and young people rely on adults to care for them and are influenced both by their own reactions and by the responses of those around them to traumatic brain injury and its sequelae. The impact of TBI both on the process of development within the context of family systems and on specific demands of later development is often difficult to assess, treat and predict. Review of the adult TBI literature reveals an emphasis on the complexity of traumatic brain injury (Gordon, et al., 2006). The developmental and relational needs of children and adolescents with traumatic brain injury add significantly to this predicament. Globally, TBI is a common cause of morbidity and mortality in children and adolescents (Babikian & Asarnow, 2009; J. A. Langlois, Rutland-Brown, & Thomas, 2005). Despite this recognition, research into Māori tamariki (child) and taiohi (adolescent) TBI is very limited. This is surprising given evidence showing that Māori taitamariki (children) face a range of poor prognostic features in terms of risks for injury and poorer outcomes post injury such as higher mortality rates (Barker-Collo, Wilde, & Feigin, 2009; New Zealand Guidelines Group, 2006).

**Definition of TBI**

There is no one globally accepted definition of traumatic brain injury. However, it is generally accepted that TBI is an acquired injury to the brain caused by an external physical force that results in some degree of functional disability, psychosocial impairment or both. TBI is sub-classified into open and closed head injuries. This definition excludes brain injuries that are congenital, processes that are degenerative and injuries sustained by birth trauma. The severity of the injury is classified in a number of ways, using the Glasgow Coma Scale and a range of other factors including post-traumatic amnesia (McKinlay, et al., 2008).

**TBI and psychiatry**

Psychiatrists in all subspecialties work with people with traumatic brain injury, though that aspect may not be the focus of the assessment or treatment. People who have experienced traumatic brain injury are likely to present to psychiatrists because they have an increased risk of developing mental illness and so the importance of obtaining a robust
history of traumatic brain injury is crucial (Hoofien, Gilboa, Vakil, & Donovik, 2001; Koponen, et al., 2002; Shoumitro, Lyons, Koutzoukis, Ali, & McCarty, 1999; Whelan-Goodinson, Ponsford, Johnston, & Grant, 2009). Importantly, these patients may not be aware of the psychiatric salience of their TBI and may not disclose this unless specifically asked, even then the circumstances of the TBI that may mean that disclosure is limited. Communicating with patients and their families about the broad array of influences conveyed by a single or multiple traumatic brain injuries on both the index patient and the family system, and how these influences evolve over time is an important part of psychiatrists’ knowledge and skill. Psychiatrists continue to play a central role therapeutically in working with those people affected by traumatic brain injury and their families, to make meaning of the injury and its effects and in providing both psychological and biological treatment as indicated.

Psychiatrists are an important part of the interdisciplinary team working with people with TBI and their families. The evidence for the efficacy of existing pediatric TBI rehabilitation is scant. Measuring outcomes is challenging because of the range of variables involved. These include the variety of injury and non-injury factors, age and developmental stage (Anderson & Catroppa, 2006; H. G Taylor, 2004). Outcomes that measure real world functional improvement are not consistently included in studies, limiting their generalisability (Anderson & Catroppa, 2006; H. G Taylor, 2004). However, key evidence based elements that have been identified include processes that include the whole family (Laatsch, et al., 2007), information for the whole family (Ponsford, et al., 2001) and specific attention and memory remediation (van’t Hooft, et al., 2005). A recent systematic review found that cultural competency was an important factor in the delivery of rehabilitation services (Hasnian, et al., 2011). However, the review excluded those under the age of 18 years, did not include any papers reporting indigenous endeavours and did not specifically review TBI rehabilitation. Unfortunately, there are no Aotearoa New Zealand studies that have assessed what works in rehabilitation for those children and adolescents with TBI and their families locally.

There are special groups of people with traumatic brain injury that psychiatrists assess and treat; for example proposed patients who are being considered for compulsory treatment, patients with epilepsy and forensic patients where consideration of traumatic brain injury in the psychiatric formulation is essential.

Psychiatrists also play a role in the prevention of traumatic brain injury. This occurs in a range of settings and across the lifespan. For example, in Adult Mental Health Services psychiatrists work with parents who have mental illness and substance abuse problems needing education and support to ensure they understand the importance of using non-physical means of disciplining children and develop strategies to consistently employ these methods. Maternal, Perinatal and Infant Mental Health Service psychiatrists see families
where risk of non-accidental traumatic brain injury is present. Similarly, child and adolescent psychiatrists working with adolescents involved in behaviours that increase their risk of sustaining a traumatic brain injury have the opportunity to educate and develop collaborative preventative strategies. “Old Age” psychiatrists may see patients who are at risk of traumatic brain injury in a range of ways, for example in the context of their high risk of falls or of elder abuse.

Unfortunately, psychiatric training programmes in Australasia have not to date routinely or consistently provided training in psychiatric aspects of traumatic injury to the brain (RANZCP, 2002). However, the curriculum is currently being revised and ‘Acquired Brain Injury’ is included in a draft under current review (Professor P. Hazell, personal communication, October 9, 2011). The extent to which psychiatrists ask about a history of traumatic brain injury is unknown. Given the limited training in this area of psychiatry for most local psychiatrists this is likely to be a small proportion.

Considering psychiatrists as researchers in the field of traumatic brain injury reveals a small local group in Australasia (Professor R. Kydd, personal communication 14 October 2011, (Sachdev, Smith, & Cathcart, 2001). Given the brain is the organ of primary interest in this medical specialty this might have predicted that traumatic brain injury would have attracted more widespread interest. As far as indigenous psychiatrists engaging in both practice and research in this area are concerned, to my knowledge I am the only indigenous psychiatrist in Australasia actively involved.

**Aotearoa New Zealand research**

Traumatic brain injury is a significant health problem in Aotearoa New Zealand. It has been estimated that between 22,000 and 33,000 people have a traumatic brain injury each year, compared to between 7,000 and 8,000 who have a stroke (Feigin & Barker-Collo, 2008). The most recent annual incidence data show that Māori rates are more than three times those of non-Māori; approximately 900/100,000 compared to 300/100,000 (Barker-Collo, Feigin, Theadom, & Starkey, 2012). The costs of these injuries are difficult to quantify. Direct costs of stroke and TBI combined are reported as over NZ$200 million annually (Feigin & Barker-Collo, 2008). Approximate costs of TBI alone have been quoted as NZ$100 million per year (New Zealand Guidelines Group, 2006). Estimates of total costs for child and adolescent traumatic brain injury have not been published.

Aotearoa New Zealand data are consistent with international findings; children and young people are high risk populations for traumatic brain injury. Almost 20% of young people will have sustained a TBI before they turn 14 years old (McKinlay, et al., 2009). Being male, coming from a family with four or more adverse life events and where punitive parenting is used have been identified as risk factors for childhood traumatic brain injury.
Using the New Zealand Information Service data, Barker-Collo et al have described the incidence for under 19 year olds as 140/100,000 per year (2009). They found those under 5 years of age and between 15 and 19 years of age are at greatest risk of traumatic brain injury. Incidence rates of traumatic brain injury were significantly higher for all age bands of Māori taitamariki (young people) compared to non-Māori (Barker-Collo, et al., 2009). Given that Māori make up on average 15% of the Aotearoa New Zealand population, and continue to be a youthful population, this over-representation is cause for grave concern (Statistics NZ, n.d). Preliminary data from the Brain Injury incidence and Outcomes Study in the Community (BIONIC) has reported traumatic brain injury rates of approximately 30%, 25% higher than previously thought (Barker-Collo, et al., 2009). Similarly, the Christchurch Health and Development Study (CHDS) found an overall incidence of traumatic brain injury reported to General Practitioners (both accidental and non-accidental) of approximately 30% in their multi-ethnic cohort between the ages of 0 and 25 years, although unfortunately ethnicity data were not available on the whole CHDS cohort (McKinlay, et al., 2008).

One important area is non-accidental traumatic brain injury (NATBI). This is defined as a pattern of injuries that cannot be explained by accidental means. In some cases this includes brain injury secondary to assault (Kelly & Farrant, 2008). Māori infants have been shown to have one of the highest rates of subdural haematoma in the world, most likely of non-accidental origin. The annual incidence rates are estimated between 32.5 and 38.5/100,000 compared to non-Māori rates of 14.7-19.6/100,000 (Kelly & Farrant, 2008). In another study 77% of a sample of infants admitted to hospital with suspected NATBI were Māori (Kelly, et al., 2009).

Evidence of disparities in Māori access to supports for serious injury, including TBI are well documented (Jansen, Bacal, & Crengle, 2008). Accident Compensation Corporation (ACC) data shows that while Māori have 1.5-2.5 the rates of all injuries compared to non-Māori and they are less likely to access appropriate rehabilitation (Jansen, et al., 2008; New Zealand Guidelines Group, 2006). One report also describes a disproportionately high rate of serious injury in Māori (Jansen, et al., 2008).

No literature was found employing specific Rangahau Kaupapa Māori (Māori methodology and methods) in addressing questions of Māori cultural significance in either tamariki (child) or pakeke (adult) traumatic brain injury. The lack of this type of research investigating Māori traumatic brain injury, let alone for Māori children and young people, points to a fundamental omission in the way in which Māori traumatic brain injury is considered. A notable absence from definitions of traumatic brain injury is culture; the impact of traumatic brain injury on culturally valued roles, responsibilities, skills and activities is not included (Stucki, 2005). One contention here is that the absence of culture from definitions of
functional impairment secondary to traumatic brain injury suggests one reason why Māori culture has not been more actively targeted as an area of research interest. There has been no literature recognising the significance of injury to the head in Māori culture. This cultural silence suggests a need for basic research informed by and building on existing Rangahau Kaupapa Māori to begin to understand more about how traumatic brain injury in tamariki (children) is conceptualised. It is only then that more practical applications of such knowledge can be implemented to improve outcomes for this group.

No local assessment tools that target possible Māori culturally determined influences secondary to traumatic brain injury have been developed. The closest assessment tools used internationally are called measures of “acculturation” (Kennepohl, Shore, Nabors, & Hanks, 2004; Saltapidas & Ponsford, 2007; A. M. Sander, Clark, & Pappadis, 2010; A.M Sander, et al., 2007). Acculturation is defined as the extent to which a person has taken on the cultural mores of the dominant culture compared to that of their culture of origin (Saltapidas & Ponsford, 2007). These measures have been utilised by researchers in a range of countries to further explore the complex role that ethnic culture plays in this context. A number of interesting findings have emerged. For example after controlling for confounders such as gender, age, injury severity and time since injury, in an emic (within ethnic cultural group) research design, a significant correlation was found between what is called “more traditional African American cultural values/beliefs” (p. 573) and lower neuropsychological test scores (Kennepohl, et al., 2004). The suggestion is made that more traditional cultural beliefs are one marker for barriers to improved test performance. Why this occurs is not clear. One idea is that “acculturation stress” (p. 574), usually found most prominent in people who reject both their own culture and that of the mainstream, may account for some of this difference. The authors make the point that acculturation measures have limitations; for example mid range scores are difficult to interpret, the role of the culture of the assessor appears to have an influence on test performance and the role of trust in the cross-cultural exchange between assessor and patient may play a part. Overall, it is recommended that acculturation measures cannot be considered a cultural assessment tool in the context of neuropsychological testing in traumatic brain injury (Kennepohl, et al., 2004).

A general acculturation measure related to health of indigenous peoples has been developed and it’s use reported in a peer review journal (Kaholokula, Grandinetti, Nacapoy, & Chang, 2008). However, no acculturation measures have progressed to implementation, nor been developed specific to TBI in Aotearoa New Zealand. It is interesting to reflect on hypotheses that could explain this. It may be because the term acculturation is not used in the Aotearoa New Zealand rehabilitation literature or practice. It remains unclear why this is the case. However, it is possible that the term acculturation resonates to some degree with the term assimilation, which historically was a goal of colonial governments. In this way the
term may attract negative associations. Another explanation may be that in Aotearoa New Zealand considerable focus has been on what has been called access to Māori cultural institutions (Durie, 1995b, 2001) rather than taking a relativistic position in comparing Māori cultural markers of identity to the dominant culture’s markers. To date these concerns have not been applied to the situation of Māori traumatic brain injury. How aspects of being Māori pre-morbidly compared to how being Māori might be expressed in the context of a tamariki (child) and taiohi (adolescent) traumatic brain injury, both in the index patient and their whānau has not previously been investigated.

**International literature examining ethnic culture and TBI**

The international literature identified in this review describes both high rates of TBI in minority and indigenous cultures as well as disparities in the way in which services respond (Adekoya & Wallace, 2002; Arango-Lasprilla, 2009; Arango-Lasprilla, Ketchum, Gary, Corrigan, et al., 2009; Arango-Lasprilla, Ketchum, Gary, Kreutzer, et al., 2009; Arango-Lasprilla & Kreutzer, 2010; Arango-Lasprilla, Rosenthal, Deluca, et al., 2007; Arango-Lasprilla, Rosenthal, Deluca, et al., 2007; Blackmer & Marshall, 1999; Burnett, et al., 2003; Chang, Ostir, Kuo, Granger, & Ottenbacher, 2008; Gary, Arango-Lasprilla, & Stevens, 2009; Haider, Cornwell, Efron, Haut, & Chang, 2008; Haider, et al., 2007; Hall, 2008; Keightley, et al., 2011; Keightley, et al., 2009; J. Langlois, et al., 2003; J. A. Langlois, et al., 2005; Nelson, Rhodes, Noona, Manson, & Al-SUPERPFP, 2007; Plata, et al., 2007; Rutland-Brown, Wallace, Faull, & Langlois, 2005; Selaissie, Pickelsimer, Frazier, & Ferguson, 2004; Shafti & Gentilello, 2008; Shafti, Plata, Diaz-Arrastia, Bransky, et al., 2007; Shafti, Plata, Diaz-Arrastia, Shipman, et al., 2007; Staudenmayer, Diaz-Arrastia, Oliveira, Gentilello, & Shafti, 2007). Only one study was identified that examined the cultural aspects of paediatric traumatic brain injury (Haider, et al., 2007). The authors found that ‘black’ children with TBI had significant pre-morbidities, penetrating trauma, injuries characterised by violent intent, higher unadjusted mortality and longer mean intensive care stays (Haider, et al., 2007). These children were more likely to be discharged to an inpatient rehabilitation facility and had increased risk of functional deficit on discharge for the domains studied. This paper received critique in the letters to the editor related to the authors’ suggestion that racism from professionals was a contributory factor to differences in responses of services (Hall, 2008). The authors reiterated their findings based on sound methodology acknowledging that these findings, while difficult to accept, were nevertheless important to consider in modifying practice (Haider, et al., 2008).
Significance of family in the TBI literature, implications for Māori

Family involvement is recognised as crucial in optimising rehabilitation outcomes for children with TBI and their caregivers, and measures have been developed to assess this aspect (Burgess, et al., 1999; Rivara, et al., 1994; Saltapidas & Ponsford, 2007; A.M Sander, et al., 2007; H.G. Taylor, Drotar, & Wade, 1995; H. G Taylor, et al., 1999; H. G Taylor, et al., 2001; Yeates, et al., 2002). Implications of these findings for Māori whānau (families) have not been explored. This is particularly salient given robust evidence that non-injury factors related to the ‘race’ of the family moderated child and adolescent TBI outcomes, when comparing ‘black’ and ‘white’ families in the United States, (A.M Sander, et al., 2007; Yeates, et al., 2002). According to the measures used, ‘black’ families utilised coping strategies such as religion, mental disengagement and denial. The differences between the two groups were largely independent of socio-economic status. The authors called for further research to examine possible mechanisms by which ‘race’ might moderate traumatic brain injury outcomes in other cultural groups. They suggested that exploration of family coping strategies and supporting families to accept the injury as one possible way of alleviating the families’ distress. Some authors have described that this process of reducing family distress would occur “only if the assistance is provided in a culturally sensitive fashion” (p. 401) (Yeates, et al., 2002). Measures used suggest that “traditional ideology” (p. 15) in Hispanic and African American caregivers were associated with greater care-giver distress (A.M Sander, et al., 2007). Traditional ideology was not defined. This begs the question, what is the traditional ideology of care giving in non-Hispanic, non-African American families? This matter has not been addressed specifically in the literature. However, a related finding in this study was that ‘whites’ made less use of emotion-focused coping.

Australian researchers found that those from minority, culturally and linguistically diverse backgrounds (CALD) demonstrated significantly greater distress about changes in their role, such as that of parent or caregiver as measured by a scale they developed called The TBI, Rehabilitation and outcome Attitude Rating Scale (TBI-AS) (Saltapidas & Ponsford, 2007). However, the scale had not been validated.

Using the family as active participants in their child’s traumatic brain injury rehabilitation has recently been the subject of positive findings published from a randomised control trial in Brazil (Braga, Da Paz Junior, & Ylvisaker, 2005). By providing robust evidence of the scope of the role of whānau, this study lends weight to the need for exploration of the role of whānau in tamariki/mokopuna traumatic brain injury rehabilitation in Aotearoa New Zealand.

In the next section several papers are highlighted given the nexus between traumatic brain injury and features of indigenous culture.
Indigenous TBI literature

The Indigenous TBI literature is largely North American with a small number of relevant Australian studies also identified. The North American literature uses the terms ‘American Indian and Alaskan Natives (AI/AN)’, ‘native and non-native’ and is adult-centric (Adekoya & Wallace, 2002; Blackmer & Marshall, 1999; Keightley, et al., 2011; Keightley, et al., 2009; J. Langlois, et al., 2003; Nelson, et al., 2007; Rutland-Brown, et al., 2005). As found elsewhere, male traumatic brain injury is more than twice as common as in the female population (Adekoya & Wallace, 2002; J. Langlois, et al., 2003). The authors note the likely under-reporting of traumatic brain injury because of use of tribal facilities and remote locations (Adekoya & Wallace, 2002). Traumatic brain injury rates secondary to assault were highest in African Americans and AI/AN reported as 30/100,000, a rate 4 times that of ‘whites’ (J. Langlois, et al., 2003).

Prevention strategies related to motor vehicle accidents (MVA) and assaults were predicated on increased rates of elevated blood alcohol levels and limited use of seatbelts and helmets (Adekoya & Wallace, 2002; Rutland-Brown, et al., 2005). Imperatives for prevention also included high rates of mood and anxiety disorder in the indigenous TBI population compared to the indigenous comparison group without TBI (Nelson, et al., 2007).

Differences in presentation between native and non-native people admitted for inpatient traumatic brain injury rehabilitation included high alcohol and other drug use; 83% of the native group compared to 9% of non-native patients, as well as in follow up support where non-native post discharge support was 90% compared to 33% for native patients (Blackmer & Marshall, 1999).

Two qualitative studies found that there were significant challenges for Aboriginal adults in North America with TBI in transitioning home from hospital (Keightley, et al., 2011; Keightley, et al., 2009).

Non-indigenous TBI literature

A number of studies have demonstrated that ethnic cultural factors are associated with different outcomes at all stages of the TBI journey in non-indigenous populations (Arango-Lasprilla, 2009; Arango-Lasprilla, Ketchum, Gary, Corrigan, et al., 2009; Arango-Lasprilla, Ketchum, Gary, Kreutzer, et al., 2009; Arango-Lasprilla & Kreutzer, 2010; Arango-Lasprilla, Rosenthal, DeLuca, et al., 2007; Arango-Lasprilla, Rosenthal, Deluca, et al., 2007; Burnett, et al., 2003; Chang, et al., 2008; Gary, et al., 2009; Kolakowsky-Hayner, 2010; Plata, et al., 2007; Selaissie, et al., 2004; Shafti & Gentilello, 2008; Shafti, Plata, Diaz-Arrastia, Bransky, et al., 2007; Shafti, Plata, Diaz-Arrastia, Shipman, et al., 2007; Staudenmayer, et al., 2007). TBI caused by violence has been shown to be higher in adult minority groups (Burnett, et al., 2003). Differences have also been shown in initial
management of TBI and in referral to post-Emergency Department Hospital care (Selaissie, et al., 2004; Shafti & Gentilello, 2008). Long-term functional outcomes have been shown to demonstrate ethnic disparities (Staudenmayer, et al., 2007). Access to rehabilitation was 15% lower in Hispanics compared to non-Hispanic ‘whites’ in one large study of almost 60,000 patients with severe TBI, after accounting for insurance status (Shafti, Plata, Diaz-Arrastia, Bransky, et al., 2007). However, findings are not consistent, with no disparity in rehabilitation placement found in another study (Shafti, Plata, Diaz-Arrastia, Shipman, et al., 2007). A statistically significant diminished quality of care was reported in minorities compared to ‘caucasians’ as measured by fewer minutes in the rehabilitation treatment modalities of physiotherapy, occupational therapy and speech language therapy (Burnett, et al., 2003). Despite ‘whites’ having higher functional status, Hispanics had higher rates of discharge home after adjusting for demographic factors, health related factors and functional status at the time of discharge (Chang, et al., 2008). Arango-Lasprilla measured life satisfaction in a retrospective study of 3,368 people, one-year post moderate to severe TBI (2009) and found African Americans had a poorer life satisfaction than other groups.

The language spoken by patients has been shown to effect TBI rehabilitation outcome. Spanish-speaking Hispanics were found to be 15 times more likely to have a disability than English speaking Hispanics with a similar injury (Plata, et al., 2007).

Australian researchers examined cultural influences on motivation for participation in rehabilitation in non-indigenous groups (Saltapidas & Ponsford, 2007). They have also reported on this groups experience and beliefs about TBI and the association with outcome (Saltipidas & Ponsford, 2008). They found that there were significant cultural differences that suggested role was very important in minority cultures and that having a value system different to what was termed ‘Australian’ was associated with worse outcomes. Interestingly, Saltipidas and Ponsford commented that:

variables related to culture, emotional response, understanding of injury and education were more strongly related to outcome than variables traditionally related to outcome, such as age and injury severity (p.11).

Finally, there has been one recently published paper that found significant differences in case closure in adult TBI vocational rehabilitation between ‘white’ and ‘non-white’ clients (Kolakowsky-Hayner, 2010).

**Implications for tamariki and taiohi with TBI and their whānau**

Why is this literature important for Māori? In this section several components of particular salience for Māori are underlined. These can be understood as both features of
risk and as areas with potential for building resilience. Definitions and examples of rehabilitation and the wider policy context are presented to illustrate this premise. These aspects are described to further set the scene for the conclusions of the chapter and provide a foundation for the rest of the thesis.

While studies of Māori across various domains of TBI rehabilitation have not yet been conducted, it is possible that because the health profile of Māori tamariki and taiohi is similar to those of minority and indigenous cultures elsewhere, that Māori experience is similar to minority cultures in other parts of the world (Flores, 2010). The persisting confluence of recognised risk factors for poorer outcomes following TBI; age (Barker-Collo, et al., 2009), low socioeconomic status (Barker-Collo, et al., 2009), higher rates of adolescent pregnancy (Dickson, Sporle, Rimene, & Paul, 2000), substance abuse and incarceration (Barnfield & Leathem, 1998), exposure to violence (Advisory Group on Conduct Problems, 2009) and pre-existing behavioural problems (Fergusson, Horwood, & Ridder, 2005) and mental illness (Oakley-Brown, Wells, & Scott, 2006) confer a substantial loading of risk for Māori tamariki, taiohi and their whānau. At the same time they suggest areas for prevention, early intervention and capacity enhancement. It is important to note that population trends show Māori will continue to be a youthful population for at least the next 15 years and that an increasing proportion of children and adolescents in Aotearoa New Zealand will have Māori whakapapa (genealogy) (Statistics NZ, n.d). Another important consideration is the growing number of tamariki, taiohi and whānau who speak Te Reo Rangatira (the Māori language) as their first language (Te Puni Kokiri, 2007, 2010). This issue drives an increasing need to ensure culturally responsive health care approaches for tamariki and whānau who feel most comfortable communicating and conceptualising in Te Reo Rangatira and who may find conversing in English, particularly at times of stress such as post-TBI, very difficult.

**Rehabilitation**

How then does the literature describe rehabilitation, and in what ways may this have particular reference to tamariki Māori with traumatic brain injury and their whānau?

TBI rehabilitation can be summarised as a treatment journey directed at maximising the functional independence of a person with traumatic brain injury by decreasing impairment, handicap and disability (Arffa, 2006; Gordon, et al., 2006; Ylvisaker, 1998). However, little or no reference is made to a cultural worldview regarding responses to cultural domains of experience that may be impacted by traumatic brain injury (Gordon, et al., 2006). This absence of cultural considerations has been elegantly highlighted by others (Uomoto, 2005). The differential response from minority cultural groups to the rehabilitation goal of community integration has been highlighted in recent literature (A. M. Sander, et al., 2010). Lack of customising of the priorities of patients with traumatic brain injury and their families is a recognised limitation of current validated rehabilitation measures. The importance of creative
activities such as dance and extended social networks in some cultures is absent from these generic measures (A. M. Sander, et al., 2010).

The dominance of focus on independence as a rehabilitation goal in the literature creates a significant challenge from a Māori perspective. Te Ao Māori (the Māori world view) places value on inter-dependence as well as independence, predicated on whakapapa (genealogical links). These values emphasising interconnection embody central aspects of Te Ao Māori (Marsden, 2003; Moko-Mead, 2003; Royal, 2002; G. Smith, 2003). However, a recent state of science paper (Gordon, et al., 2006) also emphasised the importance of therapeutic interdependency stating, “establishment of an effective therapeutic relationship is associated with better traumatic brain injury rehabilitation outcomes” (p.358). Exploration of how the values of interdependence and independence might be used in strengthening a shared approach for whānau and clinicians to improve TBI rehabilitation outcomes therefore has merit.

Another important feature of traumatic brain injury rehabilitation is that outcomes are improved by ensuring exposure to both an enriched environment of therapeutic interventions and one that reflects real world experiences. This is because incorporating aspects of the real world better attunes the neuronal re-organisation, predicated on the concept of neuroplasticity, necessary for the recovery of everyday function (Beaulieu, 2002). This evidence suggests that the inclusion of real world cultural activities could be regarded as an important part of Māori traumatic brain injury rehabilitation. This possibility has yet to be investigated. Evidence also suggests early traumatic brain injury rehabilitation more effectively decreases impairment and disability (Ylvisaker, 1998). Impairment and disability may therefore be diminished by including Māori specific aspects that come from the real lives of these patients from the earliest juncture.

Three specific examples illustrate implementation of Kaupapa Māori (Māori specific) practices in clinical rehabilitation services. Two of these come from the mental health sector and one from adult traumatic brain injury rehabilitation. One of the inherent challenges for these services is to attempt to measure the impact of Kaupapa Māori interventions in the context of the range of other modalities of treatment offered.

Tanewhakapiripiri is the name of the Kaupapa Māori psychiatric rehabilitation unit which opened at The Mason Clinic Regional Forensic Service in Auckland in 2006. The rationale for the rehabilitation approach taken is well described (Tapsell, 2007). Development of an outcome measure relating to this Kaupapa Māori rehabilitation has been a core feature of the service (N. Wiki, personal communication, 2010). Tamahere Hospital and Healing Centre is another example of a Kaupapa Māori rehabilitation facility in the Waikato region also utilising tikanga Māori to improve outcomes for forensic psychiatric whānau (R. Wirihana, personal communication, October 14, 2011). Lastly, ‘abi’ is an Accident
Compensation Corporation funded regional provider of adult TBI rehabilitation services (http://www.abi-rehab.co.nz/). ‘abi’ has contracted “What ever it takes, Ū ki te whānau ora, Home Rehabilitation and Support Services Ltd”, a Kaupapa Māori provider to ensure a Kaupapa Māori model of care is provided for Māori whānau within the service since early 2009 (http://www.whateverittakes.co.nz/). Building cultural competency within the clinical team has continued to be a challenging area of work (C. Tinana-Williams, personal communication January 21, 2011).

**Policy imperatives**

A number of policies form another contextual layer of this literature review. The New Zealand Disability Strategy, developed in consultation with disabled people and the disability sector, outlines fifteen objectives (Minister for Disability Issues, 2001). Objective 11 is specific to Māori and includes this statement:

> Build the capacity of disabled Māori through equitable allocation of resources within the context of Māori developmental frameworks, establish more disability support services designed and provided by Māori for Māori, ensure mainstream providers of disability services are accessible to and culturally appropriate for disabled Māori and their whānau, train more Māori disability service provider professionals and increase the advisory capacity of Māori (p. 25).

The document also includes point 11.5 which states:

> ensure that Government funded or sponsored marae-based initiatives meet the access requirements of disabled people (and encourage all other marae based initiatives to also meet those requirements) (p. 25).

While not directly locating disability services on marae the strategy recognises marae as places that are important to Māori especially in meeting the needs of Māori with disabilities. Later in the thesis the role of marae is expanded on as playing a significant role in the methods of this study, resonating with the identification of marae as important places for Māori in the New Zealand Disability Strategy.

As is pointed out by Wiley (2009), the New Zealand Disability Strategy holds significant potential as it is underpinned by a social model of disability. This position advocates the premise that full participation in society is a consequence of a range of contextual socially determined factors. This is in contrast to the medical model which focuses on an individual’s physical and or psychological illness factors determining their disability. Informed analysis of the New Zealand Disability Strategy and proposed culturally effective framework for Māori provide useful consideration for this project (Nikora, Karapu, Hickey, &
Awekotuku, 2004; Ratima, et al., 1995). The issues of disability as an identity for Māori are raised, and whether Māori with disabilities choose to use the word disability. Lack of acknowledgement of tikanga Māori is reported as one aspect influencing the barriers of access for Māori to disability support services (Nikora, et al., 2004; Ratima, et al., 1995).

Another piece of policy work, Te Kōkiri, the mental health and addiction plan 2006-2015 outlines the need for building quality health services based on research to inform innovation in health and disability care delivery based in the New Zealand context (Minister of Health, 2006). This policy then provides a structure and direction for efforts that might meet that need in the area of tamariki and rangatahi traumatic brain injury and their whānau.

Gaps in the literature
As has been highlighted throughout this chapter, there are major gaps in the peer review literature which signal the need for specific areas of research. While Māori health inequities are well described (Robson & Harris, 2007), there are no current publications that place mātauranga Māori (Māori knowledge) and tikanga (culturally determined lore) at the centre of research related to tamariki and rangatahi TBI rehabilitation.

The scientific literature is recognised as demonstrating a number of general biases. These include the influence of funding sources, researcher interests, and publication bias (Tallon, Chard, & Dieppe, 2000). These issues are likely to contribute to the paucity of peer review literature specifically addressing tamariki and taiohi traumatic brain injury rehabilitation not only as a topic worthy of exploration, but also one which requires culturally appropriate methodological approaches to begin to understand the Māori world view of traumatic brain injury. The literature also highlights the limited number of psychiatrist researchers in the field. A cautionary note is sounded about the importance of research investigating this area addressing the “unique needs of Indigenous persons with disabilities”, otherwise discrimination already experienced will be perpetuated (Wiley, 2009).

The Accident Compensation Corporation and the New Zealand Guidelines Group have a clearly described research agenda in an attempt to address their analysis of gaps in the literature (New Zealand Guidelines Group, 2006). Entitled, “Objectives for future research on Traumatic Brain Injury in New Zealand” they articulate their priorities towards the conclusion of their evidence-based best practice guideline (p. 203). These include children and young people as a priority because “there are many areas where there is simply no information” (p. 203). The study presented in this thesis can be seen as a response to that agenda.
Summary

Analysis of the literature presented in this chapter has explored the size and shape of Māori child and adolescent TBI, and has reviewed the wider international literature related to cultural factors and TBI.

There is clear evidence of over representation of Māori children and adolescents in populations of TBI. However, what is striking is the paucity of published research that focusses on the children and young people at highest risk of traumatic brain injury. The absence of specific research exploring aspects of TBI for this group and their whānau is a significant gap in the literature.

Given the gaps identified in the literature there is a clear role for the application of indigenous knowledge systems to inform both the process and content of research on this topic. In Aotearoa New Zealand recognising these gaps invites an approach from within Te Ao Māori (the Māori world view). In this way culturally salient Māori explanatory models could be identified. However, introducing the topic of traumatic brain injury from a Māori perspective needs to be carefully done, mindful that in Te Ao Māori (the Māori World View) ‘he tapu te upoko’ (the head is sacred). Utilisation of Rangahau Kaupapa Māori methodologies is required so the process of investigation remains culturally safe. The next chapter expands on these ideas, describing the methodology and methods taken in exploring the uncharted waters of Māori child and adolescent traumatic brain injury rehabilitation.

A version of this chapter has been accepted for publication in the February edition (2012) in the journal Australasian Psychiatry (Elder, 2012).
Moana was 10 years old when she was first referred for neuropsychiatric assessment. She had experienced a non-accidental brain injury as an infant and had significant sequelae including reduced cognitive capacity. She and her whānau had access to a comprehensive network of professional supports. Her whānau attributed her "short fuse" to the momo (traits) inherent to her whakapapa (genealogy). I recommended work to strengthen whānau capacities be undertaken. The whānau commented they appreciated having their experiences as Māori reflected in the clinical reports through the use of Māori terms and understandings.

Introduction

This chapter characterises both the rationale for the research decisions made and the research procedures. Firstly, a review of relevant Kaupapa Māori theory and rangahau (research) locates the approach taken. These together with theory building from other paradigms sets the scene for the methods employed. The existing use of Māori cultural frameworks, both interventional and theoretical provides further orientation to the theory building and framework development proposed. Because Rangahau Kaupapa Māori means different things to different authors this chapter defines what it means here; research conducted by a Māori person using Māori practices informed by a system of Māori determined checks and balances with the aim of improving a serious health issue, traumatic brain injury, impacting on Māori whānau.

The aims of this rangahau (research) are described. These are twofold: first to find out what Māori people say in marae wānanga (discussion fora in traditional meeting houses) about traumatic brain injury using the well known Māori notion “he tapu te upoko” (the head is sacred) as a starting point. The second goal was the use of these responses to illuminate both a Kaupapa Māori Theory of tamariki (child) and taiohi (adolescent) traumatic brain injury and a practical framework for use in rehabilitation settings. Having identified an absence of literature describing how Māori conceptualise traumatic brain injury in the previous chapter, despite compelling evidence that traumatic brain injury is an area of particular need for tamariki Māori, it is argued that this formative descriptive method is needed, in the first instance, to provide a robust platform for future research.

Specific Rangahau Kaupapa Māori practices are delineated. How noho puku (self–reflection), whanaungatanga (connection with others) and kaitiakitanga (guardianship) have
shaped decision making demonstrate the bones of the rangahau design. The nature of the subject matter, having tapu (a sacred and restricted quality) as a central component, raised challenges of where these discussions would best take place, who could be asked to participate and how. What supports would be required to safely undertake this study was a central question. These matters were carefully considered. Resolution of these dilemmas came in the form of marae based wānanga using pūrākau (stories) and establishment of a Rōpū Kaitiaki (guardianship group).

The overarching purpose of this chapter is to be transparent about the rationale for what was done, to describe the method, thereby reporting the inherent strengths and limitations of this process.

**Rangahau Kaupapa Māori**

How this type of rangahau might best be done warrants enquiry into the relevant methodology literature. There is extensive scholarly Māori discourse addressing the question what is Rangahau Kaupapa Māori, with many authors also referring to ‘Kaupapa Māori Rangahau’ (Bishop, 1998; Borrell, 2005; Cheung, 2003, 2010; Cheung, Gibbons, Dragunow, & Faull, 2007; Coupe, 2005; Cunningham, 2000; Durie, 1995a, 2002, 2003, 2004; T. K. Kingi, 2002; McClintock, Mellsop, Moeke-Maxwell, & Merry, 2010; Metge, 1995; Moewaka Barnes, 2000a, 2000b; Moko-Mead, 2003; Pihama, 2010; Pihama, Cram, & Walker, 2002; Royal, 2002; G. Smith, 2003). This body of critical engagement with the concepts of kaupapa (subject/agenda), Māori (normal, ordinary, an indigenous people from Aotearoa New Zealand), mātauranga (knowledge systems), tikanga (cultural lore), whānau (extended family) and hauora (wellbeing) has established conceptual conventions which provide a rich platform for the deliberation of methodological considerations for this study. Defining Rangahau Kaupapa Māori is no simple matter (L. T. Smith, 1995). The intricacies of thinking into this area are eloquently described in Smith’s seminal work “Colonizing Methodologies. Research and Indigenous Peoples”. Here Smith dissects the roles of researcher and participant cautioning against pitfalls where researchers, Māori and non-Māori alike, unwittingly assume power over participants (L. T. Smith, 1999). Nepe’s early work provided formative parameters about the unique epistemological and metaphysical underpinnings of Kaupapa Māori (Nepe, 1991). This body of analysis resonates with other contributions to the field where use of tikanga (cultural lore) can be employed to contain a research space where there are both protective and connecting elements conferred by manuhiri (guest) status (McClintock, et al., 2010). One emerging theme in this literature is the description of specific application of Rangahau Kaupapa Māori practices (Cheung, 2010; Cheung, et al., 2007; Durie, 2002; Elder, et al., 2009; Glover, 2000; Hudson, Milne, Reynolds, Russell, & Smith, 2010; Lilley, 2009; McClintock, et al., 2010; Pihama, 2010;
Pihama, et al., 2002; L. T. Smith, 1999). With this in mind, detailed description of this study’s methodology and methods adds to the range of Rangahau Kaupapa Māori approaches already in use.

How Rangahau Kaupapa Māori and understandings grounded in Te Ao Māori (The Māori World) might relate to other paradigms of knowledge has also been described (Cheung, 2010; Durie, 2004). This interface between the Western scientific paradigm and Indigenous knowledge has been described as an opportunity for the expansion of knowledge and understanding (Durie, 2004). As Durie says:

The challenge is to afford each belief system its own integrity while developing approaches that can incorporate aspects of both and lead to innovation, greater relevance and additional opportunities for the creation of new knowledge (p. 1143).

These ideas are reflected in both Cheung’s published work (Cheung, 2003; Cheung, et al., 2007) and in her doctoral thesis (Cheung, 2010). From her perspective, these knowledge paradigms can co-exist and overlap, forming places where Māori researchers, who stand in both worlds, can observe the “other” world view as well as the confluence of both.

The decision to call this approach Rangahau Kaupapa Māori was determined by the rules of grammar in Te Reo Māori which place adjectives after nouns (Harlow, 2001). Therefore, rangahau, the noun denoting the research is followed by the attribute of being specific to Māori. For those familiar with the rules of grammar in Te Reo Māori and aware that using two adjectives one after another usually requires two phrases, I trust the use of the term ‘Kaupapa Māori’ as a single descriptive entity will be accepted.

Other methodological considerations

Initial conceptualising of the methodology was focussed on the idea of the interface of two worlds: Te Ao Māori and the world of traumatic brain injury rehabilitation. However, as consideration of the methodology continued it became clear that the issue of the interface was more appropriately considered at the theory building and framework development phases rather than the data collection phase. The risk of continuing to link the interface of Māori experience and the world of traumatic brain injury rehabilitation at the earlier stage was that rehabilitation paradigms would dominate and Māori participants might be more likely to share their thoughts relative to their experience of “other”. This study aspired to ensure participants would contribute in ways that minimised a relativistic stance. In this way the decision was made to focus entirely on the Māori voice, in a non-rehabilitation space, rather
than eliciting information from rehabilitation specialists or those whānau in current rehabilitation programmes.

A summary of related cultural frameworks for both Māori and other cultures is now outlined. This is to further establish the rationale for choosing a framework as an outcome of this study’s design. The central challenge of how the data is transformed into a framework, using Kaupapa Māori theory building approaches and those from other aligned research paradigms is then described.

**Māori cultural frameworks; interventional and theoretical**

Frameworks have been used internationally in a range of fields closely related to the current rangahau. These include rehabilitation classification of functioning (Stucki, 2005), nursing practice (Blackford, 2003), multi-ethnic counselling for consumers with disabilities (Lewis, 2006), violence rehabilitation (Howells, Day, Byrne, & Byrne, 1999) and in the description of cultural identity of American Indians in rehabilitation services (Pichette, Garrett, Kosciulek, & Rosenthal, 1999).

For more than fifteen years Māori cultural frameworks have been published that articulate and advocate for the cultural needs of Māori who need rehabilitation and disability services and their carers, though none specifically for traumatic brain injury, nor for tamariki (Collins & Hickey, 2006; J. Kingi & Bray, 1999; Nikora, et al., 2004; Ratima, et al., 1995). This emergent literature may reflect both the growing awareness of data related to cultural influences in disability rehabilitation outcomes as well as a response to the invisibility of culture in ‘mainstream’ definitions of disability and rehabilitation needs found to date. It is also likely this has also been in response to the influence of Māori cultural frameworks that have been effective in other related spheres such as health and education. A description of some of these frameworks is provided next.

**Māori cultural intervention frameworks**

Māori cultural intervention frameworks have been developed to provide clarity and guide practices in a range of arenas including ethics, policy, research, health and education (Cunningham, 2000; Hudson, et al., 2010; McClintock, Mellsop, & Kingi, 2011; Ministry of Health, 2002; Pere & Nicholson, 1991; Pihama, et al., 2002; Pitama, et al., 2007; Ratima, et al., 1995; Tapsell, 2007). These frameworks can also aid the assessment of response (T. K. Kingi, 2002; McClintock, et al., 2011; Ratima, et al., 1995). These attempts to structure thinking and practice, sometimes also called models, have been developed by similar processes; literature review, interviews, discussion, theorising and finally crafting of the framework. Elements of these frameworks include; a set of underpinning values, how these
values manifest in activities and the details of what these values-driven activities entail. Sometimes consensus hui to validate or measure findings are held. Aspects that relate to all people are sometimes considered as well as those that are Māori specific (Ratima, et al., 1995).

The extent to which Māori cultural frameworks are implemented and used for their original purpose varies and questions remain about what aspects of the frameworks actually result in culturally responsive action (Hudson, et al., 2010; McClintock, et al., 2011; McClintock, et al., 2010; Tapsell, 2007). Nevertheless, Māori cultural frameworks are an established approach to building culturally robust responses to Māori needs in a variety of domains. While it could be more commonly considered that Māori cultural frameworks are used to inform responses from a non-Māori organisation or individual, Māori cultural frameworks are equally important in assisting Māori responses to Māori. This can be understood as necessary because of the dimension of Māori cultural competency within the Māori workforce (Matua Raki, 2010). It is therefore the contention here that a framework for response to tamariki and rangatahi with traumatic brain injury and their whānau would be a useful guide to all those involved in this area.

A table briefly outlining a range of selected frameworks is presented below in alphabetical order according to the first author’s name, to illustrate the range of frameworks already described in the literature.

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<th>Table 1</th>
<th>Frameworks</th>
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<tr>
<td><strong>Author</strong></td>
<td><strong>Year</strong></td>
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<tr>
<td>Cunningham, C</td>
<td>2007</td>
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<td>Durie, M</td>
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<td>Durie, M</td>
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Pitama, S. et al 2007 Meihana model. A psychological assessment and intervention framework, based on Te Whare Tapa Whā with two additional elements; Taiao (physical environment) and Iwi Katoa (societal context). Developed by literature review, interviews with practitioners about implementation of Te Whare Tapa Whā, testing in clinical practice, peer review and use in teaching and cultural competency training.

Ratima, M et al 1995 Te Anga Whakamana. A framework of effective disability support services. Based on literature review, structured interviews, discussion, draft philosophy and consensus hui.


Māori theoretical frameworks

While there is no one definition of Kaupapa Māori Theory, theory building has been a central activity which serves to draw together the key aspects of Kaupapa Māori frameworks (ref). Although not always described as theory building, the process exemplifies this practice (Cheung, 2010; Pere & Nicholson, 1991; Pihama, 2010; Pihama, et al., 2002; G. Smith, 2003; L. T. Smith, 1995, 1999; L. T. Smith & Reid, 2000). Central tenents of Kaupapa Māori Theory include the assumptions of Critical Theory examined in the context of Te Ao Māori (G. Smith, 2003). In this way Kaupapa Māori Theory is a critial examination of the social and cultural elements of Te Ao Māori with the view to liberation from oppression and dependence. Māori theorists describe the territory of Kaupapa Māori theory as a safe and evolving space for engaging in ways of thinking that are authentically and intrinsically Māori. How Kaupapa Māori theory and rangahau relate to other theoretical positions is a matter of debate (Grant & Giddings, 2002; Pihama, 2010; Pihama, et al., 2002; L. T. Smith, 1999). Smith describes the territory as, “both less than and more than” a paradigm (p. 190) (L. T. Smith, 1999). Nevertheless, what Māori scholars emphasise is that Kaupapa Māori approaches, both theoretical and research based, are about Māori development. They underscore that those working in this field respond to those aspects of Māori social development most in need (L. T. Smith, 1999). It would appear then that Kaupapa Māori theory and practices are continuing to evolve and develop according to Māori perceptions of
the gravity of need. Reasons for a reluctance to specify and define the characteristics of Kaupapa Māori Theory have been proposed (Mahuika, 2008). These include caution about the appropriation of any such definitions leading to the exclusion some Māori (Mahuika, 2008; Mane, 2009). One of the tensions described in this discourse is that of the contested nature of cultural authenticity (Kukutai, 2004; Linnekin, 1991). This writing describes the risks of creating hierarchies of exclusivity. This aspect has been reflected on throughout this study. Methods employed to invite participation in this rangahau (research) on cultural terms that are determined by participants are described later in this chapter.

One central idea continues to be reflected in this body of scholarship. This is the importance of Kaupapa Māori theory and research as an autonomous indigenous approach, and of the risk of perpetuating indigenous realities as defined by colonisation when these endeavours are defined relative to western scientific practice. These autonomous Māori practices may also be difficult to identify or may remain unnoticed because they are lived experiences and deemed “ordinary” by Māori (Moewaka Barnes, 2000). This marginalisation of Māori practices is further perpetuated by the privileging of other knowledge systems over Māori knowledge. This can be considered an influence of both internalised and external effects of colonisation whereby Māori knowledge and mechanisms for the transfer of that knowledge were systematically destroyed (Jackson, 2007). However, reclamation of Māori knowledge traditions over the last thirty years has seen the burgeoning of exploration and discussion of these contemporary Māori experiences, forming an evolving Kaupapa Māori theoretical discourse, in large part driven by the revival of Te Reo Māori (the Māori language) (Cunningham, 2000; Durie, 1994; Pere & Nicholson, 1991; Pihama, 2010; Pihama, et al., 2002; L. T. Smith, 1999).

“A call to theory”

Smith’s work (G. Smith, 2003) describes a “call to theory” (p. 4) and lays down a specific set of rules for this process. He describes that in order to be useful any Kaupapa Māori theory must first be a positive transformational tool, in that it must respond to an observation that something that is occurring needs to change. He cautions the importance of recognising that theory can be used in both positive and negative ways. While emphasising that struggle has long been recognised as a key component of the Kaupapa Māori imperative, Smith suggests that theory needs to provide for adaptation and to move beyond struggle. Theory must, in the end, be accountable to the Māori community. Smith goes on to elaborate on the components or tests of a Kaupapa Māori theory. To paraphrase his list of requirements, he outlines that the theory must be able to take up a position within the current knowledge systems recognising the power relations of academia and governance dominated by non-Māori structures (p. 5). The theory must be robust in that it will face scrutiny and
critique from colonising imperatives, hegemonic influences and Kaupapa Māori colleagues. This sentiment resonates with Durie’s description of the dangers of working at the interface of knowledge systems where practitioners and researchers run the risk of being pilloried and having their findings rejected by both Māori and Pakeha (Durie, 2004). The theoretical contribution must make sense to the Māori community and be able to make a positive difference. And finally, the theory must be designed to be part of ongoing quality assurance from those it seeks to serve. This set of guidelines provided a useful navigational tool for the process of this rangahau and the analysis of its findings and their implications. These aspects will be returned to in the final chapters to assess how the actual rangahau unfolds.

Overall then, Rangahau Kaupapa Māori in this study means rangahau that is sited within a Kaupapa Māori theory. Kaupapa Māori theory is distinctly Māori and continues to respond to contemporary Māori experiences, it’s source being Māori defined and privileging Māori self-determination. This study aims to add new theoretical constructs to existing Kaupapa Māori Theory via Rangahau Kaupapa Māori practices. Specific Kaupapa Māori theories have not yet been described in the TBI literature. One of the outcomes of this rangahau will be to generate specific Kaupapa Māori theory about tamariki and rangatahi traumatic brain injury rehabilitation within whānau.

Theory building from other paradigms

Theory building is a term that has come into usage across a range of disciplines (Reynolds, 2007). These include case study research (Eisenhardt, 1989; Eisenhardt & Graebner 2007; Yin, 2003), grounded theory research (Janesick, 2000; Rowlands, 2005), the analysis of organisational systems (Langley, 1999) and in trans-cultural research (Chiu, Morris, Hong, & Menon, 2000). In these contexts the process of theory building serves to analyse material and uncover underlying theoretical positions that aid understanding and prediction of ways of thinking, feeling and behaving not apparent at first glance, or hidden, in a Māori context, by their “ordinariness” (Moewaka Barnes, 2000b). Methods for strengthening the process of theory building have also been the subject of publication (Nicholls, 2009; Sutton & Shaw, 1995). Overall, the elements of the theory building process includes observation, data gathering and coding, grouping data into nuanced concepts, then establishing categories which form the basis of the theory (Aubusson, 2002; Rowlands, 2005). The theory can be broadly assessed via four characteristics. First, how closely the theoretical concepts represent the issue being explored. Second, the relevance of the matter in question for participants, in other words the issue is not only of academic interest. Thirdly, the degree of workability of the theory is questioned; to what extent does the theory explain the way in which the matter in question is being solved? And finally modifiability; the ability
of the theory to be added to by new data (Rowlands, 2005). As Keesing puts it when writing about the theory of culture (Keesing, 1974):

…the actor’s “theory” of his culture, like his theory of his language, maybe in large measure unconscious. Actors follow rules of which they are not consciously aware, and assume a world to be “out there” that they have in fact been created with culturally shaped and shaded patterns of mind (p. 89).

This quote concisely describes the sphere of interest of this rangahau; an attempt to determine what those “patterns of mind” are for Māori whānau in the context of a tamariki with traumatic brain injury. This approach places Māori theory building alongside other theoretical constructs commonly used to underpin techniques used in TBI rehabilitation (Anderson & Catroppa, 2006).

**Rangahau Kaupapa Māori practices specific to this study**

The aims of this study demanded that the research design ‘walked the talk’ of the outcomes required. In other words, decisions about who to include and where the discussion would best take place and in what form were crucial, recognising the influence of these decisions on the type of data elicited and therefore the outcomes of the analysis. How to design a research process that most authentically revealed an underlying Māori theoretical position about traumatic brain injury which itself can inform a practical framework was the critical question. The importance of the complementary roles of process and content in delivering an honouring description of the korero (discourse) in attempting to answer this question was clear. Achieving this marriage of process and content required consideration of a number of culturally appropriate safety checks.

A number of practices have been identified in the process of this study that contribute to all layers of the rangahau. The Māori practices of noho puku (self reflection), whanaungatanga (connection, relationship with others), kaitiakitanga (guardianship) were employed as a starting point. These practices had been written about as part of the Takarangi Cultural Competency Framework training undertaken by the author from 2007 (Matua Raki, 2010). These practices and values provide an overarching korowai (cloak) for both thinking about and conducting this rangahau. One of their fundamental roles was to provide transparent layers of Māori cultural protection for all those involved.
Noho Puku

Noho puku invites an exacting process of self-awareness and critique at every stage of the rangahau. It gives a name and significance to ensuring the transparent intentions of the kairangahau (researcher).

While writing in the first person is not always appropriate in theses, in this situation where transparency about the researcher is required, it is necessary. In this way then, description of my role and background follows, first by way of pepeha (traditional Māori introduction):

Ko Parengarenga te wahapu (Parengarenga is the opening of the ocean)
Ko Mareitu te maunga (Mareitu is the mountain)
Ko Awapoka te awa (Awapoka is the river)
Ko Te Reo Mihi, ko Potahi oku Marae (Te Reo Mihi, the language of welcome and Potahi are my traditional meeting houses)
Ko Ngāti Kuri, Te Aupouri, Te Rarawa, Ngāpuhi oku iwi (Ngāti Kuri, Te Aupouri, Te Rarawa and Ngāpuhi are my tribal affiliations)
Ko Murray raua ko Yates oku whānau (Murray and Yates are the names of my families)
Ko Hinemoa Elder tōku ingoa (Hinemoa Elder is my name)

As a Māori woman, mother, whānau and community member, Child and Adolescent Psychiatrist, with basic fluency in Te Reo Rangatira (the Māori language), I was aware of “wearing a number of hats” during this process. I had been the kairangahau (researcher) in small qualitative research projects in the past (Elder, 2000, 2008; Elder, et al., 2009). However, I felt more experienced and confident in my roles as a whānau member and clinician. The potential tensions between these roles were evident. Questions arising from these considerations included wondering if participants would relate to me as a clinician and how this might bias their responses? Would participants speak in English because they could see I was not fluent in Te Reo Rangatira and how might this influence the findings? How might I interpret findings given my own experience of being Māori and how might this bias the outcomes? How could the methodology best put participants at ease, reduce the risk of my clinical role being influential and how could the design signal and support that language of preference being determined by the participants, not their perception of what might suit the kairangahau? The first step in beginning to explore these questions was through noho puku, quiet time alone considering the implications. What emerged from this reflection was the need to describe my own world view.
Kairangahau (researcher) world-view

My world-view (lower case is deliberate here to emphasise my world view is located within a higher order world view) can be seen as my personal expression and experience within Te Ao Māori World View (Māori world view with capitals is deliberate as this defines my sense of an overarching world view). My view is defined first by my pepeha (personal introduction). This locates me as being part of the land of Muriwhenua in the far north of Aotearoa New Zealand, the Parengarenga Harbour, the urupa of Te Hapua at Mareitu overlooking the harbour and white sands beyond, Potahi marae at Te Kao, my connection with the place where the spirits leave this country, and the meeting of two seas. These places have special significance for me. I also value my role as a descendant of groups of people who sailed across Te Moana-Nui-a-Kiwa (The Pacific Ocean), who brought their language and lore. I feel an intense connection with these histories, with my part in this lineage, with my responsibility as representing those who have gone before and preparing the way for those to come. My being both a mokopuna (grandchild) and a mother is also a constant reminder of the connection I hold across time: past, present and future. When I articulate this pepeha I experience standing in those places, viewing the world from those vantage points. I sense the strengthening effect of deliberately calling into present consciousness those links that constitute a tangible essence of my being Māori.

I recognise that I also descend from other cultural ethnic groups; Celtic, Dalmatian and Jewish peoples. However, for me the experience of being Māori dominates. One example of a particularly defining experience is that on entering marae I am aware these are the only places on earth that Māori protocol specifically acknowledges that I bring my dead with me.

At the same time, I am a Western trained medical doctor, a Child and Adolescent Psychiatrist, with specialist experience in the neuropsychiatry of child and adolescent brain injury. My world-view is further informed by the experiences of working alongside Māori whānau who have a tamariki with a traumatic brain injury and learning that when I use my knowledge and skills as a Ngāti Kuri/ Te Aupouri/ Te Rarawa/ Ngāpuhi Māori woman along side my clinical skills it seems the collective experience of the traumatic brain injury is different.

My world view also recognises I have not had special training in Māori understandings of the brain other than an awareness from childhood, passed down from my mother, that "he tapu te upoko", the head is sacred. I have also been privileged to hear a presentation about a Ngāpuhi classification system of the mind (S. Wikaira, personal communication, 29 November 2008). My world-view suggests that exploring Māori mātauranga (systems of knowledge) and related Māori specific skills around Māori determined views of traumatic brain injury would help me to provide more options and
understanding to serve the needs of my Māori patients and their whānau.

Another part of my world-view stems from the fundamental belief that as Māori we are the best people to determine our own processes and content of our solutions, that our solutions reside within us and that time-honoured solutions are held in Te Reo Rangatira me ōna tikanga (the Māori language and lore). Part of my sense of role and responsibility as a Māori medical specialist is that I have a unique opportunity to explore what works better for Māori whānau in this setting. The alternative, a turning away from this awareness, would be to continue a restricted practice; using only my Western medical skills and limited Māori cultural knowledge (limited by both my place of origin defining a particular knowledge base and my limited mātauranga). This avoidance or rejection of my own awareness that Māori cultural resources could assist in enhancing outcomes for this group cannot be contemplated, particularly given the evidence from other ethnic groups that ethnic culture plays a part in traumatic brain injury outcomes. From my world-view this response is an anathema to me as Māori, it would mean rejecting a part of myself. The prospect of pursuing this area of clearly identified need has continued to demand my attention since I first began working with these whānau, with both determination and a sense of responsibility. This rangahau is the beginning of attempting to fulfill this drive and obligation.

Part of my world-view means I seek to make sense of this predicament in other ways. One of these is what I call a cultural competence argument. The Health Practitioner Competence Assurance Act 2003, section 118, requires that the Medical Council of NZ, of which I am a member, sets standard of cultural competence (http://www.legislation.govt.nz/act/public/2003/0048/latest/DLM204334.html). There is no explicit standard of cultural competence for working with Māori tamariki and taiohi with traumatic brain injury and their whānau. My perspective suggests this is an important omission. Regulations about expectations of doctors are clearly described and these include working in partnerships with patients, listening and responding to concerns and preferences, supporting them in caring for themselves, acting with integrity, having competency in medical care, communication, collaboration, scholarship and professionalism. These standards also include that research is vital for improving care and reducing uncertainty for patients now and in the future and improving the health of the population as a whole. However the individual cultural competence argument is one that is necessary but insufficient; it neglects the importance of the cultural competence of the systems within which these services are delivered. I could go further and propose that it would be difficult for non-Māori structures and even for some hegemonic Māori structures to authentically sustain and deliver the cultural competency required. However, I do not hold that this recognition justifies nihilism, rather, it stimulates and fuels continuing struggle to refine and influence Māori self-determination that shrugs off hegemony and sustains it's own intrinsic truth.
Another part of my world-view is a medical ethics argument. This thinking takes me back to my medical school days. I was the spokesperson from my medical school class who read out the Hippocratic "declaration of professional dedication" in Te Reo Māori at our graduation ceremony in 1999. Central to this oath is the commitment to "first do no harm". If I did not pursue the exploration of Māori knowledge related to traumatic brain injury that might be helpful in responding to affected tamariki, taiohi and their whānau I become an agent of perpetuating harm. I am concerned about the ethics of continuing to provide a neuropsychiatric service when I am aware that my Māori cultural capacity to deliver all that may be needed is limited.

My world-view also encompasses ideas of science. In this way, it would be unscientific not to explore Māori views, knowledge and skills around traumatic brain injury and healing. The way I am undertaking the exploration however is informed by the protocols and practices of my tupuna (ancestors), a process aligned with the term “native science” (Cajete, 1999).

In addition, I experience some tensions in my world-view that as a specialist doctor there are subtle cues that encourage me to minimise, discount or override the world-view of other Māori people. This is because of unwanted effects of the acculturation process of my medical training and of the systems of provision I work in. These concerns can be considered those of cultural safety, a perspective developed by an esteemed Māori nurse, Irihapeti Ramsden. This concept now being widely used to analyse the power relations between health professionals and those we have committed to serve (Ramsden, 2002). Perhaps a more personal element of this study seeks to illuminate these areas of risk to my practice and the practice of others by uncovering mechanisms that mitigate this risk.

Overall, this research is an attempt to resolve some of this tension in adding to resources which I and other health professionals, managers, funders and policy makers (Māori and non-Māori) can use to reduce the tensions in the way our world views make us think and feel, perhaps even to extend the emancipatory power at the interface of our world views.

Noho puku practices have also served a vital function in relation to approaching the data collection. It ensured that I engaged in this practice throughout the process. For example reflecting on my role before each wānanga as part of my preparation, my reflective capacity during wānanga, in the iterative process of reading transcripts and watching wānanga footage, coding and re-coding and the writing and editing of this thesis.

Whanaungatanga

Whanaungatanga, the second aspect of approach to rangahau design flowed naturally as a problem sharing and relationship strengthening technique. First, I returned to
one of my home marae, Potahi, in Te Kao, a remote part of Northland, to ask permission of my whānau and hapū to conduct this rangahau and to begin a dialogue about how this could be done. At the hui, held on May 2nd 2009, Glass Murray, our kaumatua asked me, “What’s in it for us?” My response was that this rangahau could improve ways in which we could help our own whānau within which there were tamariki with traumatic brain injury and we could consider the findings for use in our Hauora (Health Service) ‘Whakawhiti Ora Pai’ in Te Kao. The hui was unanimous in it’s support for the project. Lines of accountability and communication were determined; a whānau contact person was nominated and feedback for the Hauora newsletter provided as well as committing to a final hui at Potahi at the conclusion of the analysis phase to present a summary of the findings as well as discuss plans for future implementation. In this way, my home marae and hapū provided clear landmarks at the beginning, woven throughout the process and at the ending of this part of the journey ensuring a fabric of cultural safety for the study and all involved.

Developing the information sheet (Appendix 1) and consent forms (Appendix 2) in Te Reo Rangatira (the Māori language), translated by Rahera Shortland, (Ngāpuhi) a registered Māori translator, also strengthened my hapū connections to ensure the way the project was presented reflected my values and beliefs as a Māori woman and whānau member. Whakawhanaungatanga with Whaea Moe Milne (Ngāti Hine) and discussion about the Te Reo Rangatira component of hui led to Whaea Moe attending several of the hui. Sadly Whaea Moe was very ill in 2011. However, on her recovery she generously continued to support the project. Dr. Waiora Port (Te Aupo uri) also attended a hui at Owae marae to support my understanding of the use of Te Reo Māori when participants felt most comfortable communicating in that way.

A further aspect of whanaungatanga was preparing a conference poster of the rangahau proposal. One of my whanaunga Richard Murray designed the artwork for the poster and power point slides for subsequent presentations. This was accepted for the inaugural Traumatic Brain Injury and Culture Conference in Washington D.C. in 2009. At this conference I was the sole indigenous presenter. Attending the meeting enabled me to establish links with a number of researchers from other cultures and to invite the conference convener to become a member of Te Rōpū Kaitiaki, the expert group providing guidance for the rangahau. The methodology, methods and early findings were presented via an invited oral presentation at the ‘Kids Trauma Conference’, Auckland Hospital, 2010 and by oral presentation at the International Association of Child and Adolescent Psychiatrists and Allied Professionals (IACAPAP) bi-annual conference in Beijing in 2010. Presentations were also given at the bi-annual New Zealand Rehabilitation conference, in Auckland in 2011, where the Otago University Prize for best presentation was achieved. Presentations at the ‘Be.Leadership’ forum for disability stakeholders, the rehabilitation research group at AUT
and to The Wilson Centre Trust Director, Russell Ness, also in Auckland in 2011, were well received. A journal article accepted for publication in early 2012 in *Australasian Psychiatry* was another example of using the principle of whanaungatanga to disseminate the considerations of this research. These opportunities were actively sought and accepted to invite critique and discussion amongst reasearchers, clinicians and other stakeholders and to begin to develop partnerships for further research building on the findings presented in this thesis.

Participating in a Māori doctoral student writing group was a further activity of whanaungatanga that invigorated this rangahau process. The cross-hybridisation of disciplines from neuroscience, metabolic animal-model research, melanoma research and earth sciences enabled stimulating discussion and critical analysis of writing approaches and rangahau ideas as well as strengthening links with other Māori kairangahau for the future.

Having collegial support from a fellow doctoral student Jo Fadyl, also engaged in examining rehabilitation in Aotearoa New Zealand using vignettes within a qualitative frame of reference was an invaluable aspect of whanaungatanga. The opportunity to robustly question each others work and consider it from other paradigms enabled further insight and creative progression of ideas. Having peer review of my coding was also a very important aspect of this whanaungatanga.

Whanaungatanga also functioned as a mechanism for approaching the data. Seeking relationships amongst the ideas described by participants can be seen as an exercise in whanaungatanga. The practice of grouping ideas into ‘whānau’ with linkages of relatedness resonated with this practice.

**Kaitiakitanga**

As the final element of this three tiered approach to designing and carrying out the rangahau it was essential to establish a Rōpū Kaitiaki (guardianship group) to provide another layer of specialised support. This kaitiakitanga (guardianship) of the project also embodied a critical nurturing role. Membership was determined on the basis of expertise in tikanga Māori and neuroscience. Establishing this group in 2009 and inviting members to attend an annual hui for three years was an ambitious task. All invited members accepted. The rōpū was comprised of Professor Sir Mason Durie (Rangitane, Ngāti Raukawa), Professor Richard Faull (Ngāti Rahiri, Te Atiawa), Naida Glavish (Ngāti Whatua, Ngāpuhi), Amster Reedy (Ngāti Porou), Dr Gregory Finucane (Ngāti Pakeha, Neuropsychiatrist) Associate Professor Juan Carlos Arango-Lasprilla (Columbian, Neuropsychologist and researcher Virginia Commonwealth University, Washington D.C.). These meetings were held at the Centre for Brain Research: Rangahau Te Roro me te Hinengaro, in Auckland.
Meeting times and dates were organised by the author, kai (food) was provided, a presentation of progress to date was delivered and discussion followed.

Kaitiakitanga was also an important component of relating to the research data. Guardianship of the data collected was ensured by both the usual means according to the Ethics Committee requirements, however, Māori specific protective practices related to data were also observed. For example, not eating food when reading or viewing data and keeping material off the floor were all undertaken as aspects of kaitiakitanga.

What has been described are illustrations of how the three aspects of noho puku, whanaungatanga, and kaitiakitanga provided a structure for the consideration of my role as kairangahau (researcher), a practice for clarifying my world-view as well as guiding the practical steps that shaped the foundations of the rangahau and infused the design with Māori cultural safety mechanisms. In addition, this approach also provided guidance as to working with the research data. I will now turn to a description of one of the central issues, the issue of where to hold the participant wānanga.

**Marae-based method**

A marae-based method was undertaken in this study. What follows is a general introduction to the concept and function of marae (traditional meeting houses), how this methodology is defined and how this approach was identified as most appropriate for the requirements of this study.

It is appropriate to define what is meant here by “marae-based”. Strictly speaking the “marae” is formed by several spaces. The “marae atea” is the open space in front of the marae buildings. This is the space that is crossed by the manuhiri (guests) during the karanga (call by women) before they enter the wharehui (meeting house) or wharetupuna (ancestral house), named according to the local custom. The wharehui or wharetupuna are the places where the discussion takes place and the wharekai (dining room) is where the tapu (sacred) status of those participants in the meeting is removed to a state of noa (non-sacred) by eating food. The term marae-based rangahau here indicates rangahau where each element of activity takes place in the appropriate part of the marae campus; welcome occurring across the marae atea, further aspects of the welcome occurring in the wharehui or wharetupuna, followed by food and drink in the wharekai, with the wānanga occurring in the wharetupuna or wharehui as indicated by the hosts. In this way, the process was governed by the tikanga (cultural lore) of this collective place according to local custom. The deliberate grounding of this rangahau in the local marae tikanga (protocols, values and practices) visibly, symbolically and actually positioned it as owned by the participants. This signalled determination of the wānanga process and outcomes as held within localised knowledge. It also emphasised the differences between kairangahau (researcher) as manuhiri (visitor) and
hau kainga (home people). The submission of kairangahau to the dominance of the kawa (rules) of that marae and those whānau groupings or ngā hau e whā histories respectively, provided a clear platform for the wānanga (meeting). There was a conscious choice to continue the tradition of wharehui and wharetupuna as places of learning, places where difficult issues could be talked through, protected by the Atua (gods) of the marae atea, Tumatauenga, and of the wharehui, Rongomatane. The practical use of these protocols provided a rangahau setting with an infrastructure of inbuilt safety mechanisms rather than one that might be imposed by a researcher. In addition, the idea of keeping marae and wharetupuna warm with activities, explicitly inviting korero watched over by tupuna in tupuna space was an appealing one.

Many sources of evidence suggest that marae are highly likely to be the optimal places for housing and supporting the korero (discussion) invited in this rangahau. This evidence comes from peer-reviewed literature, books and other written accounts as well as traditional Māori forms of information sharing. Several books about marae and the history and role of marae describe the symbolic and spiritual aspect of these places (Barlow, 2005; Brown, 2009; Moko-Mead, 2003; Souter, 2008; Tauroa & Tauroa, 1986). Marae have been described as places for discussion by Māori people about Māori things (Tauroa & Tauroa, 1986). Ngata and Pomare, two esteemed Māori doctors (1992), comment that marae “have come to symbolise the essence of Māori health aspirations” (p. 3).

Marae, regardless of affiliation, be it iwi (tribal) ngā hau e whā (non-tribal, literally of the four winds), rural, remote or urban, have clear rules of encounter. Marae uncompromisingly privilege the local histories, daily lives and future plans of local lands and people. The process of welcome (powhiri), entering a marae, the means by which the assembled collective are signalled to prepare themselves for the subject of the meeting, the meeting itself, the closing and aftermath are highly ritualised. The concept of tūrangawaewae, literally a place to stand, is intimately associated with marae. This concept conveys the rights of residence through whakapapa (genealogy), emphasising that marae provide the people of that marae with their own place where their identity, their views, their mana (status) is respected (Barlow, 2005; Moko-Mead, 2003). These aspects of the tikanga (cultural lore) of marae convey their suitability for the location of information sharing needed for this rangahau; both protecting and nurturing all parties.

Consideration of what to call these encounters and sharing of information was warranted. These meetings, held on marae, while initially conceptualised as hui (meetings) are best described as wānanga. Wānanga are a specialised form of hui. The word ‘wānanga’, as a noun, is used to describe a form of meeting that emphasises shared learning and an outcome that is not pre-determined (R. Pere, personal communication 2011). The word comes from traditional fora of learning and is used in contemporary Aotearoa as a
Māori word similar in meaning to the word University, such as in the names of large Māori tertiary institutions such as ‘Te Wānanga o Aotearoa’ and mainstream Universities. Wānanga is the name chosen here as it underscores the coming together of opinions, sharing of stories and the sense that at the conclusion of the wānanga, a synthesis of the subject has been illuminated. Significantly, at one of the first round of wānanga, a participant marae made this statement confirming that wānanga was an appropriate label for the rangahau encounters.

“And one of the benefits that came out of the revival of Māori arts and crafts was the proliforation of meeting houses, wharenui, and with that proliforation of meeting houses our people had a place to wānanga, like what we doing now.” (Araiteuru Marae 2010)

Māori researchers in the area of Māori neuroscience, health, identity and disabilities have utilised marae rituals in various forms as part of their work (Cheung, et al., 2007; Collins, 2007; Lilley, 2009; McClintock, et al., 2010). As described by Cheung (2007) working with brain tissue, because of the significance placed by Māori on the structures within the head, is “culturally challenging” (p. 3). Cheung utilised support from her home marae, with specific visits there with her research team, reinforcing the links to her home marae documenting in her thesis the special role that her marae and the people there had in making her work safe (Cheung, 2010). She noted that it was, “nice to have a hui at home that wasn’t a tangi (funeral)” (p. 48) and the highlighted the value of a, “noho marae (staying on the marae)” (p. 51). The use of powhiri, derived from those occurring on marae, and generalised to other research settings outside the realm of marae, to protect the roles of researcher and of participants is eloquently described in McClintock’s recent paper (2010).

The unique role of marae as a place for research discourse has been reported. Marae as “information ground” has also been described (Lilley, 2009). Lilley called marae “the ultimate Māori information conduit with a smorgasbord of information available for exchange” (p. 1). Adele Collin’s work in the area of Māori concepts of disability has utilised marae as a special space for these discussions to occur (Collins & Hickey, 2006). Other evidence that suggests marae might be the appropriate place for discussion about injury includes findings that a spiritual guidance element of a caregivers’ role was important related to concern that injuries may be the result of a metaphysical transgression (Nikora, et al., 2004). This study further underlines the importance of spiritual safety in relation to discussion of this topic, pointing to marae as places where protocols to protect wairua (defined in that study as the spiritual element) are most tangible (O’Connor & MacFarlane, 2002). Interestingly, non-Māori literature has also described related concepts. “Guesthood”,

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a concept similar to manuhiri status has been described as an ethical decolonising research methodology (Harvey, 2003).

There is also empirical evidence to suggest that marae provide favourable conditions to discuss matters related to 'he tapu te upoko'. An oral presentation of the Ngāpuhi (specific tribal group from the northern part of Aotearoa New Zealand) 'Classification of the hinengaro (mind)', was shared at Matai Ara Nui Marae, Whirinaki in 2008 (S. Wikaira, personal communication, November 29th 2008). It is unlikely this type of presentation could have been conducted in a place other than a marae. Documents from wānanga held by Kaumātua Hohepa Delamere about te roro (the brain) held at Hoani Waititi Marae in the 1990s, gifted to the author, detail a significant mātauranga Māori (knowledge system) (C. Bailey, personal communication, 2009). The sharing of this information on marae was deliberate. These two encounters suggest that there is a precedent for exploration of 'he tapu te upoko' (the sacredness of the head) in relation to tamariki and rangatahi traumatic brain injury on marae.

The well known policy and practice framework ‘Te Whare Tapa Whā’ (the four walled house) (Durie, 1994), depicted graphically as a whare tupuna on marae, provides another layer of support for the consideration of marae-based rangahau. This way of thinking about Māori concepts of health, “wholistically” (spelling as per Cunningham, 2002, p. 63) contributing to overall well-being, symbolised by the whare on marae emphasises the iconic status of these buildings and their role in the minds and the lives of Māori people in the contemporary world. This rangahau design could be considered as an example of Te Whare Tapa Whā in action.

The question as to where else this rangahau could take place can be asked. Other spaces considered such as whānau homes, which while providing the possibility of assisting participants to feel at ease would be unlikely to convey the degree of cultural containment for the discussion stemming from ‘he tapu te upoko’. Holding meetings in family homes may also be complicated because of the real and perceived burden of hosting. Similarly, schools and community halls, while sheltering Māori participants in their familiarity would not necessarily be able to convey the sense of cultural safety required. Theses venues may also convey other messages related to authority or social hierarchies that would be unhelpful to the aspirations of this rangahau.

It could be argued that marae no longer reflect contemporary Māori realities. The approach taken here could be criticised given the spectrum of Māori lifestyles. Borrell has cautioned that using what might be termed ‘traditional’ concepts of Māori identity can be seen as enacting a deficit model of Māori identity. She has shown that other markers of identity have primacy in an urban setting (Borrell, 2005). However, the dimension of contemporary Māori experience continues to resonate on marae (Brown, 2009). Interestingly two reports in the last 10 years, one published in 2010 have shown that marae continue to be
places that the majority of Māori people are familiar with visiting (Statistics New Zealand & Ministry of Culture and Heritage, 2003; Te Puni Kokiri, 2010). The report from 2003 using data from the Cultural Experiences Survey found that of three cultural activities (visiting marae, visiting exhibitions of taonga tuku iho such as art and artefacts, and visiting historic sites) visiting marae was the most popular. Sixty nine percent of Māori in the survey had visited a marae in the previous year. The survey also found that younger people, the unemployed and those in areas with a high proportion of Māori were most likely to visit marae. In the Te Puni Kōkiri report, 55% of the 1031 Māori aged 15 years of age and older surveyed, indicated they go to marae “often or very often” (Te Puni Kokiri, 2010). These findings suggest marae continue to be relevant to contemporary Māori.

Marae-based wānanga as method has resonance with a focus group approach. Studies which employ focus groups gather data from “multiple voices” (Madriz, 2003). Scholarship from working with focus groups highlights vigilance in response to power relationships between researchers and participants. This resonates with the approach taken here.

Overall then, marae have been developed across a range of settings, including in cities, in urban neighbourhoods, and university campuses for example, to continue to meet the needs of the majority of modern Māori. Different types of marae; iwi (tribal), ngā hau e wha (literally, “the four winds”, non-iwi), urban, rural and remote exist and are used regularly by a significant proportion of Māori. These marae provided a culturally sound choice of location for exploring the questions of this rangahau.

**He pūrākau (stories); Rangahau Kaupapa Māori tool**

The tradition of storytelling in Te Ao Māori (The Māori World) signals that everyone has something to say, has a contribution to make (Bishop, 1996, 1998). Storytelling forms an antidote to any suggestion that the type of information that might be perceived as most highly prized if it is academic or laced with medical jargon. In this way, it signals that participants’ experiences and their meanings are of prime importance. Listening to the pūrākau on the marae, and across marae honours the story telling tradition of marae (O’Connor & MacFarlane, 2002).

Recognising this tradition, pūrākau were considered here to encourage participants to operationalise their ideas. There are a number of words that exemplify the Māori story telling traditions; kōrero (story), kōrero tara (story), kōrero takurua (story without authority), pakiwaitara (fiction, legend, folk lore) (Biggs, 1981; Ryan, 1997; H.W Williams, 1975). The word pūrākau has a number of meanings including an ancient legend, myth, an incredible story, a story (H.W Williams, 1975). It was this aspect of a story, that led to it being chosen for the purpose of this research. The word pūrākau has another layer of meaning linked to
ceremonies connected with making and launching a waka which was not known at the beginning of this research, but which became curiously apt later in the process (H.W Williams, 1975). Some qualitative studies use “vignettes”; brief cases to illustrate and to encourage discussion (Barter & Renold, 2000; Hughes, 1998). These researchers have shown that the use of these short stories can help to mitigate the possible disjunction between beliefs expressed and actions that might be taken. These vignettes can also allow discussion of sensitive topics. Using pūrākau in that sense, as a means to stimulate korero about particular aspects of how problems arising from traumatic brain injury in tamariki and taiohi might be resolved, was chosen as a useful approach to investigate how expressed beliefs might be put into action. Mindful that maximising the potential of inviting responses to pūrākau would require a preliminary discussion of broader ideas and that both activities would be too much for a single wānanga the decision was made to ask each marae for two wānanga. This decision also proved advantageous in adding a layer of member checking. This is a recognised qualitative research tool which enhances the internal validity of findings by providing additional opportunity for participants to review the researcher’s perceptions of findings, enhancing audit and transferability of results (Giacomini & Cook, 2000).

**Working with data - final comments**

Considerations of how data would be managed in addition to utilising noho puku, whanaungatanga and kaitiakitanga demanded careful thought. Centrifugal thinking previously described by Durie was a useful guide (2002). This was proposed as a form of whakaaro Māori (Māori thinking) found on marae. In other words, the activity of taking detailed information and grouping it into larger and larger overarching themes or categories was undertaken. This ensures there is transparency about the origins of the broader themes. Centrifugal thinking also informed grouping data in ways that acknowledged potent ideas that were expressed by small numbers of participants as well as those expressed by many. Overall, this approach guards against the description of “emerging themes” not clearly linked to their underlying data which brings into question the validity of the process and therefore of the results (Braun & Clarke, 2006).

A description of the practicalities of how these collective ideas and their underpinnings were implemented follows.

**Procedural methods**

Ethical approval was sought and approved via Massey University Health Ethics Committee (MUHEC, Southern A 09/48 dated 28th September 2009) (Appendix 3).
Nine marae were identified through whānau links and links with Te Rōpū Kaitiaki. These marae were across a range of settings; three in remote areas, two rural marae and in urban settings, four marae. The marae were also varied as to their affiliations, both according to iwi (tribal) links and others were ngā hau e whā (literally of the four winds, not tribally affiliated). These marae were:

Potahi (Te Kao, Te Aupouri, remote),
Owae (Waitara, Ngāti Ruanui, remote),
Rauru (Ruatoria, Ngāti Porou, remote),

Piritahi (Waiheke Island, Tainui kawa, ngā hau e whā, rural),
Tutanekai (Owhata, Te Arawa, rural),

Te Mahurehure (Tamaki Makaurau, Ngāpuhi, urban),
Pukemokimoki (Napier, Ngā hau e whā, urban),
Araiteuru (Dunedin, ngā hau e whā, urban),
Tapu te Ranga (Wellington, ngā hau e whā, urban).

(schedule of wānanga in Appendix 4)

These marae were chosen via whānau connections (Potahi, Araiteuru, Te Mahurehure, Piritahi, Pukemokimoki, Owae), recommendations from the Rōpū Kaitiaki (Rauru) and Whaea Moe Milne (Tapu te Ranga) and Kaumatua Arama Pirika (Te Kaunihera Hauora Hinengaro Māori, Royal Australian New Zealand College Psychiatrists) (Tutanekai). One additional marae was identified but was unable to participate because of the number of other hui taking place there (Te Ohaki, Huntly).

Two wānanga were held at each marae in 2010. Panui were sent out via marae committees to their networks (Appendix 5). Koha and marae costs were paid directly by the kairangahau according to the protocols of each marae. Kai (food) was provided either by the kairangahau or the marae and costs reimbursed. All participants were given consent forms in a choice of either Te Reo Māori or English (Appendix 2). Participants were consented for recording in both sound and video footage.

The purpose of the first wānanga was to invite discussion about taitamariki (children and young people) with traumatic brain injury and their whānau using “he tapu te upoko” as the springboard for the korero (discussion). A semistructured questionnaire was developed to assist with the wānanga to be used if prompting was required (Appendix 6). However, this was not used after the first wānanga as it’s use seemed to inhibit the flow of the korero. The discussion was opened with a broad invitation to the participants to share their thoughts and
stories about tamariki and taiohi traumatic brain injury. On completion of the wānanga video footage was sent to the transcriber, who had signed a confidentiality agreement (Appendix 7). Rough drafts of transcripts were returned for review and correction by the kairangahau (researcher) while watching the footage. The footage and transcripts were reviewed multiple times over several months with notes taken. Reflections on ideas, via noho puku, whanaungatanga and discussion with the Rōpū Kaitiaki enabled consideration for presentation at the second round of marae wānanga.

The second, follow up wānanga at each marae, was held some months after the first. The purpose of the second wānanga was two fold. Firstly, to present back the key ideas that had been identified in the kairangahau processes of noho puku, whanaungatanga and kaitiakitanga and to check these were accurately conceptualised and documented. Additional ideas were also invited at the second wānanga. Each marae was only privy to the responses from their own wānanga. The second activity of this return wānanga was to discuss one of the three pūrākau, short stories written to encourage discussion about implementation of the ideas generated. The three pūrākau were allocated to each of the nine marae, such that each pūrakau was discussed at three marae. The pūrākau each presented different elements of traumatic brain injury in tamariki and taiohi and their whānau, based on common features exemplified by age and developmental stage from the epidemiological literature. These included non-accidental brain injury in an infant, fall related mild traumatic brain injury in a prepubertal child and moderate to severe traumatic brain injury in an adolescent associated with a motor vehicle accident. These were discussed with a fellow doctoral student using “vignettes” as part of her research design (Fadyl, J personal communication, 2009).

The pūrākau are as follows:

1. **Tama is a 3 month old pepi. He was brought to hospital by a whānau member as he wasn’t breathing properly, he wasn’t opening his eyes or moving at all. He needed to be treated in Intensive Care. The doctors found he had a break in his skull, bleeding in his brain and damage to the brain itself. They called it a severe brain injury. Other tests showed he had partially healed broken leg bones and a broken arm, at different stages of healing. This was evidence he had been hit at different times. He left the hospital with long term physical problems with weakness on his left side and visual problems. His mothers new partner was convicted of physically abusing the baby.**

   (Discussed at Te Mahurehure, Owae and Tapu te Ranga marae)
2. Tamahine is an 8 year old girl who fell down some concrete steps at school. She seemed confused after the fall, the teacher noticed she was holding her head. She was taken to the family doctor by her whanau. The doctor diagnosed a mild traumatic brain injury because of her confusion. She had disrupted sleep for several days and seemed a bit withdrawn, she was fidgety, irritable and was lacking in confidence and found it hard to get on with her friends when she went back to school the following week. Several years later, when she started high school she found studying very difficult and continued to struggle with making friends.

   (Discussed at Pukemokimoki, Rauru and Potahi marae)

3. Rangatahi is a 17 year old who had a serious knock to the head in a car accident. He was a passenger and wasn’t wearing a seatbelt. Two people died at the scene of the accident. He was in hospital for several weeks. When he left the hospital he lived in a rehabilitation unit for almost a year.

   (Discussed at Araiteuru, Tutanekai and Piritahi marae)

At the first return wānanga at Te Mahurehure marae the issue of naming the tamariki and taiohi in the pūrākau was proactively raised by the kairangahau with participants. Discussion informed the decision not to name those injured in the pūrāku because this would have an impact on the mana (in this context meaning respect, vitality and strength) of any children known to the participants with those or similar names. The decision was made to name the taitamariki in the pūrākau after the generic terms; “pepi” (baby), “tamahine/ kotiro” (female child/ daughter) and “taiohi/rangatahi” (adolescent/ teenager). Given the depth of discussion anticipated only one pūrākau was discussed at each return wānanga. The pūrākau were allocated randomly except for the return wānanga at Owae marae where a participant spontaneously presented a pūrākū about a non-accidental traumatic brain injury in an infant.

In this way three sets of findings resulted. Firstly, the clusters of ideas that were identified through reading the transcripts and watching the footage. These results were taken back to the marae at the second round of wānanga for discussion and checking. Secondly, responses related to the pūrākau enabled specific enquiry into issues related to non-accidental infant traumatic brain injury, school child mild traumatic brain injury and adolescent motor vehicle related brain injury. A third level of analysis was then conducted using a qualitative internet tool, “dedoose” (http://www.dedoose.com/), with the purpose of theory building. Using this tool the ideas and themes were coded and hierarchies for developing theoretical constructs developed. These were then further advanced to build the framework.
Each marae was sent a DVD copy of their wānanga. At the completion of analysis and framework construction a documented summary of the findings of the study, including the framework was sent to each participant marae recognising the information shared belongs firstly to the marae to utilise as they wish (Appendix 11). A final hui (meeting) was held at Potahi Marae on 28th October 2011 to present and review the findings with available Koroua, Kuia and Pakeke. Attendees were Pineaha Murray, Errol Murray, Bill Halkyard, Aunty Loui Harris.

**Considerations for the approach to research participation**

It is important to consider the effect of the study design on the participants. From the outset there was no plan to analyse the data according to individual age or gender. The design focussed on each marae as having it’s own collective voice. Considering marae as housing the collective responses to the research invitation in this way had, on the one hand, a useful impact. It set a Māori cultural standard for participants to become involved which was self-determined. In this way, these participants had a shared level of awareness, knowledge and practical skills sufficient to attend and participate in marae wānanga. This can be considered as an alternative to a measure of acculturation. Rather than developing a questionnaire to attempt to assess what could be termed Māori acculturation, those who attended represented a range of Māori experiences of being Māori that involve valuing being on marae and sharing discussion in such a culturally defined space. This unspoken shared sense of being in a Māori cultural comfort zone in the company of like-minded others, was likely contributed to by being related to other participants or by living in the same locality or both. On the other hand this can also be viewed as a cultural bias at the entry point of the study.

The result of using marae wānanga participation as the entry point determined a collective cultural competency. It is likely that individuals cultural competencies related to their participation in marae wānanga varied. However, the sense of a shared level of necessary and sufficient cultural competencies relying on interdependency was a strength of the method given it authentically reflects the variety of cultural competencies within whānau, who together have a higher level of cultural knowledge and skill. These aspects of the research design were employed in recognition of a local self-determined expression of being Māori, authentic to that marae. Equally, this approach did not allow for exploration of where individuals’ knowledge base and skill set might be assessed on a continuum of cultural competency to participate. Rather this method accepted the groups collective ability to provide for it’s own cultural needs in the wānanga as the threshold for the group decision to participate in this study. This method could not provide any answers as to how prospective participants made the decision not to attend.
It is possible that power dynamics within communities may have been played out in the marae wānanga. For example what might have appeared to be support for what the speaker was saying may have been related to support for the speaker because of their status within the community. In addition, the issue of interpreting the meaning of participant silence remains an important consideration. Whether silence meant acceptance or an unwillingness to share a different view or a view that might be challenged are all possibilities. Wahine (female) and tane (male) dynamics may have rendered some participants reluctant to share their ideas. This design makes no attempt to modify the interactions of participants. Thus the design privileges the mana (respect) of the tikanga (rules) of each marae and the content and manner of communication within those constraints. Overall, this provides a strength in the rangahau design, in particular related to the explicit position of the kairangahau as manuhiri (visitor) and the cultural protection for the tapu quality of the subject matter. An inherent weakness is that the methods do not investigate the meaning of the dynamics between the participants and how this may have influenced their contributions.

The decision not to include rehabilitation specialists or to seek out participants who had experienced traumatic brain injury limits the scope of this study. However, this is a deliberate constraint aimed to maximise a Māori response with as little reference to existing ideas or experiences of rehabilitation as possible. The aim of this approach was to bring what could be deemed a conservative, and yet distinctly Māori view to assist with theory building and framework development. The concern was that other approaches may lead to collecting culturally diluted data at the outset, leading to rather devitalised material emerging for working at the interface with the clinical world view. The view taken was that anything less than this conservative approach would be insufficient to meet the dominance of clinical traumatic brain injury knowledge systems.

It could be argued that given the dimension of Māori identity and variability of access to Te Ao Māori that an approach sited within Kaupapa Māori thinking and practice might marginalise some Māori or make findings irrelevant to some Māori. For example, how this approach might appropriately explore the Māori identity issues for Māori tamariki and their whānau living in Australia who experience traumatic brain injury is likely to have nuances that respond to Māori in that context. This methodology takes the position that Te Ao Māori is, by definition, inclusive of all experiences of Māori people and this work attempts to reflect that. That being said the design of this rangahau determines a resonance with a particular group of Māori, those who are comfortable on marae. Further generalisability of the outcomes of this research will be determined by future testing.

A further omission from this study was sport related TBI. Māori have high levels of participation in a number of contact sports where risk of TBI is high and this is recognised as a major cause of TBI in the Māori population as a whole (New Zealand Guidelines Group,
This area was deemed to be a complex and specialised area of investigation which could be explored in future.

In using the term Māori, another potential risk is of signalling a homogeneity of what it means to be Māori. This is something this method seeks to avoid. Aspects of this design that specifically place rangahau practices in localities that represent whānau, hapu and iwi as well as ngā hau-e-wha (literally of the four winds, in this study, this means marae that are not defined by traditional iwi defined catchments) is an attempt to mitigate this risk. The choice of the positioning of this study within the Kaupapa Māori paradigm may lead to a seemingly circumscribed field of applicability. Aspects of the design deliberately seek to reduce this possibility, such as the diversity of marae settings and the hosting marae’s determination of who participates within their own protocols of engagement. The overall premise here is one where every person with whakapapa Māori (Māori genealogical links) is by definition Māori, no matter their experience of being Māori. To put it simply, it is not possible to be partly descended from an ancestor, you either are or you are not.

Summary

This chapter has outlined the basis for a Rangahau Kaupapa Māori design deemed most likely to address the rangahau questions posed.

The background to the Rangahau Kaupapa Māori approaches taken here was described along with the rationale for the choices made. This background included discussion and summary of the substantial framework literature that informed this rangahau. The distinction between methods and details of this methodology were then outlined. Mapping out the wider philosophical context before describing the finer details of the method was an important part of ensuring transparency, a mechanism for audit and in terms of transferability of the method for other researchers consideration in future.

The chosen design described the progression through layers of rangahau practices; noho puku, whanaungatanga and kaitiakitanga which guided both decision making inherent to the fabric of the rangahau as well as providing a practical structure that continued to shape the rangahau itself.

The use of marae as places to safely house the korero was described. The marae being employed both as a unit of participation and as alternative to an acculturation measure was described. The choice of using the concept of pūrākau, as a Rangahau Kaupapa Māori tool in the second round of marae wānanga, which encouraged a type of theoretical questioning to occur, inviting participants to put their ideas into action was explained. This process and content of this chapter sets out clearly the manner in which the results could then be further examined and nuances reflected on and coded.
This chapter provides the form that defines the type of research journey envisaged. What follows is a description of the findings as the waka rangahau continues on its’ journey.
Kia tere te waka ki tai

Chapter Four: The first set of results

Tama was a 17 year old rangatahi (adolescent) who sustained a mild traumatic brain injury in an altercation with police. He had significant alcohol and other drug problems and a previous forensic psychiatric history. He had sustained mild traumatic brain injuries in the past and had not sought medical attention at the time. He had persistent low mood following the injury. As well as recommending treatment options for his low mood and substance abuse problems I encouraged him to follow his strengths in Te Reo Māori. It was not until I met with his whānau that it came to my notice that there were significant negative Māori cultural associations with his name. His whānau sought help through whānau networks to address this.

Introduction

The next three chapters present the different layers of findings of this study. This chapter describes the first set of results which answer the initial question posed: what do people talk about in marae wānanga when invited to discuss ‘he tapu te upoko’ in the context of mokopuna traumatic brain injury? The following chapter presents what I have called a Māori cultural formulation of traumatic brain injury in response to three pūrākau (stories) aimed to invite participants to operationalise the ideas they shared in the first wānanga. Chapter six, represents the arrival of the waka rangahau at it’s destination. In that chapter the second question of the study is answered; how can what was discussed be developed into a framework for work with tamariki Māori with traumatic brain injury and their whānau?

A note about the way the data is presented. Quotations and their respective marae wānanga are presented in italics. The name of each marae identifies the location of the korero (quotation) followed by a number. This indicates either the first wānanga, with number 1, or the second with number 2.

The language used to describe the tamariki and taiohi is modified from this point on. The word mokopuna is used instead. This word, meaning grandchild, has been chosen to describe the child or young person, no matter their age or stage. This is because of the emphasis in the wānanga of the special relationship between mokopuna and their koroua and kuia, grandparents.
Results 1

This section describes the participants, summary of first layer of themes and comments on the research process. 79 people attended the first round of wānanga and 56 attended the second round. The table below shows the attendance at each marae.

<table>
<thead>
<tr>
<th>Table 2</th>
<th>Wānanga features</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Marae wānanga</strong></td>
<td>Number of participants</td>
</tr>
<tr>
<td><strong>Marae name</strong></td>
<td><strong>First wānanga</strong></td>
</tr>
<tr>
<td>Potahi</td>
<td>9</td>
</tr>
<tr>
<td>Owae</td>
<td>26</td>
</tr>
<tr>
<td>Te Mahurehure</td>
<td>3</td>
</tr>
<tr>
<td>Araiteuru</td>
<td>7</td>
</tr>
<tr>
<td>Rauru</td>
<td>11</td>
</tr>
<tr>
<td>Pukemokimoki</td>
<td>6</td>
</tr>
<tr>
<td>Piritahi</td>
<td>4</td>
</tr>
<tr>
<td>Tutanekai</td>
<td>9</td>
</tr>
<tr>
<td>Tapu te Ranga</td>
<td>4</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>79</strong></td>
</tr>
</tbody>
</table>

An initial group of seven ideas were identified following analysis of the first round of wānanga. Participants’ checked the material presented in the subsequent round of wānanga as to whether it was an accurate reflection of the earlier discourse. The process of deriving these ideas involved repeated viewings of the wānanga footage as well as checking the accuracy of the transcripts, reading the transcripts and much time spent in reflective thinking mode. This aspect was considered as the practice of noho puku. Field notes were added to the printed transcripts, ideas underlined and pertinent quotes highlighted. Lists of themes and subthemes were generated. These notes were returned to again after the second round of wānanga for consideration in the writing of this chapter. These processes of grouping ideas and considering their linkages into the most parsimonious group was an action of whanaungatanga using centrifugal thinking. Centrifugal thinking has been described as a mode of thinking where the flow of thoughts is outward, where larger and larger ideas are generated (Durie, 2002). This is in contrast to centripetal thinking, described as an inward type of thinking where ideas are broken down into smaller units (Durie, 2002). Kaitiakitanga was examplified by presenting these ideas to the Rōpū Kaitiaki. The themes were:

1. Wairua is fundamental and attended to as a priority,
2. Whānau are the functional unit of healing,
3. Whānau experience the clinical world as an alien culture,
4. Mātauranga Māori has a wealth of resources specific to mokopuna traumatic brain injury,
5. Māori identity is about connection, 
6. Places have a healing role because they define identity, and 
7. Other trauma remembered when traumatic brain injury discussion invited.

In addition to the seven central ideas distilled, the participants responded positively to having two wānanga. There were positive comments about the research design as a whole.

Make sure we got the research done right, don’t be whakama about the korero you got within your family, tell it. Owae 1

Because it’s critical we find the answers and it isn’t i te taha Pakeha (in the Pakeha side of things), it’s within our own. Piritahi 1

So, I think in relation to this study I’m excited about the outcomes. I’m excited to contribute in a way that says ka nui tēnā, this is not a scientific experiment. Tapu te Ranga 1

This is a karakia that when anything eventful such as this (research) happens that they use this as a closing. Rauru 1

The humour and warmth of interaction was also a notable feature. Both Whaea Moe Milne (Kaitiaki) and Dr. Waiora Port (Kaitiaki) confirmed their support of the rangahau design as they experienced it in action when they attended wānanga. There was also support by participants for the application of whanaungatanga (the connection of relationships) in the grouping of their ideas into whānau (extended family groups) for use in the process of member checking at the second wānanga. These whānau idea headings were written up on large sheets of paper or white boards where available and then verbatim quotes were read out. New participants, who had not attended the first wānanga often asked for clarification as to what had been discussed (for example at Araiteuru 2). Participants commonly expanded on their ideas (for example at Tutanekai 2, Tapu Te Ranga 2, Araiteuru 2). One wānanga expressed their surprise that their initial wānanga discussions had been “so deep” (Potahi 2).

There was no disagreement voiced about the way that the ideas were fed back.

Writing about these results is done mindful that at times it may appear that items are held in focus as separate and distinct. This mode of presentation is an attempt to provide clarity about the components of the wānanga data, however, it is important to emphasise that this is done holding in balance the context and the dynamic connections amongst the ideas. These relational features go on to form important aspects of the theory development and then to inform the design of the framework in subsequent chapters.
What was immediately apparent from the first group of wānanga was that participants had plenty to say in the context of mokopuna Māori traumatic brain injury. What was also striking was that the wānanga participants described broad experiences, not limiting their expressions to those related specifically to traumatic brain injury. The wānanga proceeded after the more formal powhiri or whakatau (form of welcome) and kapu tī (cup of tea and snack). The wānanga were followed with a meal at their conclusion. The wānanga typically lasted at least two hours in duration. None of the participants declined the consent process. A semi-structured questionnaire was trialled, however, it’s use appeared to interrupt the flow of the discussion at the first wānanga and so for subsequent wānanga, after the introductions were completed, the discussion was free flowing with minimal prompting, if at all.

Over the course of this phase of the rangahau a larger number of key ideas coalesced into supersets that reflected the korero. For example, individual topics were initially labelled “Barriers”, “Professionals” and “Communication”. However as further immersion in the data occurred the category of ‘Whānau experience the clinical world as an alien culture’ was used to better encapsulate these ideas in action.

In order to show the links between what participant wānanga said, and the theory building and framework development presented in subsequent chapters, quotes from the data will now be presented which justify and support each heading. A number of quotes are presented. This recognises and honours the richness of the participant narratives and seeks to ensure the reader has sufficient material to experience the depth and subtleties of the material.

1. Wairua is fundamental and attended to as a priority

The importance of attending to wairua was a potent theme. What was also communicated is that the timing of attending to wairua is crucial. Ideally, wairua is attended to immediately or soon after the time of the traumatic brain injury, as a priority. Activities that attend to wairua needs were linked to the role of the whānau.

* I was thinking that in a point of time when the person has their accident or injury that, you know, that is an ideal time, because whānau do gather in that point in time and that, you know, all the tikanga (lore) and kawa (rules) that are put down to ourselves as the future generations need to be addressed in that point in time. The things like karakia (prayers) and waiata (song) and the concepts of awhi (support) and manaaki tangata (helping people), tiaki tangata (caring for people) all those sort of things need to be bought on board at that point. I think next, the step after, when that person is well enough to participate, because we do need participation from the tangata whaiora (patient) or the person seeking wellness after
injury as far as oranga (recovery), hinengaro (addressing needs of the mind) plan or recovery plan is required. Rauru 1

He mea wairua (it’s a wairua thing). He mea wairua nei (this is a wairua thing). Te Mahurehure 1

Wairuatanga, that really is where we come from. Owae 1

So immediately it was a process of everybody come together and karakia, ngā karakia tawhito (ancient prayers), nga karakia inanahi rā (modern prayers), and whatever, you know, so it was the whole joining forces to ensure ‘A’ that this mokopuna can be cared for in it’s current state. Tapu te Ranga 1

So if the wairua of that baby is completely calm and settled and safe which they get through touch and mirimiri, ‘cause that’s the first sensory that comes on board. Then it still allows that child to at least feel relaxed enough and so that all the other connections can happen. Araiteuru 1

It is what the wairua is doing to the body, not what those, you know, operation people are wanting to do. Owae 1

2. Whanau are the functional unit of healing

The wānanga talked about the importance of whānau, with an emphasis on the collective needing to be considered as the unit that both provides healing and requires healing. This was linked to a desire to return to ways of healing that were more prevelant in former times where the whānau experience was one of being more intimately involved in healing processes, regardless of professional input. There were close links between this idea and Māori specific knowledge and practices that exist within whānau with which the whānau might be able to begin healing. The idea that “bringing back” knowledge and experiences from former times was on one hand a challenge, but nevertheless described as much needed in contemporary Māori society in order to address the healing needs of a whānau with a mokopuna with a traumatic brain injury. Interestingly, there were no wānanga where the importance of whānau was dismissed or minimised, or where Māori specific knowledge and practices were regarded as of no current relevance.
As I can recall my mother and father saying that, back in the day, you know their nanny’s, nanny’s days. You didn’t really hear much about problems with the mind with our Māori people because if there was a problem, the family will help out, with the mother, the father and you got the extended family, the nannies. Different today in a way of hospitals to prepare to get well. But then in the old days my mum used to say the family looked after each other, took away that burden you know, helped out, always awhi (support). Rauru 1

That’s another trauma to the family because if you take them out of the comfort zone here, it’s really not a comfort zone, it’s that his healing is with his people, he is not going to heal I know that, but just to see them it’s a healing agent for him. Pukemokimoki 1

I still rely on my kaupapa tikanga mātauranga Māori taketake (indigenous knowledge and practices) in terms of what I would do with my children. Tapu te Ranga 1

And also just that connection, the talking, acknowledging that person and being there by the whānau. Doctors and nurses aren’t going to do that, they just there to check the blood pressure, flip charts, or whatever, so a huge whānau involvement. Araiteuru 1

Yeah, and I just really think that there is just such a lot of power that grandparents have if you want to use that, you know the knowledge that you have. And you mightn’t know it, what it is. Pukemokimoki 1

The realities of modern life were also commented on as challenging the intergenerational aspirations of ideal settings for the caring roles of whānau in the lives of mokopuna.

Ok, our nannies sat in the harakeke plants weaving the kumara baskets and everything else, they don’t do that anymore, they don’t have the time to be sitting watching our tamariki while they weave. They out doing hui, they out giving us knowledge like (name removed) is, a lot of them are so busy because there is so few of them, they are so sought after and the lucky ones who can sit there and just nurture their mokopuna, that’s wonderful, but I know a lot of them would love to do that but because of the dilemma that they can see the rest of us in, they want to help and so they are out there. Tapu te Ranga 1

The importance of the whānau role in their own healing was seen as key. In particular, the wānanga emphasised the whānau role in terms of addressing the wairua of the injured person and their whānau being a central and ongoing activity.
I imagine, I’m sort of romantically going back in time, and sort of put myself in a place, if there was a child hit their head on a rock, diving into a river, had a bash on the head and just suffers something, I could just imagine karakia (prayers), moteatea (chants), all day every day and the whole whānau, ahakoa he iti he korero (no matter how small the contribution), will play a part in that just to ensure that this person is awhi-ed (supported) until there is some sign of shift or some sort of tohu (sign) that this person was on the road to recovery. Araiteuru 1

And sometimes I watch on TV about people in that sort of situation, that dedication, that father and mother to their child, it’s about aroha, it’s the respect of the tapu in that child, he tapu rātou (they are sacred). Araiteuru 1

Some wānanga pointed out that whānau (and tupuna) can contribute to the cause of the injury. They reflected on those aspects needing to be exposed for positive outcomes to be made possible. The wider impact of abuse of children on the Māori community as a whole was also described. A sense of the collective responsibility for the welfare of Māori children was expressed.

Don’t be whakamā (ashamed) about the korero you got within your family, tell it, so it’s identified, tell it so it’s identified. I feel aroha (sorry), coz, some of our men they look so good, but in the kainga (home), different, open up be honest, open up be honest, teach our men to awhi (support) and you wonder why the kids are going crazy because they can’t speak about it. Owae 1

Our babies have been sacrificed. And every day we turn that television on, we sink another foot every time there is another Māori mama or Māori papa, one of ours that has abused one of our own and the horrific way they doing those things. Piritahi 1

So that is a real concern to me that these young people are exposing themselves to levels of violence but there is actually not much help out there for them, so it leads them into a vicious cycle where we keep on getting violent offenders beating up on their partners and their partners taking that, it’s all those effects that go on with that. Rauru 1

Other contributions to injury across generations of whakapapa were given as examples of how the actions of tupuna might influence events in the contemporary world.
But my koroua felt that it was something that he may have done in the past, but mainly his ancestors, and he talked about how two generations from him his ancestor was playing with skulls. And sort of putting it above their head and they were just young, they were just children and they thought here we go, just do the re-enactment with the skull and he felt that that was maybe the reason that that issue had followed the family. Another one of the ancestors was playing with the koiwi (bones) down by the river going into Matata and one of them was a rib cage so he put the rib cage around him and the generations after that had suffered some form of rib injury. Tutanekai

The wānanga emphasised that professionals need to share the recovery roles with whānau.

And I think that’s what we need to take on more, is about maybe doctors and GPs, whoever it may be, is actually sharing that, and sort of say, we can help in this part of the recovery and remind them maybe, if they don’t already know, is that this is how you can help them in the recovery as well. Potahi

The individual contribution of the members of the whānau as a group was highlighted; the importance of everyone having a role to play emphasised.

It’s really the grandmother or the mother imparting their wairua into the child, I ro ake, I ro ake (further inside, further inside) and through waiata (song) and through oriori (lullaby) that’s all, and willing them, y’know, it’s a mind thing from a caring grandmother, mother, even sister, because everyone of us has a gift, taku whānau tonu (which persists in my whānau), each one of us have a different gift and yeah, these are the kinds of korero (discussions) that will open doors for our people to think, “yeah there’s a spot there for me and I can deal with this”. Te Mahurehure

And I think we all, each and every one of us have an element of belief and if that person should fall down there, I’m pretty sure that the whole, how many of us, ten of us will have some input of some sort into that person’s recovery, whether it is hands on, whether it is to say a prayer, or whether it is to, whatever, we would all have, we all would have an element of rongoa (medicine), contribution to the welfare, well-being of that person. Potahi

Recognition that the injury affects the whānau as a group in different ways and that the recovery needs to include the whānau was expressed.
I see that in order to help my son I needed to be well within myself but because I was searching for some help for him, I did not know what I am looking for. Pukemokimoki 1

I’m just talking about the journey from A to B was a very long one, a very difficult one, a very traumatic one for himself, his whānau and his children. And then there had to be a whole lot of other supports put in place because you know the children themselves, one minute they had a dedicated dad, normal, and then the next minute there a person there that wasn’t not quite reacting to them how he had been reacting in the past. Rauru 1

3. Whānau experience the clinical world as an alien culture

Participants expressed the sense that the clinical world was alien to them; having different values and a different language that was hard to understand. Participants expressed their experiences of being Māori within the clinical world meant they were not understood. Participants highlighted the importance of this understanding of who they are as Māori as central to their experience of recovery. There was a sense of an adversarial relationship between whānau and professionals. Solutions for the reduction of these barriers included use of Te Reo Rangatira and ōna tikanga (Māori language and protocols) and professionals actively demonstrating respect for Māori values and needs. Concern was also raised about tokenism of Māori values without real substance of Māori knowledge and practices truly imbedded in clinical practice.

They are all practitioners in their field, nowhere near to understanding you as a Māori person. Owae 1

They don’t believe in the wairua, the psychiatry people and they have said it most often. Owae 1

So I suppose it’s just, really mindful of professionals, Māori and Non-Māori, it is the way you speak to others, be careful not to get lost in the jargon, relate it to the reo, yeah, and I suppose te reo, anyway, hold onto their tikanga, I believe that. Araiteuru 1

So too many professionals, from any ministry, they’re not listening to us, they are not informed of what being Māori is, to even give the person that choice. Araiteuru 1

I think too, some of the terminology they use is not very nice, like ‘anger management’ for a eight year old child you know, there’s got to be a better term than ‘anger
management’. It just seems like such a big, huge raruraru (problem) that this child has, it might be something quite small that’s just triggering him off. Some of their terms, they just drive me a bit spare, I think they just make the job a bit bigger than what they really are. Pukemokimoki 1

How is the government stratospheres of our health system responsive to a Māori worldview and Māori vocab? Is it just another sort of a institutionalised tokenism korero that is going to kick in and listen to our kuia saying wairua this, wairua that, you know, I understand where they are coming from, but how many of our Doctors just going to nod their heads and tick the boxes and then our tamariki become, who was saying, statistics, Māori stats, ay? Piritahi 1

So, y’know I go to the dentist now a days, and y’know the dentist says, “do you mind if I put this around your head”, and it makes all of a difference. Araiteuru 1

The wānanga expressed preferences of seeking out services from places where their values and cultural experiences, in particular wairua, would be understood.

So if I was to go to the Hauora, I prefer the Hauora because you know when you talk, when you say, “I’m starting to feel my wairua”, you know they actually understand that. If I was to say that up at the Doctors, they’d say, “what’s this guy on?” sort of thing, you know, they can’t relate to the vocab. Piritahi 1

I just want to say that for Māori, when you, if I was to go to a mainstream Doctor and start talking, unless those Doctors have put their feet in a Māori world then they wouldn’t be receptive of how I feel as a patient, you know what I mean? Piritahi 1

A further aspect of the alien nature of services was related to whānau feeling that services were either not well equipped to deal with Māori traumatic brain injury or that services were actively trying to avoid managing Māori with traumatic brain injury.

The other unfortunate fact was that the services, you know, kind of, nobody quite knew who was going to manage what or who wanted to own what for example, so the medical services would say, well you know, that belongs in the mental health service and the mental health services would say no, that belongs in medical services. So unfortunately for them they were kind of juggled back and forwards in the system, and you know that put extra stress on the whānau, on his parents as well. Rauru 1
It will be beneficial to us if ACC was to come out more often and talk about what’s available, because from my experience, they’re not very forthcoming you know because they are trying to save money and so they don’t really tell you all your entitlements, in fact, you have to put up a fight for any bit of entitlement that you think you want. Rauru 1

Strong negative feelings were expressed about professionals that whānau come into contact with. The need for senior whānau members to provide leadership so that these emotions did not impact adversely on the healing potential for the injured mokopuna was described.

And so it was for us to be able to share that korero so our mokopuna’s don’t go seeking and feeling a sense of hate towards the medical staff or to that profession and think koretake noa iho i enei takuta (they are merely useless these doctors). Tapu te Ranga 1

The idea that whānau would not ask or challenge medical staff because of whānau priviledging medical roles and knowledge was expressed.

There may have been incidents of this kind within our whānau but they don’t talk about it, because they feel, they leave it up to the Doctor, don’t even ask questions of the Doctor, because the thinking is still, Doctor knows best, so the Doctor’s got the cure for me. Te Mahurehure 1

Judgement and assumptions by professionals that injured mokopuna taken to hospital had been abused was a concern raised by participants. Difficulty was recognised in the relationships between professionals who may report suspected abuse who are then continuing to be involved with medical care and whānau.

I’m just thinking often when Māori babies are taken into hospital the first thing that happens is they come in, there’s all those judgements, they got a bruise or they got something wrong with them they are immediately reported both the police and to CYFS (Care and Protection Services). It is almost like automatic even if it’s just a bruise there is a suspicion already there. Te Mahurehure 1

No, if I’ve taken my baby to the hospital and I’m reported, because they immediately think it’s because of my action that that baby’s got a problem even though I didn’t, it’s got nothing to do with it, I didn’t bash the baby, or dope it, or drop it all that sort thing.
Immediately I am in suspicion. How then do I participate? What’s the korero then that you need to start to think about around this whole rehabilitation, because then you’re the Doctor that reported it, he even said it, how come, you went and bloody said I bashed my baby, you didn’t even ask me if I bashed my baby or not, you just assumed it, and yet that’s the person who going to be part of this rehabilitative process? What does mean, how do we do that and how can we actually also maintain the integrity of that mokopuna. Te Mahurehure

The question of who provides leadership or has authority over the processes within clinical services was raised.

Because I always believe that you have a kuaha Pakeha (non-Māori entry point) and you have a kuaha Māori (Māori entry point). The difficulties we have when we walk into kuaha Māori and got a jolly fulla from the kuaha Pakeha who leading them in. And that’s where we have difficulties. Tutanekai

4. Mātauranga Māori has a wealth of resources specific to traumatic brain injury

The body of knowledge related to “he tapu te upoko” was evident. The participants described practices that were deemed to be specific to injury to the head because of it’s sacred status. Personal experiences were shared that expressed this knowledge as well as sharing knowledge collected and stored by others. An appreciation of the Māori methods of intergenerational knowledge transmission was also described. Participants put forward their view that this knowledge be retained as remaining relevant in today’s world.

And there is the oriori by Tuatoriki for Tuteremoana. Oriori, lullaby, they are just amazing things. Then it talks about the midwifery practices of birth, of birthing, in the old days, but it’s the korero, it’s beautiful in Māori, but I just took some parts out of it, the Māori is beautiful, the reo. ‘Thus like the stars, whakawhetu, thus like the stars, oh son were you conceived’. If you look at these things, they have an explanation. Apirana’s explanation was, the coming into being of the child, the shaping, the growth of bone, sinews, flesh, blood stream, etcetera, beautiful eh; ‘thus like the stars oh son, were you conceived’. Beautiful, if you go right through, it goes right through the whole thing, conception, and all that, beautiful. (reading) ‘Acquire the recesses of the mind the recesses of the spirit’, when the child is fully formed the mind is implanted, nga mātauranga, the intellect is implanted. When I first read it, I thought, gee our people are incredible, now this was pre European time, how did they know about what was happening within the womb as the baby was developing? See when we talk
about the mind, it’s implanted we call it, rua te pukera (important skills are embedded), rua te atamai (skills of inspiration are embedded), rua te horohoro (skills that need to be widespread are embedded), it’s about the different aspects of the intellect, it’s incredible. ‘Then you strive oh son, strive, strive for renown, strive for self persistence, the child moves, it stretches forth his legs, hands, head and the tongue in his mouth, strong; happy and healthy baby, I suppose. So that’s just those three lines from, it’s moteatea, you must read it. It talks about the child before birth, he tapu, he tapu, and that’s what it’s all about, it’s incredible when you read it. Araiteuru 1

A well known contemporary model exemplifying mātauranga Māori, ‘Te Whare Tapa Whā’, was used to describe aspects of brain function and the impact of injury at different stages of child development.

I was also thinking around the tapa whā in relation to brain development that our understanding of that the four parts of the brain fit into the four parts of tapa whā. So the brain stem, where all the survival mechanisms happen, when babies first being formed, is the taha wairua, because when a baby’s life is not threatened, when they are completely calm then it’s the brain stem that allows you to have the access to all the other parts of your brain, so if the wairua of that baby is completely calm and settled and safe which they get through touch and mirimiri, ‘cause that’s the first sensory that comes on board. Then it still allows that child to at least feel relaxed enough and so that all the other connections can happen, the brain injury also depends at what age it is happening, if it’s over three then you would hope that the core pathways that need to be connected by three years old would already be hard wired as they do at three years old. And then the next part of the brain that’s formed is the movement brain, is the mid brain, which is y’know, when he was talking about making sure the baby always moving, they know that at least fifty percent of all our brain cells are held in the cellebrum in the mid part of our brain, so there’s got be a lot to do with movement and brain connections and so that part of the brain is the taha tinana. So if people are using that model, then to understand which parts of which are going to affect the brain more than others. The limbic system or the emotional brain is when they are around two years old, everything is emotional, that’s the taha whanau part of the brain, because it’s reliant on relationships, its reliant on babies being able to feel attached and attuned and connected to the human beings that are supposed to be protecting them and nurturing them. A lot of it for me depends on what age the babies experience the trauma or the injuries or whether it’s actual physical brain structure injury, or whether it is emotional trauma on the brain because we know when any kind of time the baby is under stress or a child is under stress there’s that massive release of cortisol. So if the trauma or injury is so severe it can actually start killing
off the brain cells, but if it’s not that’s there. If someone is yelling at the baby that still actually
going to damage the connections in the pathways, but if that taha whānau is in place and the
taha wairua is in place and then that whole thing about repairing the rupture is also what
builds resilience in children. And then the last part of the brain is the cortex or the prefrontal
cortex that gets formed, so that’s the thinking brain, so that’s the taha hinengaro, so again
that’s the intellect, kai (sustenance) that needs to be fed into the babies. Araiteuru 1

Mātauranga was evident in the importance of the understanding that the head is a
sacred part of the body. Some participants expressed concern that younger generations
may not understand the importance of this tikanga. The link between the tapu quality of
the head and damage to it impacting on the whakapapa was eloquently emphasised.

...ka patu te upoko, ka patu te whakapapa (when the head is injured, the
genealogical line is injured)’. Araiteuru 1

I mean there’s all those, and ok that’s ancient stuff and some people would say well,
but yeah you know, but you don’t live like that anymore. And I think, that gap is where we
need to bridge, because it was so right, our tipuna had it so right, I mean in terms of our
mind, the tapu of the head. Tapu te Ranga 1

Yes, I think it is a common knowledge amongst Māori that the head is tapu purely
because of the symbolism of our whakaaiko, the tukutuku panels, how the wharenui is used
to store social lore of Māori people living in 2010. Piritahi 1

What I’m sort of saying is that there are more things put into the mahunga, the upoko,
than other parts of the body. Pukemokimoki 1

And tapu I think is, a lot of us don’t really understand that, our tipuna called our head
tapu and for me, one of the prime reasons is, if you were to cut your arm off you’d still be
alive. If you cut off your head you are, ka mutu, dead, straight away. With that head comes
responsibilities. When people get sick, a lot of times their tapu is being desecrated, so it’s to
get them back that tapu, the word is originally, I believe a lot of us we all got our brain intact,
and part of it is what I call a tawhito (something ancient), it’s a connection to your ancestors,
 somewhere in there is some sort of ancient knowledge that we already store genetically.
Owae 1
I was just thinking about my own experiences in terms of wairua, in relation to our head. And I grew with up the korero from my mum, my dad, my kuia about your head being tapu and that’s where all your knowledge is stored. So being really careful with it and that was always been something that’s been foremost in my mind. Owae 1

Do you think that we actually think about protecting the, I mean he tapu te mātenga, do you think we think about protecting the child’s head, protecting the child’s head? Not this younger generation. No they don’t know such things. Te Mahurehure 1

Participants commented on aspects of mātauranga Māori such as mākutu (a particular type of potentially harmful spiritual process) continuing to be acknowledged in Māori who had been raised in urban settings. They provided a description of how, at times of traumatic brain injury, culturally determined factors were apparent.

Because the other thing for me is that I’m kind of interested in is that if all of that knowledge still exists, even though people are born and bred urban without a lot of connection, because as soon as you get into it, talking about the injury, you see eyes popping, you tell me what’s happened to my baby? They do it from a place of fear, not because of the fear of what is physically or whatever happened to that baby, it’s really the fear about “oh my god that mākutu has come on me again”, that’s the first assessment or analysis and even though people have not been brought up with that it still exists, it’s quite an interesting phenomenon. Te Mahurehure 1

There was a lot of discussion about a range of Māori activities that were seen as beneficial and necessary elements in response to a mokopuna who were sick and also specific to those with traumatic brain injury. Practices such as mirimiri (a type of massage), skin to skin contact, waiata (singing), patere (chants), karakia (prayer), maurākau (traditional martial arts) were described. The vibration of the voice and of the words in Te Reo Rangatira were identified as a powerful components of this aspect of a culturally effective response to sickness and injury. Many of the examples highlight the role of grandparents and other senior members of the whānau as having particular expertise with delivering these responses in the right way at the right time.

I definitely do believe in the power of touch and mirimiri and in terms of, often that sort of tinana stuff that gets effective with severe head trauma, keeps the tinana moving, keeps that energy flowing, keep the toxins moving, all that sort of stuff makes total sense to me.” Araiteuru 1
As the mother would have had probably a few other kids and when this brain damaged child, either was born or had an accident she couldn’t cope, couldn’t look after them, so the kuia, the grandmother would have taken that child and the grandmother would have the time, kei te mirimiri (to massage), kei te waiata (to sing), kei te awhi (to soothe), kei te poipoi i te pepi (to nurture the baby). Potahi 1

I was talking with one fulla and he said the kaitiaki (guardian) of that, particularly of that third eye was Tupaiwhakarongowananga. And that kaitiaki (guardian) of that place and I’m likening it to that person in a coma who is aware of what’s being said and who is there and who, they are actually in this void though, not even like they are in their body. I liken it to the korero about Tupaiwhakarongowananga. Araiteuru 1

More general responses to mokopuna who are sick were also described.

But I need to say when I had my babies, my mother use to sing to my babies, and it went something like this: (singing) ‘Moe mai pe pe kaua e tangi (Sleep little baby don’t you cry), ka hoki mai a mama, akuanei (Mummy is coming soon.)’ Āna? Mohio koutou? (That one? You lot know it?) Owae 1

Me he tino mauui te pepi (when the baby was very sick), it was the men got naked and tangohia nga kakahu o te pepi (took off the babies clothes) and they’d walk the night, it was actually the men that walked the night with the pepi, skin to skin and I don’t know where that came from? Potahi 1

I believe aye, cause the mother always held the baby in this arm, ne (yea), in her left arm, ne (yea), and the taringa (ear) of the baby was right up to tana ngākau (her heart), so there the baby was oblivious to outside hearing, all it could hear was the pana, pana, pana, pana o te ngākau o te mama (beating of the mother’s heart) and it was rhythmic, you know, something would happen to that baby, it would calm down. Potahi 1

…I in our ancient martial arts like our mau rākau, that’s our reflexes, our karakia, getting us into that realm of tapu. Where we understand ourselves better, understand our wairua better. Even our whakairo, in there is our mātauranga, wānanga, hui all these things but again I go back to atuatanga and karakia because that puts you into a state of tapu where you can meditate, use your brain to find answers. Owae 1
When you listen to a tohunga when they deliver their karakia and patere (chant), tuturu (original), all those other, I think it’s the integrity behind the vocab and the vibration of that delivery I think that it adds a potency to it. Piritahi 1

I use to remember my mother singing with a baby, that song, ‘Ka tahi tī, ka rua tī’ (nonsensical ditty). When I grew up and I heard somebody else singing and I recalled it, you know o wera waiata (that song). Potahi 1

Participants described use of mātauranga to understand the causal factors, such as trangression of tapu. These informed preventative practices related to protecting the tapu status of the head of a mokopuna.

…so they took the mokopuna, and then they would talk to you, where have you been or what did you take? For the pepi to be this way? Ae (yes), or during the times that you were hapū (pregnant), there were certain places that you shouldn’t have gone, but you’re so anxious to know, what is over there? Ka haere koe (you went) and they’d know you’re been somewhere. Pukemokimoki 1

Because I believe there is still that practice within different places and many of you get a feeling, certainly get a feeling of good or bad which ever area you’re walking in. And you can certainly get a nasty feeling in certain elements, then you start wondering why did I step to one side as I was walking to this place? You stepped to one side because your spirit told you, hang on, you’re walking over a tūpāpaku (corpse). Tutanekai 1

The hinengaro they explained to me, the hinengaro was the place where your thoughts sat, your brain was the taha tinana, your hinengaro was the taha wairua and they believed that the hinengaro had a shape, it was a shape like that (makes a upturned curve shape with her hand). In English they call it convex, I think and then you turn it over it’s called a concave. Well, to me it’s he waka, he whare, to me, so it gives us knowledge and it shelters us. So, for me that’s what hinengaro was all about, ‘oh, so that’s why nan said I wasn’t allow to bash the kids on the head, ok!’ Owae 1

I had grew up with different nannies really, would be around, he tapu te upoko and it was generally practiced around things like um, don’t take the brush, you don’t leave the brush at the table, don’t do your hair at the table and when you cut your hair there is a karakia for this and a karakia for that. Tapu te Ranga 1
I transgressed somebody’s wairua, therefore that’s what is happening, it’s coming back, it can’t get me, but it will get my child. You know all those kinds of things, we can’t get away from that kind of thinking, if we can address it and say yeah there’s a place for that and that actually happens, ok let’s look at how can we best deal with it, tērā momo (that type). Te Mahurehure 1

One of the things I want to say is that if my mother was alive, she would be in her early eighties now, but I could remember as a child her saying to us and crying out to us, she would say to us never shake a baby. Now this is over fifty years ago, she knew that and she would have learnt that from her parents, never shake a baby. And it’s what we have lost from that now, I’ve grown up knowing never shake a baby. Owae 1

For that reason, kia tiaki te mātenga (look after the head). Didn’t want to be susceptible to those things that travel in the night. To come into your baby, to come in through there (indicates the fontanelle). Te Mahurehure 1

You bury the placenta, you don’t bury the pito (umbilical cord), but now all these youngies are burying the pito as well. You don’t bury it, you put it in a tree. Because somebody learnt that is a tikanga. And it’s not tapu, those are healing places, where the whenua goes or where the pito goes. If your babies get sick you go back to those places. Just to do karakia, mirimiri or whatever you need to do. Te Mahurehure 1

Mātauranga was expressed about the understandings of Non-accidental traumatic brain injury.

The word that you used to hear from people was whakataurekarekatia, well, the person is put down, way down there, his worth as a person, his tapu as a person, has been denied. Te whakataurekarekatia, you hear that term, the lowest of the low, he is tapu. A good example, off the cuff, if a women who has been raped, or a women who has been bashed or a baby being bashed and killed, y’know. That’s the things I am talking about whakataurekarekatia; their worth as a person created by god in this image has been violated, desecrated or debased whatever you can think of. Araiteuru 1

5. Being Māori is about connection
Māori identity was another theme of discussion at the wānanga. Positive aspects were emphasised. Māori identity was described in terms of profound connection, to meaningful places and people, across generational time working collaboratively and knowing your role within the whānau this sense of connection seemed to be almost synoymous with the use of the concept of wairua. One participant defined Māori as being wairua people. Profound links to the environment and to ancestors guided by tikanga were consistently highlighted, rather than the concept being defined by the english concept ‘spirituality’. The power of naming and use of tupuna names as a mechanism for strengthening Māori identity was discussed as possible non-accidental brain injury prevention strategies. The sense that a strengthening Māori identity could prevent abuse of children was raised.

It’s everything to do with wairua it was to do with the spirited people, the get up and go, y’know, you connect the spirit, you kick the heart off and get the mind going, you get the physical stuff going, but this is why we’re the iwi wairua te iwi Māori (a ‘spirited tribe of people the Māori people’; A. Reedy translation 2011), mai rā anō tātou (we are from ancient times), we see the rivers, mountains are meant to be climbed, seas are meant to be sailed, there is no such thing as a horizon to our people. Tapu te Ranga 1

So you know I think something that I admire about being Māori is working together so that we acknowledge that we all have a piece of the puzzle to contribute, you don’t have to be the everything and that I think helps soothes your wairua too and knowing that you don’t have to be responsible and take ownership that everything is shared, I think for me that’s always been a real special trait for being Māori. Araiteuru 1

We had a big discussion one time about, particularly that discussion was around people, whanau choosing to, in a reclamation of ingoa Māori o ngā tamariki (Māori names for children), we’re giving our babies beautiful, fantastic old tupuna names. And yet those are babies, but we still choose to hit and smack our babies particularly around the head. So y’know, take a step back and look at that picture. If that’s the name we give to our tamariki, that’s who has been beaten or smacked or it could go a bit further, or the other not so good things we might choose to do to our kids. Araiteuru 1

So I think about tapu in that way, and if tapu is, if you like, it’s a connection to your mauri, it’s a connection to all that is there around you that makes you who you are, if there is brain injury, like if there is wairua injury, or injury in your whānau, or in the tinana in other areas, then those connections are severed. Araiteuru 1
In many ways I’m very Pākehā-fied but I’m ok with that and I’m finding I’m getting a hybrid of values from both of my parents you know and I’m going more towards the human attributes, ira tangata (the essence of being human). I think in response to that last comment tino rangatiratanga (self determination) is so important for our people, our identity is so important and I think that if that seed was definitely a point in the compass, the moral compass, well I think our children will be treated a hell of a lot more differently. Piritahi 1

But we don’t have to be isolated, everyone was born with a brain and if their brain was dysfunctional at some stage of their life then it’s not to say you’re nothing, you know, you have a role, you have a part in society and we have role in nurturing you and ensuring that there are systems in place for you to be cared for, in whatever matter. Rauru 1

Our brains were said to be of brilliant capability by Elsdon Best when he came here in the early 1800 period and the Māori mind was magnificent! So how can we capture what we came from, those wonderful kaupapa that we lived by once, that we’ve been assimilated out of and how to captured that again for a better way forward, a better way of rehabilitating. Rauru 1

Y’know, that’s being Māori, it’s being a Māori; an environmentalist. Our people were so in tune that they always did things where they didn’t exploit it to a point where there was nothing left. Rauru 1

I whai tātou i tērā ao (we can follow that era), how can we go back and implement these things that were talking about. We’re all doctors, we have it in our hands but we don’t utilise it because we’re colonised, we’ve been colonised, totally contaminated, thinking Pakeha. Nā reira tātou, we become too dependant on it, but if you stop for a wee while and think, who are we? Rauru 1

What eponymous ancestor runs through your veins, how your umbilical, nanni, gee, ties to the whenua and where your blood runs through that whenua? Those are powerful things but we don’t think like that anymore and we have to teach ourselves again and decolonise our minds. Rauru 1

The point was made that Māori values are accessibe to non-Māori people too.

Can I just quickly acknowledge y’know that being Māori is empowering, is healthy. Because I think I know lots of non-Māori take on Māori values, and one of them is my dad
and we often laugh because we thought, y’know he was more Māori than us, only because he practiced the values, but we felt on reflection possibly more so than we did, but he was a really good role model. So those values and attitudes about being Māori can be something that can empower anyone. So it’s not just solely because you got Māori running through your blood, it’s just because you’re open to participating or develop those attitudes and values, I believe. Araiteuru 1

6. Places have a healing role because they define identity

The healing role of a range of places was discussed. These places were recalled through memories of tupuna (ancestors) and through a sense of synergy and shared “vibration” between people and their land of origin. Examples of connection between land and living creatures were presented as pre-colonial patterns of relationship between Māori and whenua.

Well I’m talking about the wharenui (meeting house), represents the body of the tipuna (ancestor), he tapu, and so Kawiti, on that thing I was talking about he tapu o te whenua (the land is sacred), and we all know that, because the whenua is Papatūānuku (Earth Mother), the mother. Papatūānuku is the beginning of our whakapapa, Papa-tūā-nuku, whaka-Papa. Araiteuru 1

And in Aotearoa it’s pēnei (like this), it’s ihi (power of excitement), it’s wehi (awe), it’s mana (respect), it’s tapu you know (demonstrates hand movements). So irrespective of our tipuna (ancestors), there is a different wairua here and in respect to that, it is wairua, the vibration, the Māori sound instruments, the pūoro (traditional Māori flute), the audience, a very different rangi (sound), an extension of the whenua (land) and through us. Piritahi 1

What we talking about today is something so very valuable that in order to understand we need to go back, way back in time, way back into the past, where our people had the ability to attend to these problems of the mind, of the spirit, of the soul, because they lived in the harmony with nature the environment and their atua (gods). Rauru 1

…we were in tune with nature, what’s happened with nature, are you surprised that the state of the human race when we look at the natural world? How disconnected we are, we can’t even see the signs our tipuna used to watch. We got no rongoa (medicinal) garden to go to because it’s all pine trees, you know so are we that surprised that there’s mate
hinengaro (mental illness) at a rate that we can’t even control when our holistic environment is mauuii (sick). Rauru 1

Those were the days when our strong belief, we were bought up with the belief in signs. The birds were our main sign bearer. The birds. The different birds had different duties. Tutanekai 1

Marae were described as specific places that brought together a number of features synonymous with a healthy sense of being Māori. Memories of time spent on marae were also re-called. Marae were described as places where Māori need to return at times of stress and distress and a place where “outside “ influences can be kept at bay.

And one of the benefits that came out of the revival of Māori arts and crafts was the proliferation of meeting houses, wharenui, and with that proliferation of meeting houses our people had a place to wānanga like what we doing now. Araiteuru 1

And I just had whānau, and even my connection with the marae made me feel being Māori is cool, that there is hope for my kids. Araiteuru 1

I say, tūrangawaewae o te marae (the marae is a place to stand), is the heart beat and we have these everywhere and we need to open the door because we do best in a collective sense, hei manaaki (for hosting), hei tiaki (for caring). Piritahi 1

And that’s my strongest point with my mokopuna is that we have many lost whānau and somehow we need to bring them back into the marae because it’s when you take on board your tikanga of your tipuna then ahakoa kei whea (no matter where you are from), if it is intrenched within you, no matter where you go, you’re balancing yourself against that. Piritahi 1

I suppose in what the marae is trying to do, pertaining to mamae (pain), is to develop an area like this which is a wānanga, whare wānanga, first and foremost. Pukemokimoki 1

I slept in the cupboard while my parents were on the piss at the pa, but I don’t hate the pa I love it. But I had really had good experiences, even though the parents were there for two days drinking, but they made sure we had nice warm beds to lie in the cupboard and that there was kai, we were looked after and we had fun. Tapu te Ranga 1
Whānau situation in those days, though they have their whare all over the place, but the meeting place was always here, only meet at the marae, if it wasn’t here it was down at the other marae, if it wasn’t there it was at another marae. Tutanekei 1

...i runga i te marae (on the marae) that’s the only place where you can do that because it’s far easier to brush away the outside influences. Tutanekei 1

7. Other trauma remembered when mokopuna traumatic brain injury discussed

Participants talked about other trauma, in the form of other medical conditions, such as stroke, brain tumours, epilepsy and birth trauma. The idea of brain trauma secondary to other causes such as incest was also commented on. The relationship between these other varying forms of trauma and wairua was questioned. The sharing of these stories was strongly linked to a sense of whānau knowledge, or lack of it, and tupuna (ancestors) knowledge continuing to have relevance today.

And so I was just thinking about stroke victims at whatever age as well, I assume there is a lot more research being done around that and that also its some other place we need to be thinking very seriously about in our own whānau here in Dunedin the seriousness of stroke. Araiteuru 1

I didn’t really think I knew much, my experience with brain injury, had been through my mother in-law, who had two brain tumours removed in the last ten years. She passed away last year, but my experience had been in caring for her before and after her operations, and just watching her. Araiteuru 1

She was injured at birth, she was a forceps baby and when they pulled her out it slipped and damaged her brain. Owae 1

What I’m interested in is that brain trauma just doesn’t happen from physical injuries, I’m talking trauma of incest, sexual assaults, and the damage that it does to affect the wairua and the shock and effect of those sort of acts on the human brain and the developing brain. Owae 1

My brother was epileptic and my kuia and koroua took him as a baby and brought him up as his spells would be few and far between but never the less he suffered that. Tutanekei 1
Summary

Seven central ideas were identified from the first round of wānanga and verbatim quotes in each of these categories have been presented in this chapter. To recapitulate, the central ideas derived were:

1. Wairua is fundamental and attended to as a priority,
2. Whānau are the functional unit of healing,
3. Whānau experience the clinical world as an alien culture,
4. Mātauranga Māori has a wealth of resources specific to mokopuna traumatic brain injury,
5. Māori identity is about connection,
6. Places have a healing role because they define identity, and
7. Other trauma remembered when traumatic brain injury discussed.

This work exemplifies specific Rangahau Kaupapa Māori practices. The practices of noho puku (quiet reflection), whanaungatanga (grouping the ideas into these seven ‘whānau’), in concert with whakaaro Māori (centrifugal thinking) and kaitiakitanga (guardianship over the material) guided immersion in the data and the distillation of the results.

In the next chapter further analysis of these ideas is presented describing how participants engaged in what I have termed ‘Māori cultural formulation’ of mokopuna traumatic brain injury.
Ka tere te waka ki tai

Chapter Five: Māori cultural formulation of traumatic brain injury

Tane was 12 years old when I assessed him. He presented with an Anxiety Disorder secondary to a General Medical Condition, namely his traumatic brain injury, which occurred during a high speed motor vehicle accident in which several people died, one year prior. He had become highly anxious, refusing to go to school, fearful others in his whānau would die when he was away from them since the accident. He became interested in learning relaxation techniques, in particular in learning about the power of the “hā”, the breath, from a Māori perspective.

Introduction

This chapter focusses on the next layer of analysis of the data. After the initial ideas were checked and discussed during the second round of wānanga, each marae was then presented with one of three traumatic brain injury pūrākau (stories). This approach aimed to form a bridge between the research questions; leading from what Māori said to how to develop a framework from their responses. Using pūrākau was the mechanism to encourage operationalising of the ideas, thereby providing a basis for the theory building and framework development. The pūrakau were based on core features of common types of traumatic brain injury in the following age groups; pepi (infants), tamariki (pre-pubertal children) and taiohi (adolescents). This process prompted participants to engage in what I have called Māori cultural formulation of traumatic brain injury. This formulation was followed by recommendations from participants about Māori specific interventions to occur alongside clinical formulation and treatments. Participants did not reject either Māori interventions or clinical interventions rather they expressed a preference for both to occur. The formulation suggested that where the clinical environment persisted in dismissing Māori interventions whānau would be less likely to fully engage in both Māori specific practices and clinical treatment plans. Conversely, where whānau felt validated by clinical services that increased the likelihood of greater participation in both utilisation of Māori cultural resources and in clinical recommendations.
Results 2

Responses to pūrākau at the second round of wānanga

Firstly, I will present the respondents ideas which formed a Māori cultural formulation of mokopuna traumatic brain injury.

This process of Māori cultural formulation of mokopuna traumatic brain injury was uncovered by analysis of the second wānanga set of transcripts and footage using the practices of noho puku, whanaungatanga and kaitiakitanga. Reflecting on how the participants responded to the pūrākau, grouping quotations and field notes, presenting findings to other researchers and to the Rōpū Kaitiaki were the processes of analysis. In addition, the process of centrifual thinking was critical here, challenging my thinking to move into the larger ideas that were being utilised by the participants to make sense of and respond to the pūrākau. Four elements were identified; Wairua (uniquely Māori profound connectivity), Tangata (people), Wā (time) and Wāhi (place). These will be discussed in detail in this chapter.

This cultural formulation was followed by discussion about the interface between whānau and professionals and recommended Māori cultural interventions. Interestingly, while the participants had described their experience of the clinical world as alien, none of the wānanga dismissed the role of clinical services. Neither did they dismiss Māori cultural needs in response to traumatic brain injury. Rather, the participants viewed people in clinical roles and clinical knowledge (stemming from the clinical world view), skills and experiences as needing to enter a Māori world view and work alongside whānau with mātauranga (knowledge systems from within whakapapa), pūkenga (skills) and kare-ā-roto (emotions). In addition, a range of ideas were shared about how the interface between whānau and these services could be improved. Finally, the wānanga reflected on difficulties with the word “rehabilitation” and the sense that this concept lacked salience in the context of mokopuna traumatic brain injury. Alternative ways of conceptualising rehabilitation from a Māori world view were put forward.

A brief comment about choice of language is needed. Discussion at Te Mahurehure, the first wānanga of the second round, led to the decision not to give names to any of the children described in the pūrākau. The recommendation was to call them ‘pepi’, ‘tamahine’ or ‘kotiro’ and ‘rangatahi’ or ‘taiohi’, or ‘mokopuna’ (grandchild). This was in order to protect the mana (status, respect) inherent to any specific names and to attempt to limit possible distress for participants if names that might be meaningful to them were unwittingly included.

To recapitulate briefly, the three pūrākau developed were:

Pūrākau 1: Non Accidental Severe Traumatic Brain Injury in an pepi (infant)
Pūrākau 2: Mild Traumatic Brain Injury in a pre-pubertal kotiro (daughter)
Pūrākau 3: Moderate – Severe Traumatic Brain Injury secondary to a motor vehicle accident in a taiohi (adolescent) (Appendix 8)

Māori cultural formulation of traumatic brain injury.

Strong statements were made by all wānanga about the meaning of a traumatic brain injury in Māori cultural terms. This Māori cultural formulation of traumatic brain injury positioned four key elements together as requiring attention, Wairua (uniquely Māori profound connectivity), Tangata (people), Wā (time) and Wāhi (place).

Firstly, wairua was identified as the Māori cultural element of hauora (health) fundamentally injured in the traumatic brain injury. The nature of wairua defined as the uniquely Māori element of connection between Māori and the universe was expanded on. Next, the tangata (people) involved were considered. The whānau was highlighted as the functional element of consideration. This was because of the specific healing actions of whānau required for optimal response to the wairua injury but also as encompassing other trauma including, in some situations, those contributing to the injury. Alongside whānau, aspects pertaining to the people from clinical services were described. Concepts of wā (time) and wāhi (place) were overarching elements that encompassed defining features of Māori identity as well as the impact of time and place on response to injury by whānau and professionals alike.

A brief note on how the quotations are presented. Key quotes in italics are grouped by theme. Each has the identified marae, such as “Araiteuru”, then number of the wānanga, “2”, and the number of the pūrāku, such as “p1”, meaning pūrakau1, the pūrākau about a non-accidental traumatic brain injury in an infant.

Again, a number of verbatim quotations are presented. This is in order to assist the reader to experience the richness of what participants shared and to ensure the linkages both from previous layers of findings as well as into the next, are transparent.

Wairua: Wairua is injured in traumatic brain injury

When participants reflected on the pūrākau presented to them they consistently responded that injury to the brain as an organ (tinana) also needed to be thought of as injuring the wairua.

If there is brain injury, there is wairua injury. Araiteuru 2 p1

And when you say that word, irrespective of the trauma, trauma is trauma, trauma is first and foremost to the spirit, you know, of a person. Piritahi 2 p3
Any form of injury, be it brain, any form, it’s a whati, it’s an interference. Owae 2 p1

Because what we’re doing, what we want to be doing with this mokopuna is in fact, we become the tupuna. The baby is three months old, we, you know for all that we’ve walked, and lived and breathed and talked, then you take on the role as that tupuna. And that’s what that mokopuna is looking for, and so the priority for us, when we’re working with mokopuna is to immediately, is to be as immediate as possible. Our responsibility is to discharge this baby from this wairua kino (damaging energy/ disconnection). Tapu te Ranga 2 p1

I think it’s soothing, very soothing, and to me it’s about invoking the presence of the wairua of a tupuna. Tapu te Ranga 2 p1

Well I think the first thing, the first thing you do when there is an accident is whakamoemiti (pray). Potahi 2 p2

Because taha wairua is installed in Maori from down here (indicates the womb), aye, mō nga pepi (since conception). Pukemokimoki 2 p2

Ways to approach an understanding about the nature of wairua were described, as was the healing ability of wairua.

But there was all this korero, what was wairua? Wai is water and the rua must be the shape, was known as the rua which was where the knowledge sat. The rua was also a number (rua is also the word for the number two) which must have been my mother and my dad, whose waters I came from. Owae 1

And the art of healing is the warmth, but not from the heart, it’s from the wairua that is sitting on their shoulder. Tutanekai 1

**Tangata: Whānau**

Participants emphasised the role of people in their formulating mokopuna traumatic brain injury. The people who featured in their descriptions are the whānau and the professionals.

Firstly, respondents expanded on the importance of the whānau as the functional unit of consideration. The whānau - both as providers of healing practices for attending to wairua
as well as their contribution to the injury - were discussed. Examples of both the presence and absence of healthy relationships within whānau and the value placed on these relationships were described as influential. The quotes suggest ‘re-building’ whānau as a way to instil resilience.

The tūroro, if it’s a child, actually grieves, the mother and the father who ever is the closest person involved with the child, that unit is the tūroro (patient). Te Mahurehure 2 p1

And that’s where I am at with this child. Because the whānau, because to get to the child, you got to get through the whānau, eh? Owae 2 p1

Because I think too, a huge part the child’s healing comes from the whānau healing. You can’t expect a tūroro to feel at ease and to be healing if the whānau is arguing amongst themselves and pointing fingers and all that sort of stuff. Te Mahurehure 2 p1

But, you see, the first assumption needs to be that whānau has resilience and supports and I mean within a whānau there is actually a whole lot of things that can happen. We should not make the assumption that’s a koretake (useless) whānau and therefore it’s going to be a burden looking after that child. Te Mahurehure 2 p1

…you know, there is an assumption that the whānau can’t do it. In actual fact, within whānau there’s a lot. Te Mahurehure 2 p1

…educating some power back into the whānau to have control into it’s own oranga. Owae 2 p1

That there are too many young pepi’s coming into ACC with head injuries. There are struggles, tribulations and challenges for whānau with a TBI pepi, or a young child. That’s the realism, we are talking about those disconnects, disconnects for whanau, disconnects for whakapapa. Owae 2 p1

You can’t actually even have that conversation if we’re not talking about the power within whānau and protecting the knowledge. Owae 2 p1

So the whānau will support, the whānau whanui (wider family system), will support the whānau of that child, if he gets taken to the hospital. Potahi 2 p2
And it’s not just about the one that’s had the accident, about the victim, it’s also about the whānau making sure that whānau understands, that your taha wairua needs to be looked after as well. Not only her, she’s ok because everybody else is looking after her. Who is looking after the family? You know it’s scary for the family, because they must be going through a lot of trauma because of what has happened to their girl. Pukemokimoki 2 p2

Sometimes I get the feeling that a whānau is unable to help their own because they going through their own healing process. Pukemokimoki 2 p2

I think anyone on the huge traumatic, yeah especially head injuries, the most tapu parts of our bodies, tragedy, which are in most circumstances tragic, you know instant trauma, children; that’s additional trauma to the entire whānau. Piritahi 2 p3

Respondents highlighted that the whānau role in healing is of equal importance as the role of professionals.

Somebody within the family needs to say, ‘Kao, kao (no, no) we’ve got to do our thing first.’ And even though it might be looking at a, well it’s getting critical, the family appreciate the critical-ness of the situation, they need to play their role which is to just as important as the doctor’s role. Potahi 2 p2

Very much important to have the family involved because they have all that background knowledge about how he functions and all the rest of it. Araiteuru 2 p3

I imagine that in the first instance whoever are the first people who are working with rangatahi that the whanau is the first point of call, if you go back as far as the ambulance people, or whatever were the first contacts are so here you are arriving at the hospital, or however that happened, that the very first people that deal with him deal with his whānau as well. Araiteuru 2 p3

That what I’m saying, it’s about the process, let the first part of the process occur. And within it is all the things that we’re talking about all the korero, because I never fail to mention that oranga is not only the person that’s lying there, it’s all the people that surround them, whether they are present absent or otherwise. Tutanekai 2 p3

It depends on the situation, because if the families there and they usually are, one of the things I always do in those sort of tragic circumstances I get the details, and I’ll say, ka
karakia tātou (let us pray)... In those sort of situations, knowing that person’s whakapapa, the family or whatever, the mother and father, that helps a lot. Araiteuru 2 p3

Don’t deny them the closeness of whānau. Encourage that as much as possible because the hotu manawa (aching heart) the he aha tēnā (what is that), the throbbing of the emotion won’t settle until mama’s there, nanny’s there, you know. Piritahi 2 p3

But we are talking about the rongoa (medicine) here, the rongoa is within the whānau itself. Whether we like it or not, but it’s in the whānau. Tutanekai 2 p3

**Tangata: Professionals**

Participants shared their views about the differences for whānau in their experiences of professionals and the services in which professionals work.

Yeah, the wairua and the hands on whānau, losing the contact, the contact with services is a big, big issue. If the whānau has a bad experience, and it seems to me that many whānau have had really bad experiences with services, so the contact drops off, and once that drops off it’s really hard to get back into any sort of loop, any sort of connection with services. Te Mahurehure 2 p1

Māori professionals were also described as being influenced by the systems they work within and that this limited their ability to support Māori whānau and the impact on whānau wairua.

And how could her wairua be uplifted at any stage of that journey with the criticism and the finger pointing that she received? And you know what was even more interesting, Māori katoa ngā (they were all Māori) social workers from CYPS (Care and protection services) the people from the police were Māori but they worked in a system that didn’t acknowledge any of the korero our koroua and kuia have talked about today, they were functioning in the main stream system, and ahakoa (even though) they were Māori they behaved like Pakeha and soon became more entrenched, more bitter and more angry and when we used to see her, her wairua had gone, literally because she was so damaged by this experience. Tutanekai 2 p1

One of the things going through my head, is that there is this, I assume enormous fear within whānau around, you know, the finger being pointed at, you know, why is this child
in this situation, who is responsible for this? You know, it’s not just necessarily a one-off event, it looks like it could be other things happened, therefore there is an enormous, total reluctance I’m sure to enter into discussion. Especially, because they feel, if it were me, I’m sure, I would be feeling that instantly that the eyes were on me, that I’m to blame in some way for this. The whole maybe misunderstanding and prejudice, of being part of that family in some way, it is huge burden to actually even begin enter into discussion.  Te Mahurehure 2 p1

I’ve had an experience like that, when I actually think about it, ‘cause you know, the whānau take the baby in, they get all these doctors’ terminology. Whānau can’t understand, what the heck is going on. Because did the father get told what is actually happening to that pepi? I would think the Maori whānau are none the wiser, in the long term. And then listening to hear that somebody’s already been arrested. Denials gonna happen, they’re gonna go into denial. And then there’s going to be a lot of, going to be hard, whānau not going to want to talk, confusion, not understanding. Te Mahurehure 2 p1

The wānanga participants had a lot to say about the need for excellence clinically and culturally as necessary in determining the best outcomes. They emphasised the need for professionals to know about “things Māori”. They pointed out that the whānau view of activity such as “advocacy” might be different than that of professionals. They expressed the desire for partnership between whānau and professionals in the care of the index patient. They told stories of professionals’ racist responses to Māori speaking Te Reo Māori. The wānanga also had much to say related to tension at the interface with professional services and Te Ao Pākehā more generally. Language was a common stumbling block, in that jargon was experienced as a barrier. Te Reo Māori was recognised as an important and undervalued aspect of what Maori whānau need as part of their healing. In terms of formulation, these ideas suggest it is important to anticipate that Māori experience of the clinical world is different and that these differences must be attended to.

They don’t have as part of their core competencies or requirement to be knowledgeable enough to know they don’t know enough about things Māori. Te Mahurehure 2 p1

But in terms of advocacy, how can you, I actually think the way people who work in health have got a different idea or notion of advocacy as opposed to what whanau think. Because a lot of health people will actually argue that they do actually advocate on behalf of the child or on behalf of the person, they do say that. In actual fact, their advocacy and what
we are talking about, what I think we are talking about, is actually two different things, yeah, it is. Te Mahurehure 2 p1

In my experience, I go back to my colleagues, our Chaplains, one thing I find, if you’re not well in the hospital you have to be very assertive, you have to stick up for that person, that whānau. Over the years, you got to stand up to the medical staff. Araiteuru 2 p3

He is a Māori child his first language is Māori and she just was not interested. So I put in a complaint to her company about it and I don't know what happened after that, just another example of that, 'you people are thick, I'm not interested'. Te Mahurehure 2 p1

I think sometimes you might need to remove the word clinical and just make, just have it there because once you talk about that to people the taha Māori start to switch off. So like you’re saying can you have the two together, I don’t know, I don’t know. It’s like saying can you have the coloniser and the non-coloniser think the same? Rauru 2 p2

A lot of barriers are also that families don’t know what their rights are. And what is out there. They don’t know that they can say, you need to tell me what other options are out there for my eight year old daughter or whatever, your word is not the ‘be all and end all’, I need another opinion. People aren’t aware of that, that is huge barrier. Pukemokimoki 2 p2

Empower them with knowledge. That was the one thing I found out in mental health. They did not know anything, it’s there, but they did not know about it, how to access it, they didn’t know what their rights were. Pukemokimoki 2 p2

That’s what’s happening in our hospitals. The lack of communication between nurse and patient. A lot of it because of cultural, you know, Māori, Pakeha. The Pakeha doesn’t understand the Māori and the Māori is pissed off with the Pakeha, you know, and that sort of thing. And ‘cause a lot of it too could also be that the terminology that doctors and nurses use. When it comes to talking to Māori you need a friendly, easier way, where they can understand it. That’s identified there in a barrier, it’s terminology the doctor coming into the room by himself and just standing up and looking down at the patient. The jargon. Pukemokimoki 2 p2

So head injury’s quite easy to lump into mental health. Yes, and that’s exactly what happened. Especially for Māori. Pukemokimoki 2 p2
So, in other words, when they are taken to the hospital you just go to your room and that’s it. They are treating the sickness, eh, but not the wairua Māori that needs to be treated. Pukemokimoki 2 p2

But the spiritual thing, you have to hold fast to that. It keeps you together that’s the understanding of tikanga. And I don’t think that it is happening in the hospital, to understand why you do it like that, it’s a choice. Pukemokimoki 2 p2

…there is a glitch between the GP (General Practitioner) and, I’ll say the DHB (District Health Board), or it could be the hospital doctors, because there is a big, once you leave your GP’s care you come under a whole new lot of care. And there’s no communication. And sometimes the GPs don’t even get your report when you’re discharged, your report back from the hospital. And because the GPs have to ask you what happened, what test did you have? Pukemokimoki 2 p2

Another thing at EIT (Eastern Institute of Technology), they’ve got the kaiawhinas (nursing students) out there part of their nursing programmes but it falls off when they register, you see, it doesn’t follow right through to the hospitals. As soon as they get to the hospitals you are given your load of eight or nine patients. Everything else goes out the window. Pukemokimoki 2 p2

And also in the another area now, which is rongoa. And I’m finding out such a lot about that whilst I need the doctor to diagnose, they also need a kaumatua, to give us the, ngā pai o ngā rongoa mai i te ngahere i awhina, hei tiaki (instructions about how to use the goodness of traditional medicine from the bush to support, for care). Potahi 2 p2

Because Maori are certainly very different from Pakeha, you know. Potahi 2 p2

Participants gave further examples as to their experience of the alien qualities of clinical environments. These included whānau being asked questions without salience to their world view as part of assessments. Lack of relationship and the experience of clinical staff as “strangers” was described as contributing to whānau stress. Suggestions related to whānau defining cultural interventions were made. The difficulty and importance of “standing up” to medical staff was noted. An adversarial relationship was described.

Even like with our dad when he went in to hospital they were asking him how old is he and what’s his date of birth, well he’s never known that you know. He didn’t know our date of
birth. And so we’re saying, he needs to be asked questions like, what is the license plate on your truck? Araiteuru 2 p3

Because if you’re all stressed and you’ve got strangers coming and looking at your body, particularly you know, people don’t like our own people looking at their bodies, let alone, pakeha, pakeha nurses, or male nurses! So there’s all that stuff that comes into the kind of stress that our people continue to be you know, just from being in hospital. Araiteuru 2

They’re not necessarily trained to include the culture of the whānau, I don’t mean the Maori culture I mean how the whānau functions. What are the things that this whānau are really good at? He might be really good at say, mau taiaha (a traditional Māori martial art form). So part of his rehabilitation-y stuff should be put a rākau (traditional martial art instrument) in his hand if that’s what he’s familiar with. Put, do something around that, don’t just put your occupational therapy methods. Ensure that the whānau is part of defining what that whole plan should look like. Araiteuru 2 p3

I think the longer that they’re in, as with many of our people, in a foreign clinical environment, the more depressed, the more loss of their own self-esteem, their motivation to self heal you know, they lose that if they are in foreign clinical, not saying unloving, but if they’re amongst their own… Piritahi 2p3

I think also with that also needs to be help actually for the whānau particularly if you are not in your area, like for us we had to go to Starship (National Children’s Hospital), we didn’t know anybody up there, so you really just a small grouping, if there’s only one or two of yous there, but always having somebody always at the bed never ever leaving him that’s what we had to do. We worked like shifts always having someone there. And you had to be in a positive mind all the time when you sitting there and some of the korero that comes back from the clinician is not very good, a lot of it’s always being negative. You’re trying to actually lift yourself up enough to help your pepi or whatever and they actually bringing you down with the clinical terms of what happening with him. And yeah that’s really quite difficult and again yeah if you are in strange area, a lot more difficult. Tutanekai 2 p3

We know we are not on the same side (as professionals). Tutanekai 2 p3

But I think it’s whole systemic approach to what you need to have happen in mainstream services to make it pai (work) for Māori and you got to have leadership from the top. And more often than not, those specialist tertiary areas that deal with cases like that,
and with head trauma are not ok for Māori. And so our koroua and kuia can korero about what’s needed, but you’ve got to have that whole systems approach. You’ve got to have the services available and the support to allow them to do their thing. You’ve got to have that leadership from the iwi (tribe) in there, and from the organisation. If you look at us, we’ve got a 20, 30 year history, hey Aunty at the hohipera (hospital)? And still we struggle, we struggle. Because to be honest they don’t really, I truly believe, that they don’t understand the importance of having this kaupapa within that environment. They see it as a ‘nice to have’ and yet we continue to preserve at the end of the day it’s is our mokopuna, it's our whanau that are important and we will continue with that, I can’t wait for the day that we won’t need those big hospitals… Tutanekai 2 p3

The emotional reactions within whānau and of services to the horror of non-accidental traumatic brain injury and violence that causes it was highlighted by wānanga responding to this purākau.

In the post care, and I wonder too, to me there is this parallel process, the blame game that goes on around it, which doesn’t go away if it’s not dealt with. There’s always going to be some sort of thing going on within the family and the services as well, and maybe at the same time as the focus is on that child, and the rehabilitation of that child. Te Mahurehure 2 p1

A fear of speaking out against their own partner. But they watch it and see it happening and prior to letting it get to the bad stage before the damage is done, they want to, but they withhold. I think in a lot of families it is like that they don’t want anyone to see, or their family’s not all that, it is out there. The wahine might be afraid of her partner, or it could be the visa versa, you know, sometimes some women are more, you know, stronger than men, sometimes. But either way it is, they don’t know how to stop it. They might talk amongst themselves, the ones they feel safe with. But it carries on until the damage is done and it’s too late. How do you get our people to be strong enough to put something in place to stop the damage? One partner may need help to just kerb the anger that they have. But they don’t know how to communicate, it’s a communication they haven’t got those communication skills. Owae 2 p1

Let’s actually explore all the reasons why that pepi turned up in the first place, but let’s actually, there might have been, violence could have been one of the reasons. Te Mahurehure 2 p1
Every mokopuna does not belong to you it belongs to us, absolutely belongs to us, as a whānau, as Māori. And you know I heard that talking about some people don’t recognise themselves as Māori, sometimes you’ve just got to light the fire underneath them and it ignites. You know this child could be the turning point, so yeah at least give them the opportunity. Owae 2 p1

**Wā: Time**

A number of participants commented on elements of time as important in formulating traumatic brain injury from a Māori world view. The importance of what happens first setting the scene for the whānau to maintain hope was one consideration.

…the question, of hope, how do you keep hope, how do you maintain it through all that time. I really think the key is about the relationship that happens right at the beginning, so the whanau feel they really have a good understanding of what the journey’s going to be, how hard it might be, so that they’re going to know what they’re going to have to do for their tamaiti, for their rangatahi…Araiteuru 2 p3

More specifically, ensuring matters of wairua were attended to as an absolute priority was presented, the word “first” being frequently used.

So first and foremost you got to deal with shock and it’s about vibration. How was that vibration (wiriwiri gestures) knocked, bent, redefined and where is it sitting now? And so I’m saying to whakatau i te wairua tuatahi (settle the wairua first), before you go in with ahakoa ki te medical ranei (no matter what the other medical intervention), whakatau i te wairua (settle the wairua). Piritahi 2 p3

So I’m saying for us and I’ll keep emphasising the wairua is different when it goes into shock you need to treat it in that manner first and foremost from a wairua perspective and tau I te wairua (settle the wairua) to be receptive to the rongoa that is coming. Piritahi 2 p3

The amount of time whānau have in contact with each other was highlighted as a protective factor.

We all talk about, those of us who are lucky enough to have access to our wider whanau on a daily, weekly basis, we’re lucky, but there are whanau who just don’t. Māori whānau who are so insular now, or who are so removed from that sharing thing. Maybe
that’s where we have to start looking at, re-building that society in Māori. Te Mahurehure 2 p1

Wāhi: Place

The idea of Māori identity was expanded on in relation to the dimension of connection and disconnection to place as an important aspect of of hauora.

And that’s so important, our people are sick because they not connected to their whenua anymore, whether it was alienation or confiscation or whatever, those of us that are semi, well still have the umbilical cord tied to the whenua. Rauru 2 p2

You hear of a lot of people, you hear this adage, ‘I want to go home to die.’ You know, it’s in everybody, they want to go home. So it is there, it works together again, you know you can send the prayers there but some people do want to come home to heal, to die or whatever, to be embraced by the family. Pukemokimoki 2

And I feel well, on a day of feeling quite down with the rain, tempest storming and standing on the hill and all the rain just goes on you the top of the hill and the wind, you feel mighty, I tell you, you really do. So it’s using the Ao, our natural world to heal you because that’s the best healer not the man made stuff. Rauru 2 p2

Participants spoke about the role of marae as places of resources for healing for mokopuna with traumatic brain injury. The marae is described as a rongoa, a medicine.

When you see kids come onto this marae, whether they are sick or not, it’s somethings lifted off their shoulders. Because they are running around, they don’t break things or do anything, they running around free, they’re outside kicking the ball, you know, they go have a meal, kai and then go outside, they come in here, they leave their shoes at the door, they know what this place is. It’s like a heart, the heart of the community. Pukemokimoki 2 p2

This is good place for them to start off feeling strong again, then they can do the other stuff that needs doing. That’s what this place can be used for now. The other stuff like, for physiotherapy and that, doctor’s clinics are easy because that’s just setting up a clinic with a bed and that. But for rehab, for physio and other stuff that’s another ball game. But we can do the simple things first, is making people strong, we can use it for that first, for their
spirituality and giving them confidence for their mental and physical well-being. So, I mean, it’s like a rongoa. Pukemokimoki 2 p2

…and the marae, the whare sews all the groups together, puts them all together, Tanewhakapiripiri (from Māori cosmology, one of the gods of the forest who binds people together). So we have to give them back the mana rangatira (esteemed respect). Pukemokimoki 2 p2

If you look around this place eh, what is it all about? First of all it’s for a whole lot of people, it’s for whanau, for the community, where they can sit together and reminisce, learn, be together, be careful about, strengthen their identity, wonderful places of, of gathering in terms not only the ritual but the history that goes with them. Rauru 2 p2

Marae are highlighted as places which house sources of intrinsically Māori healing technologies, such as tukutuku (woven panels).

If I could just mention, and go back to the tukutuku, as an implement to be used for healing from trauma, if you look around the walls, there’s a symmetry happening, within the tukutuku, it’s brilliant. If we can tap into that brilliance and use it for a form of healing, it will be a huge thing in regards to that. Tutanekai 2 p3

You’ll find every wharenui is the same, that’s possibly why the old people say hoki atu ki te tupuna whare kei reira tonu ta rātou korero (return to the house of your ancestors their message remains there). Tutanekai 2 p3

Responses to the pūrākau included solutions for improving the whānau experience of services and outcomes were consistently highlighted.

I think a partnership, a partnership rather than one side giving care and the other one well, I’m not saying that, the professional side giving medical care, and the other side giving, you know sort of that, wairua care. Te Mahurehure 2 p1

The whole way in which the health and rehabilitation services deliver to that pepi and their whanau needs to change. Totally. Because there’s still, I mean there’s no question that when a whanau is traumatised, the child is traumatised, they want the best. The best is actually a combination of really good clinical skill and really good Maori skill. And that is actually very hard to find. Te Mahurehure 2 p1
If it gets known that there is this forum to reach out for help, I guess if it was done in a caring way, whatever happened in that parent’s life to make them that way, and they are willing to put their hand up and say it was me, I have a problem, I want to fix it, change my life, then some sort of avenue that they can do that, because I would think that handled in the right way most parents, most people would want to. Te Mahurehure 2 p1

You know picking up on your thing of the professionals and them having the ‘nous’ to know they don’t know some things, and when it comes to the cultural thing to be able to just step aside, still be involved, but just to step aside and allow the whānau to show them how it’s done, it’s like a process of learning, it’s not a one way learning thing. And for them to have that ‘nouse’ to know, hey, I can take this opportunity to learn from this whānau. And step away and observe and start taking on some of those qualities that we have and then you know, just marrying them and then maybe those gaps start to close up, start to close up. So that we’re sharing, they’re sharing. Te Mahurehure 2 p1

You walk into this place and it’s like you walk into a gallery. It’s not like going into a hospital, that’s about illness and mauuiui (sickness). It’s coming into a gallery where there are these beautiful images that tangata whaiora can connect with being Māori. Tutanekai 2 p3

Bring in, in every hospital there is usually a whānau unit, bring somebody in that can broker and make sure the needs of the family as a whole are addressed, you know. Piritahi 2 p3

In many ways it is about the senses. The seeing, the looking and the feeling and creating this environment that is ngawari (relaxing) and can, people can relate and connect to. Tutanekai 2 p3

One thing that I think about, the really little thing is, it may be a simple thing like a karakia with the surgeon. Because the surgeon’s hands will be working and touching directly ēra rangatahi (those teenagers). So while they are in their critical condition and they’re going straight to the theatre or whatever, that if whānau are present at the time and they are not able to see or touch their rangatahi, that perhaps, because the hands of the surgeon are the ones that will touch their rangatahi, that they ask if the surgeon is available to have a karakia with them, or touch them. One of the things I do remember talking about is mirimiri, was about the power of touch. Araiteuru 2 p3
And so, like I said, in a working situation you would more than likely have kaumātua at your beck and call. Their task is to support you to get the right person to korero with the whānau. Tutanekai 2 p3

Because I know when our lot are telling a teko (a lie) to the doctor. Eh? Just the body language ‘oh, I’m fine’. And you, but you see, I don’t necessarily open that up as a fact. Because that’s between me and the person. All the clinician needs to know is whether it is true or not. I’ve seen a lot of, excuse me, because you’re a doctor, I’ve seen a lot of diagnosis and care planning occur, because they have taken on board what this person has told them, whether it is true or not. And a lot of it is not true. Like I said, they tell them a whole lot of tito (lies). The tone of the voice is important, and so is the physical movement of the body. We’re talking about English as well in that thing. It’s the Reo Māori, absolutely no doubt, very important. Tutanekai 2 p3

Ideas were presented about improving communication by professionals with whānau. Use of Te Reo Māori, as a mechanism for delivering Māori specific modalities of healing, was described as a method for enhancing the whānau experience of injury recovery. This was because through the Māori language the wairua is directed addressed.

That at all times whoever is caring for that rangatahi has to be building some kind of relationship with the whānau, because then it’s just easier. When the whānau are not stressed and know what’s happening and feel like they can talk to whoever is looking after their whanaunga then they are also more likely to be able to tell their whanaunga what’s going on as well. ‘Cause you’re not going to be able to get Te Reo speaking nurses. But if you’ve got, say, a nurse that’s going to tell whānau what’s going to happen then the whānau will, can talk to their person. But you don’t always get that, they just you know, they leave the whānau sitting out there, they’ve got no idea what’s going on, they’re doing all this stuff. And to me that’s about maintaining the tapu. I think that when the head is injured that’s when the tapu is injured, I don’t know, I could be wrong, but that’s my whakaaro. But I think how it can get injured perhaps, is when people aren’t looking after the person correctly. Araiteuru 2 p3

‘Cause it could also depend on how, what’s the right word, how engaged the whānau are in their taha Māori, that could determine the differences. We’ve got people fully raised in tikanga and Te Reo and all that and they would probably want kaumātua or tohunga even, perhaps over and above kaumātua. Tohunga from their own iwi if they possible could to take care of some of that taha wairua stuff, that hospitals not going to, that whānau might not
know how to do, they might not even know what it is. But they want something to look after that sense of wairua around that person. Araiteuru 2 p3

Māori defined rehabilitation

Interestingly, further thoughts about rehabilitation as a word and a practice coming from a non-Māori paradigm were presented. It was suggested “rehabilitation” was not able to be modified into a Māori practice because of it’s non-Māori origins. Again, the importance of Te Reo Māori was underlined. Differences in goals such as “independence” privileged by rehabilitation services compared to Māori approaches were highlighted.

I think you can think about it because it’s different concept, you can’t whakamaori (māorify) ‘rehab’. Because it’s already a whole kaupapa. It’s not really Māori, so you actually have to think away from the notion of that ki te whakaaro Māori (in Māori thinking). Things have to be done differently, eh? Araiteuru 2 p3

So that’s a realisation, it’s like fighting with the powers that be and these regimes, these regimes have to support this kaupapa of re-establishing the reo for real, if we are going to even consider a rehabilitating thing for our people. And we already know without our reo you’re nothing, you just part of this other mono-culture. Rauru 2 p2

One of the things that was really interesting in the disability korero, with this woman that I met with. She was paraplegic as the result of a car accident, from Rotorua. She was talking about how whenever they went anywhere the brothers, uncles, and that would have to carry her from the car into the marae or into the whare. What all the rehab people had tried to teach her was to be independent, to be able to do everything on her own. She said one of the biggest things that she learnt was actually because she’s Māori she doesn’t have to be independent, and getting her brothers and uncles to carry her to the marae meant they had learnt about her disability. And they learnt to cope with her and everything as well. What they been taught at the spinal injury unit was totally not relevant. Araiteuru 2 p3

Participants used traditional Māori concepts, such as poutama (a traditional Māori graphic design and concept using a series of steps to embody improvement and aspiration) to describe ideal approaches to traumatic brain injury healing and detail specific interventions for consideration.
I like that idea something around poutama, puts it back into a Māori world. Saying there’s always going to be steps and challenges, it reminds me of that whakatauki, ‘taihoa tonu te hinengaro, he kake ai a Tane-nui-a-rangi ki tikitiki o rangi o te hiringa i te mahara’, the one thing that helped Tane take that journey through the twelve heavens, up the poutama, was the power of his mind, the power of determination. And that was all set about because he had this whānau structure pretty much around him, who believed. So that was what the poutama was built of? You know like that (makes stepwise gesture). Every step is supposed to be challenges and struggles so you build new characteristics about yourself. But I think things like waiata, oriori, mirimiri those kinds of things that we have in our world have to be an absolute part of his rehabilitation, part of his poutama. Because, that’s kind of whether the whanau are into Māori things or not. They might not be into it, but actually he needs it because the brain stuff says that people need touch, they need sound and singing, like music therapy. It’s not just a Māori, it’s not only Māori healing, but that’s how we do it in our world, but it’s universal. That those things need to be done. But if you can do it through a Māori world, then not only is he gaining strength in his head injury, he’s also gaining new insight into being a Māori. Araiteuru 2 p3

The ideas that responding to Māori whānau needs in Māori cultural ways being ordinary and “normal” was described.

But do you know, this is actually a real question, do you know that things that are done are normal to Pakeha people because they think it’s normal. It doesn’t matter if somebody wants it or knows or whatever. If you start doing Māori things to a Māori it becomes normal, because it is normal. We spend a lot of moumou taima (time wasting) worrying about whether they want to be Māori or not. Actually for Pakehas it’s normal to be Pakehas, it’s normal for Māori to be Māori. So it’s not optional. Whether there should be Māori stuff. Araiteuru 2 p3

The metaphor of a revitalised piece of wood used in the construction of a marae was presented as another way to think about rehabilitation from a Māori perspective.

So rehabilitation to me with those ones that have had brain trauma and that, it’s about giving them hope, giving them a future, giving them that permanence that they are part of the this world. It’s not about judging them. If I was to judge that piece of wood, when it was like full of holes, if you thought like that, well chop a tree down. If we thought like that. We don’t think like that. I thought, well let’s give that piece of timber a mauri, a life force, a reason for it to be here. So we carved it. Did the carvers like it? No, they swore at me because their
chisels were getting blunted by all the nails and that. Those holes and that. So they were swearing at me, then I told them the story about mauri, and they stopped swearing at me and started carving again, so you know rehabilitation to me is about mauri. Pukemokimoki 2 p2

Comments about the perception that legislation, such as The Privacy Act, 1993, was a barrier to best outcomes were made. The need for awareness of legislative aspects was noted.

What has killed us is the Privacy Act, that’s what has killed us, the Privacy Act shuts a lot of doors on whānau. So you know when we talk about whakapapa, it has no place, has no place. We talk about people we work with, what is important in my field is whakapapa because I know the momo in those families. I absolutely know the momo. Owae 2 p1

Legislation and all that sort of thing, and we got to be really knowledgeable about that sort of thing. Owae 2 p1

You know we can say, we want to do this, this and this, sorry dear we can’t give that out because of the Privacy Act. Pukemokimoki 2 p2

Summary

This chapter presented the second stage of findings from the eighteen wānanga held in 2010. The first group of seven core ideas were operationalised by participants into what I have called a Māori cultural formulation of mokopuna traumatic brain injury in response to three hypothetical pūrākau, or stories. The central tenets of the Māori cultural formulation were Wairua (uniquely Māori sense of connection), Tangata (people), Wāhi (place) and Wā (time). These four elements can be considered as hierarchically broader concepts encompassing the first group of seven central ideas, and their development was further evidence of the use of centrifugal thinking as well as noho puku, whanaungatanga and kaitiakitanga. Recommendations for cultural interventions which responded to the elements of the formulation were described. Treatment interventions were predicated on the description of a large body of mātauranga Māori held within the whakapapa of whānau. The importance of Te Reo Māori as a mechanism for delivery of whānau knowledge was emphasised. The words and concepts used by participants showed a recognition that interventions occurring in Te Reo Māori had particular potency. Reconsidering rehabilitation from a Māori perspective also expressed this awareness.

The next chapter represents the arrival of the research waka at the destination which answers the second research question posed; how can the ideas expressed by participants
be developed into a practical framework for working with mokopuna with traumatic brain injury? Chapter six presents two critical elements that together answer that question. First, a theoretical position, the theory of wairua injury in traumatic brain injury which guides the interventional framework is presented. Then Te Waka Oranga, the framework is described.
Ka ū te waka ki uta

Chapter Six: Theory and framework

Kotiro fell off her bicycle aged 9, she wasn’t wearing a helmet. She sustained a mild traumatic brain injury. However, a distinct change in her ability to concentrate persisted. Her whānau found the ongoing difficulties at school and home hard to cope with in a child who had previously been easy to parent. What emerged were a number of unresolved experiences of intergenerational trauma which complicated whānau reactions to Kotiro’s presentation. These whānau reactions seemed to perpetuate Kotiro’s ongoing difficulties. I recommended a whānau ora (culturally determined holistic family systems) approach with a Māori clinical psychologist to work with the whānau as a group.

Introduction

This chapter describes two key outcomes of this rangahau; a theoretical position The theory of wairua injury in mokopuna traumatic brain injury and a framework Te Waka Oranga.

Previous results chapters have contributed the foundation layers of results produced by this rangahau; the seven core ideas and Māori cultural formulation of traumatic brain injury. This section adds the final aspects, derived from the earlier results via coding. In this way theory building was used to develop the framework. The second question posed by this study is then answered; how can what was discussed in marae wānanga be used to develop a framework for the rehabilitation of mokopuna Māori with TBI and their whānau?

Codes were developed using the online qualitative programme dedoose (www.dedoose.com) with the specific purpose of theory building. Centrifugal thinking, an idea put forward by Durie and constant comparison (Boeije, 2002), a Grounded Theory tool involving oscillation between codes and text data, coding and recoding resulted in the development of 109 codes (Appendix 9). Key words and concepts were initially recorded in the dedoose programme as “child codes” and linked to quotations in the texts. These were grouped together following further reflection into “parent codes”. The programme assisted by making clear the relationship of the codes through various visual presentations of the codes. Whanaungatanga practices included peer review of coding and theory building by a fellow doctoral student (J. Fadyl, personal communication, September 6th 2011). The resulting codes enabled a more detailed understanding of the broad concepts previously identified as seven core ideas and then the four aspects of Māori cultural formulation of mokopuna TBI.
Coding the ways that participants interacted in the wānanga also gave guidance as to further understanding as to how Māori can feel at ease discussing this subject matter.

**The theory of wairua injury in mokopuna traumatic brain injury**

This theoretical position has four critical elements which will each be described in detail in this section. In order to to clarify what these are they are briefly summarised. Central to this theoretical model, wairua is injured in TBI. This means a cultural response is both indicated and expected. The cultural knowledge required to respond to the wairua injury is housed within whakapapa (genealogy). This being activated via a cascade of events initiated by the effect of the injury to wairua being communicated through wairua to whānau.

So, expanding further on the details of the theory, the proposal is that traumatic brain injury is not only a injury to anatomical structures of the brain and their function but for Māori, who are comfortable to participate in wānanga on marae, this is also fundamentally an injury to wairua. The crucial tenent of this theory is predicated on the centrality of wairua present in the narratives throughout the wānanga. These narratives expressed the qualities attributed to the function of wairua as well as the impact of the TBI on mokopuna wairua, the wairua of the collective whānau and whakapapa. Both the seven core ideas distilled from the first round of wānanga and the four aspects of cultural formulation exemplify the fundamental aspect of wairua in this situation. The relationships between wairua and other culturally important concepts and experiences that emerged in the coding analysis are described here.

My theory proposes that culturally-oriented Māori conceptualise traumatic brain injury to a mokopuna as an injury both to the head, which is sacred, and an injury to wairua. Further, when a whānau conceptualises TBI in this way, culturally determined solutions are indicated alongside clinical solutions. The whānau of the child are likely to be in the best position to access the relevant knowledge (mātauranga) because they possess attributes of being the people in closest genealogical proximity, having the opportunity to priviledge the time and being in the right place. These aspects of people (tangata, in this case the whānau), time (wā) and place (wāhi) are highly important parameters, as described by the distillation of Māori cultural formulation of mokopuna TBI. In clinical settings the different people, clinical imperatives that influence timing and how much time is available for various activities and the location of a hospital or other clinical setting determine a very different experience for whānau. Experience of wairua in clinical settings, in the context of mokopuna TBI, is likely to be complex. Healing of cultural aspects of the TBI difficult to achieve in that location.

This proposed theory is a guide to intervention. This theory is postulated to operate for some Māori people, who like the participants, have some operational connection to their
marae in contemporary Aotearoa New Zealand society. It is of interest to reflect that despite the awareness of a diverse experience of being Māori, 55% in a recent survey of Māori reported they attend marae “often” or “very often” (Te Puni Kokiri, 2010). Another report from 2003 found that almost 70% of Māori had visited a marae in the previous year (Statistics New Zealand & Ministry of Culture and Heritage, 2003). What this degree of contact with marae might mean in terms of engagement with this theory has yet to be tested. However, these data suggest that resources that have been developed with participation from people who attended marae wānanga have potential appeal to a majority of Māori.

According to this theory wairua is understood as a profound sense of connectivity, unique to Māori people, connecting Māori and all aspects of the universe. This injury to wairua activates a cascade of culturally determined responses. The theory proposes that Māori whānau have latent cultural knowledge resources (beliefs, attributions and practices) held within whakapapa (genealogy) that are relevant to traumatic brain injury, which the whānau may or may not be aware of, prior to the injury. This aspect is predicated on the commentary from participants about cultural activities they advocated to occur in the aftermath of a mokopuna TBI. These cultural activities were not aspects of daily life that were in the fore-ground, rather they seemed to come forward out of necessity in the context of this injury.

Why does this happen? This happens because in Te Ao Māori (the Māori world view) "he tapu te upoko"; the head is the most sacred part of the body. Why is the head regarded as sacred? A number of participant marae made reference to this including acknowledging that survival is impossible without the head, that the head is usually the first part of the body to emerge at birth, that the head holds the brain and the hinengaro, the mind. Awareness of the head’s special status is commonly held mātauranga, and this awareness is re-awakened within whānau in the context of the mokopuna traumatic brain injury. Given the nature of this understanding, the wairua injury to the head demands a Māori cultural response. The whānau awareness that these resources exist and what they entail are held within the mātauranga of whakapapa. This mātauranga also recognises that clinical services do not necessarily have the understanding or skill to respond to the wairua aspect of the traumatic brain injury. While there may be Māori staff working in these services who may be able to contribute to attending to the wairua injury in some way, it is the whānau who have the most important part to play in responding effectively to the wairua injury. This important role is determined by the whānau being the most closely linked in their wairua to the mokopuna. This linking and communicating function of wairua is expanded on next.

Another reason these resources are made more explicitly available is because in causing injury to wairua this initiates another function of the wairua itself, that is to communicate. In this way wairua communicates the injury’s occurrence through the whānau
into the whakapapa, both into the past and forward into the future. How do we know wairua communicates in this way across the whakapapa? This communication is made clear because the whakapapa responds in two ways. The whakapapa stretches across time and holds within it's memory both other traumatic events and mātauranga of specific practices for use in mokopuna traumatic brain injury. First, the memories of past traumatic events are rekindled when discussing a traumatic brain injury. In addition, concerns about the impact of this brain injury on future generations comes to the fore. These whakapapa implications reveal mātauranga across time about potential risk of discontinuity to the whakapapa in the context of a current traumatic brain injury. Second, the mātauranga resources required to attend to the wairua injury component of the traumatic brain injury are recalled.

This theoretical proposition does not exclude the importance of other world views and approaches to attending to the needs of a mokopuna with traumatic brain injury. The narratives did not reject western medical interventions. Rather, it proposes that these approaches are necessary but not sufficient to meet Māori needs. This analysis also suggests that adjunctive attempts to heal the range of trauma that pre-existed within whakapapa, as remembered at the time of traumatic brain injury, will enhance the outcomes both for this mokopuna with traumatic brain injury and their whānau.

How do we know this mātauranga is held within whakapapa? We know because the mātauranga is shared through being passed down from generations of tupuna in many forms; written, practised and remembered in waiata, oriori, moteatea, karakia spoken, and relived in memories and pūrākau, carved in whakairo and created in tukutuku (woven panels) on marae.

In this theoretical space the experience of being Māori is a fluid dimension characterised by the privileging of the concept of wairua, a profound connection with others, places and time. Recognising however, that regardless of personal definitions of identity or experience of identity, being Māori is defined by being part of a whakapapa, a line of people connected through time by kinship. This theory proposes that wairua can be thought of as the sense of this dimension of connection, the “glue” which connects the elements of people, time and place. The experience that being culturally Māori is different to being culturally non-Māori is reinforced at the time of mokopuna traumatic brain injury because of the distinct sense of need for strengthened connection (wairua) with regard to people, places and time that Māori people have.

How does this activation of mātauranga occur? This activation occurs through a number of different interwoven modalities. Fundamentally, the wairua of the mokopuna, their whānau, hapū and iwi is affected by the traumatic brain injury because of the disruption of the tapu status of the head. Here wairua is at the base of the hierarchy of cultural needs in the context of traumatic brain injury in a mokopuna. This is in contrast to the Whare Tapa
Whā model where the four elements of tinana, whānau, hinengaro and wairua are equally weighted.

Practices that are activated from the whakapapa storehouse of mātauranga are contained within Te Reo Rangatira me ōna tikanga (the Māori language and protocols). By being in Te Reo Rangatira and structured as part of tikanga Māori, the mātauranga held within whakapapa determines that these practices have a direct and potent effect on attending to the wairua needs of the mokopuna their whānau, hapū and iwi in this situation. The sound or vibrational qualities of Te Reo Rangatira is highlighted as an essential feature of the positive impact that this has on healing. Combining healing practices in Te Reo Rangatira such as oriori with specialised forms of touch such as mirimiri and romiromi is proposed to further enhance healing opportunities.

Activation of whakapapa mātauranga also occurs through whakawhanaungatanga. This study informs the theoretical position that whakawhanaungatanga is the action of wairua. That is, active pursuit of this mātauranga through establishing and strengthening connections and communication opportunities between people (mokopuna, whānau, hapu, iwi, professionals), places (maarae, whenua, hospitals, clinics) and across time (for example the expressed importance of memories and of bringing "old ways" into the present day and for future generations). These connections, developed through whakawhanaungatanga, raise awareness of the whakapapa resources and bring them into the foreground. Use of specific mechanisms to strengthen the connection and communication that come from mātauranga, held in whakapapa, can most effectively achieve and maintain whakawhanaungatanga. This is proposed as having a wairua strengthening effect.

Clinical services validation of Te Ao Māori: A theoretical mediating factor

Medical services ability to both acknowledge Te Ao Māori and to support the whānau to engage in Te Ao Māori, the Māori world, is a proposed theoretical mediating factor. A mediating factor seeks to explain the relationship between an outcome and an intervention. Here medical services active acknowledgement and support of whānau utilisation of their cultural resources is proposed to improve outcomes in mokopuna TBI and for the whānau. How might this mediating factor operate? When medical services express their respect and validation of mātauranga, this strengthens the whānau ability to connect more closely with their own Māori-defined healing processes. The analysis suggests that this clinical validation of mātauranga would also lead whānau approaching clinical recommendations more positively. Conversely, when the medical services have limited ability to understand and support the need for whānau to fully access mātauranga, or negate this need, this is proposed to have two key effects. First, it could compromise the whānau capacity to fully
address their culturally defined healing needs, resulting in whānau being distanced from their cultural resources because whānau are using energy and time managing their negative experience of the clinical interface. Second, this also increases the likelihood that whānau disengage from what is recommended by the clinicians.

This theory could help understanding of what supports mokopuna with traumatic brain injury and their whānau need, to have better outcomes, because these outcomes will be defined firstly by the culturally appropriate response to the wairua injury. This could also help understanding of considerations that may risk poorer outcomes, such as circumstances that actively reject this mātauranga or in more subtle ways marginalise whānau cultural needs. Overall then, this theory suggests that strengthening connections between whānau and their mātauranga enables whānau to respond to wairua injury. The theory also suggests that when professionals optimise their Māori cultural competency and actively upholding cultural safety practices whānau will also be more likely to participate in clinical recommendations.

A better understanding of cultural influences in other situations involving injury or insult to the head and brain is possible using this theoretical position. For example, for Māori adults with traumatic brain injury, Māori with neurodegenerative diseases, infections of the brain and surrounding structures, tumours and cerebrovascular injury. This theory could also have relevance for Māori experiencing mental illness and addiction.

Analysis of theory of wairua injury in mokopuna traumatic brain injury

Analysis of this theory and its development is appropriate at this point. Reflecting on other authors’ approaches to theory building is warranted.

Graham Smith provided a useful guide to Kaupapa Māori theory previously articulated in Chapter Three (G. Smith, 2003). Reviewing this theory in the light of his criteria is one way of providing a searching examination of the theory’s quality. First, the theory of wairua injury in mokopuna traumatic brain injury meets requirements for being “a useful theory” (page 4) in recognising that the current state of mokopuna traumatic brain injury rehabilitation does not meet Māori needs. Smith cautioned that theory can be used in both positive and negative ways. Certainly this theory could be applied in ways that compromise Māori whānau if it were applied without consideration for the whānau sense of their Māori identity and the risk of cultural alienation if used insensitively or without appropriate infrastructural support. The theory does not focus on struggle, rather takes a proactive and positive position that Māori are a resilient people with resources to inform and deliver self defined hauora. The theory is accountable firstly to the community of nine marae that participated and also to the wider Māori community. Inclusion of tikanga experts as well as whānau participants at Potahi Marae demonstrate relationships that embody this
accountability. This theory recognises Te Ao Māori in traumatic brain injury rehabilitation where unequal power relations exist with the clinical realm. The theory also has the capacity to withstand challenge from Māori hegemonic thinking and Western scientific approaches as it is based on a robust methodology and is internally consistent. Finally, it will be possible for the theory to be reviewed by those it wishes to serve. While it has been outside the scope of this study, it is envisaged that mokopuna with traumatic brain injury and their whānau will be asked to review the theory in future studies. This will be discussed further in the concluding chapter.

It is also worthwhile reflecting on how this theory can be evaluated according to other theory building philosophies. Grounded theorists describe use of a nodal point surrounded by six dynamic and interconnected elements; causes, contexts, contingencies, consequences, covariances and conditions (Sandelowski, 1993; Sandelowski & Barroso, 2003). In this case the mokopuna traumatic brain injury can be understood as the nodal point with the other features or how, what, why, when and who surrounding it. Other writers highlight that a theory needs to meet the conditions of science, such that theory needs to organise and classify, explain and predict (Reynolds, 2007). The theory of wairūa injury in mokopuna traumatic brain injury also aligns with these approaches and meets their criteria.

David Nicholls has described the importance of the transferability of theory to other settings (Nicholls, 2009). This aspect is emphasised here given the potential for use of this theory to other conditions affecting the head and brain in Māori.

The theory has potential limitations however. The approach was focussed on child and adolescent TBI and their whānau and so whether this theory is applicable to adults is unknown. How this theory might resonate with Māori who do not feel comfortable participating in marae wānanga is also unknown. It is also possible that there is some element of missing data. While saturation appeared to have been reached it is possible this is not the case. It is possible that either participants were not encouraged to share important insights and understandings, or these were miscoded. In addition, bias is possible. It is difficult to know why fewer participants attended the second round of wānanga. There are likely to be a number of reasons. It is possible they disagreed with the discussion at the first wānanga. It is also possible that they were busy. They may have felt satisfied the discussion was progressing appropriately meaning it was unnecessary to attend the second wānanga. Methods that were utilised to attempt to counter these possibilities were the range of marae in the sample, communication with the organisers of the marae wānanga to check any dissatisfaction with the kaupapa, none of which was voiced and the use of the rōpū kaitiaki expert guidance group. Comments from the rōpū included;

“what a wonderful explanation of wairua” (Reedy A. Personal communication 3rd October 2011)
The rōpu supported the theory and framework. They pointed out that this approach would require what they called “functioning clinical services” (Rōpu Kaitiaki hui 11th November 2011) to provide robust partnership with the whānau. They made positive comments about the model being located in a clearly Māori space and the whānau having a clear contribution to the process. Comments about the word rehabilitation being problematic were made, aligning with the discussion from the wānanga participants.

Feedback from the hui whakamutunga (final meeting) at Potahi on 28th October 2011 included these comments:

“Māori will go with this, they can relate to all aspects”

“Will the other side accept and respect how we do things? That is just as important as their interventions in the ultimate healing success”

“This is the best of both worlds”

“There is the need to develop mutual respect and trust”

Having described the theoretical position I will now present the resulting framework.

**Te Waka Oranga; a framework for whānau and clinicians**

This framework outlines the necessary elements for addressing the needs of Māori whānau where a mokopuna has sustained a traumatic brain injury. It is informed by the theoretical position of wairua injury in mokopuna TBI which proposes that cultural resources are needed to respond to traumatic brain injury because of concommitant wairua injury.

The framework takes the shape of a waka (Appendix 10). This iconic Māori symbol has been chosen for a number of reasons. The waka is a Māori mode of transport; it embodies and houses mātauranga Māori that traverses intergenerational time and space. It symbolically privileges the Māori world view and invites other world views to “come aboard”, as opposed to Māori mātauranga having to try and find it’s place within the world of traumatic brain injury rehabilitation. The Waka is made from rākau (trees), from Te wao tapu nui o Tane (the sacred forest of Tane), from the natural world. In this way the framework honours the korero shared at the wānanga about the importance of the environment and the importance of the relationship between people and the land in the experience of wairua, the uniquely Māori connection with the universe, fundamental to the experience of hauora (wellbeing). A karakia about the transformation of a felled tree into a waka as it falls through the air that was shared during this study encapsulates the importance of the building of a waka for a specific purpose. The waka is complementary to the whare (house), thereby reciprocating and resonating with the well-known Whare Tapa Whā model.

Te Waka Oranga framework provides a platform for mātauranga held within
whakapapa to serve the needs of mokopuna with traumatic brain injury and their whānau. The symbol of the waka resonated as useful here and was chosen for a number of reasons. Waka were mentioned throughout the wānanga. Being a kaihoe (paddler) on a waka was something the kaumātua who supported this project was known for. Waka are clearly about movement and change, defining features of the recovery journey for mokopuna with traumatic brain injury.

The framework does not use the word ‘rehabilitation’. This is an English word that comes from a different paradigm of knowledge and understanding, it has it’s own history and traditions. This study identified that the word ‘rehabilitation’ was problematic for participants and would likely to be problematic for Māori whānau in this situation. Te Waka Oranga framework enables a Māori structure with Māori defined healing to be used, it is a Māori space. This framework recognises it is ‘normal’ to interact in ways salient to Māori with Māori people, just as it is ‘normal’ to interact in ways salient to non-Māori people for others.

The framework recognises that being Māori is a fluid continuum and whānau who may not “look” or “feel” Māori to others or within themselves, nevertheless are supported to access their mātauranga Māori held within their own whakapapa. Just as Te Whare Tapa Whā model emphasises an holistic understanding of hauora for Māori, Te Waka Oranga Framework presents a detailed approach to bringing Māori views of hauora into action, in the context of mokopuna traumatic brain injury.

Using the framework has two stages:

1. Hoe tahi. How to paddle as one on Te Waka Oranga. This stage establishes the ground rules of Te Waka Oranga

2. Te Haerenga o Te Waka Oranga. The Journey of Te Waka Oranga. Launching, sailing and arriving on Te Waka Oranga

Each stage involves consideration of four elements; Tangata (people), Wā (time), Wāhi (place) and their Wairua (which can be thought of as a profound and uniquely Māori sense of connection) embodied within the form of Te Waka Oranga. These four Pou (pillars) came from the distillation of the seven central ideas and were used by participants in formulating the pertinent issues when presented with the pūrākau (stories). The Waka Oranga embodies wairua because the waka itself connects the elements and is positioned within a Māori world view, providing a safe space for inviting non-Māori world views, people and activites that can benefit the whānau in the context of mokopuna traumatic brain injury. These non-Māori features can be thought of as guests in Te Ao Māori, in the same way that manuhiri status was employed in the design of the rangahau that underpinned this framework. Thus as guests, roles, reciprocal connections and responsibilities are outlined in
the ways it will be possible to paddle as one on board Te Waka Oranga.

Using the framework involves completing taonga (pictorial representations) as a way of guiding and recording the essential elements of Māori cultural formulation of traumatic brain injury and subsequent cultural interventions alongside non-culturally determined formulation and interventions. These taonga provide a structure to record on A4 paper the collective whānau and clinician work of Te Waka Oranga and represent each healing journey as needed. The taonga may exemplify periods of a day, a week, or a procedure or other episode of care as needed. The completed and partially completed taonga can be displayed on the walls of the whānau home, the hospital room and as part of the clinical records. Reflecting the mokopuna’s world is another important aspect of the taonga. They can be decorated in ways that reflect the mokopuna’s preferences. A template of Te Waka Oranga taonga is included (Appendix 10).

Hoe tahi: Establishing the ground rules of how to paddle as one

This first stage establishes the mechanisms of ‘paddling as one’ on Te Waka Oranga. A waka cannot safely and cleanly move through the water towards its destination unless all are paddling as one. This stage represents this process, covering the roles and relationships, the protocols of encounter, as well as where and how these activities occur. This process can be thought of as honing and shaping the rākau (tree) into the shape required for Te Waka Oranga. This work mirrors the words of the karakia where the felled rākau is transformed into a waka as it falls through the air. It is envisaged that this set of practices of establishing how to ‘hoe tahi’, is repeated on a regular basis. In this way the respect and trust amongst the whānau and the clinicians is strengthened and refined by use. These practices are represented on the template as the horizontal lashings that bind the waka together as well as the positioning of the people on board the waka. This stage then requires both whānau and professionals to agree to guidelines for their working together that reinforces their sense of connection. These practices are the tools for negotiating differences of opinion, managing situations that have not progressed as planned and for discussion of difficulties. The codes which described ways that participants interacted with each other are a helpful guide to what is important here. These were “acknowledging each other”, “setting the foundation for the korero”, “exploring around the topic”, “putting thoughts and feelings into words”, “using humour”, “sharing experiences”, “getting back to the kaupapa” and “questions”.

Using the guiding principles of Tangata (people), Wā (time) and Wāhi (place), continuously mindful of Wairua, a comprehensive approach to establishing and maintaining the kawa can be developed. These aspects are located in different areas of Te Waka Oranga.
Te Waka Oranga is divided longitudinally down the middle, on one side sits the whānau and on the other, the professionals involved. These people are the paddlers. The Waka Oranga is jointly navigated; culturally and clinically. However, the ultimate leader is the koroua or kuia (elders) of the mokopuna with the TBI, as this is a Māori determined framework. Each of the aspects of Te Waka Oranga and how it can be used will now be described in more detail.

**Tangata: People**

Identification of the people who are involved occurs first. The mokopuna with traumatic brain injury is paramount and their participation must be actively sought and encouraged throughout. The mokopuna and their koroua or kuia or other senior Māori are positioned on Te Waka Oranga in the area that represents Wā (time). This area embodies the role of the koroua and kuia as bridging “then and now” and their special relationship with mokopuna in steering the direction of Te Waka Oranga. This position ensures that the mokopuna is recognised as having a central role in their own healing journey. Alongside these whānau members on the other side of Te Waka Oranga is a clinical leader, the person who is identified as leading the clinical team. This person shares in navigating on Te Waka Oranga with the kaumatua (koroua and kuia) and mokopuna. However, the ultimate navigator on board comes from the whānau. Negotiating under what circumstances clinical leadership might be considered is anticipated as a topic for regular discussion.

The kaihoe, or paddlers on board are the next consideration. It is likely that some efforts will need to be made to locate and include whānau who can support the closest access to mātauranga specific activities. As well as those who are present it is important to think about people who may not physically present such as perpetrators of non-accidental injury, or those who have passed away who continue to have an influence. Making these peoples’ presence more visible with use of photos or other taonga (treasures) is an important way of reminding participants of this dynamic. Or, if this is not appropriate, recognising that total collective healing will at some stage on the journey need to attend to those not actively present on Te Waka Oranga at the outset.

One side of the waka is peopled by the whānau the other by clinical staff. In this way the organisation of the Waka Oranga makes the interface of the two world views clear. Again, those not present and who exert influence may be important to include such as case managers, and practitioners who have completed pieces of work with the mokopuna in the past, such as psychologists. The whānau and professionals together can be considered a “kaupapa whānau”, those who become whānau for this reason and who share collective goals. This collective kaupapa whānau emphasises the reciprocity of relationships and strengthens the connections between whānau and professionals, while also emphasising
there are two world views participating in the process. This approach may take people from both groups “outside their comfort zone”. However, this way of working is likely to promote pathways that strengthen both wairua and clinical goals.

How the whānau prefer to express their sense of connection and who might best assist with that is the next task. Using Māori protocols of encounter for those identified as participants as part of establishing the means by which the participants ‘hoe tahi’, provides containment for a safe process; for example using karakia, mihi, pepeha, waiata, whakatāau. These elements are recorded in the horizontal bars which keep both sides of the waka together.

All whānau involved will be able to identify some skill they bring to the journey. The names of the kaihoe (paddlers) and their relationship to the mokopuna are recorded. Each kaihoe has a hoe (paddle) with two aspects; skills and emotions. Each hoe is labelled according to these elements. This makes plain the importance of everyone playing his or her part in the healing journey. Whānau may identify possession of a number of skills which may be used on different parts of the journey, or on subsequent journeys. Identifying that the people involved experience complex emotions and dilemmas such as guilt, grief, loss and re-awakened trauma and that these continue to be influenced by changing aspects of the healing journey is an important task. Recognition that these feelings are subject to change over time and in response to Te Waka Oranga journey is important. Anticipation of these complex feelings, particularly at decision-making times needs to be factored into whānau processes and in interactions between whānau and professionals. Feelings such as confidence, uncertainty, fear, hope, anger and loss are documented by kaihoe on either side of the waka. Locating these feelings in time and place assists with monitoring how emotions are modified by Te Waka Oranga journeys. This process is particularly important as it makes tangible the Māori cultural roles and skills from mātauranga held within whānau alongside roles and skills of the professionals. Balancing the numbers of people and skills on board the Waka Oranga will require discussion and negotiation.

Identifying the professionals involved and acknowledging that the teams of professionals will change as the journey progresses is a further step. Recording their names, roles, skills and feelings is also completed. Establishing how these people interface with the whānau respecting, valuing and accepting of whānau cultural needs are essential considerations for professionals involved. Professionals will also need to be prepared to participate in aspects of Māori cultural practices as requested by the whānau, such as karakia for the surgeon’s hands and whānau hui, for example. These skills and feelings form the hoe or paddles that move the waka from the clinical perspective.

Establishing regular routines of interaction for within whānau and for whānau with professionals for connection via whakawhanaungatanga is an essential element of using this
framework. It is critical that professionals recognise that they are being invited into a way of interacting that is determined by Māori values and practices. It is the whānau experience that is paramount as this determines optimal outcomes.

The resourcefulness of mātauranga stored within whakapapa which will be in the process of coming to the fore enables the whānau to think and talk around the kaupapa of traumatic brain injury and to consider the Māori belief that “he tapu te upoko” and what that means for this whānau.

**Wā: Time**

Time is crucial. The whānau experience of time will be affected by the injury. Time may literally “stand still”. During other periods it may feel as though it is moving very rapidly. Time will influence the experience of who is present and who is not physically available, for example waiting for particular people to arrive, from the whānau and groups of professionals alike. Professionals’ interactions may be experienced as not making sufficient time to meet whānau needs. Professionals need to be aware of the possibility of this perception. Time is also an important consideration for the professionals involved, clinical imperatives related to time may be different to those of the whānau. Ensuring that the ‘hoe tahi’ practices are used to effectively communicate what time means for each group is important to develop a shared understanding.

Koroua and kuia stand as conduits between contemporary and past time points. Their leadership comes from this direct link to mātauranga held in whakapapa. Their place at the back of the waka steering the way forward provides appropriate guidance to the journey. This underscores the value of the past directing the future. The unique relationship between the koroua and kuia and the mokopuna further exemplifies the links of past, present and future. Flowing from the back of Te Waka Oranga when it is in motion is the wake. This is the symbolic area where reflecting and recording of accumulated learning is made, in order to better inform future journeys. Maintaining a chronological record of what has been learnt informs a shared knowledge base. This type of information is often missing when clinical teams change or when whānau members take breaks from being intensely involved, or both.

When journeys begin and end are important aspects to record. The relationship to these aspects of the journey and the interplay with emotional reactions is also important to discuss and record. The cultural and clinical responses required at the time are also important considerations to document. Time recordings about anticipated arrival at destination points is also critical in dividing time up into pieces that make the process easier to manage for all concerned. Both whānau and clinical staff can become disheartened by a seeming lack of progress when time stretches out into the future without clear landmarks. Deliberately utilising shorter time frames can make the experience of Te Waka Oranga
journeys more manageable.

Wāhi: Place

The location of the treatment provider will impact on whānau sense of tinorangatiratanga (self determination). They may be a long way from their usual places of residence, and at some distance from what can be considered Māori specific sources of healing and comfort; papa kainga (home) and marae. Making the places where treatment is occurring feel more comfortable and more familiar to whānau is very important. What happens in the place of treatment is also crucial, places for food are kept separate from places for other activities for example. This aspect of Te Waka Oranga is located at the prow of Te Waka Oranga taonga; documentation of important places to both whānau and clinicians is made here. For example, use of pepeha, a Māori structured personal introduction, which locates Māori identity as part of ancestral landmarks, mountains, rivers, lakes and seas and other places is a vital practice to be encouraged. Alongside this the clinical places of importance are recorded.

Overall, this stage of learning to ‘hoe tahi’ on board Te Waka Oranga is an iterative one. It sets the scene and will be returned to repeatedly to re-invigorate the whānau and professionals as to both their separate and collective roles. It is used throughout the healing journey to guide contact between those involved. The first time these principles are used is fundamental and sets the scene for future strengthening of this stage and the next phase of using Te Waka Oranga framework.

Te Haerenga o te Waka Oranga: Launching, sailing and arriving

This part of using Te Waka Oranga is about putting the processes agreed upon in the ‘hoe tahi’ phase into action for a specific journey.

Sailing a waka requires knowing where you are leaving from and where you are going. It requires knowledge about the oceans that are being traversed and anticipation that unexpected things happen. Sailing a waka requires a shared understanding of what is required and collective will to work towards that goal. The wairua of the work is the most important part from the perspective of Te Ao Māori. Consistent attention to the wairua and necessary adjustments made to this work to ensure that wairua is optimised is vital, the ‘hoe tahi’ processes ensure this is done. It can be useful to remember that ways of working that enhance connectivity enhance wairua. Appropriate attending to the wairua restores the tapu status to the upoko. It requires collaboration, skills sharing and high quality communication. Ensuring there is a plan for each journey of Te Waka Oranga and for the sailing and arriving, for responding to unexpected events along the way, is critical. The plan must include the means and coordination by which Māori cultural processes will occur.
This phase determines the provision of Māori cultural elements of the healing as the platform for other interventions. Actions predicated on whānau being the functional unit of healing is the crux of the journey. Leaving the whānau out of participating limits outcomes for all. Efforts to ensure the whole whānau are supported and maintained on that journey are essential.

The power of naming is a part of mātauranga. The name of interventions, the difficulty relating to jargon are important considerations. Clinicians need to remain mindful of their communication styles, modifying these as needed, checking with whānau as to their understanding, recognising that whānau may appear to agree when this is not the case. Of note, another area of naming that is important to consider is the specific name of the mokopuna. Mātauranga about the significance of the name and responses to that may be addressed. The whānau may wish to name Te Waka Oranga in order to influence the healing of the wairua injury.

Elements of this phase are establishing access to skilled provision of Māori determined interventions such as karakia, mirimiri, romiromi, waiata, oriori as well as a plan as to how these modalities are used to maximal effect, when they are to be used, by whom and how the clinical recommendations would fit in with these interventions. Whānau, hapū and iwi leadership in helping determine how this is done safely is critical.

**Tangata: People**

Leadership of Te Waka Oranga is essential, the whānau must identify their leadership, recognising that certain members of the whānau will be so distressed they cannot easily communicate their wishes and that they delegate their views to other whānau members. Professionals need to be sensitive to these shifts.

Questions to be answered in this phase are:

Who is on board?
What are the roles and responsibilities of those on board?
Who is not coming on this journey? How will their role be re-integrated later?
Who has the mātauranga (knowledge and skills) to know what to provide in terms of Māori cultural practices needed to honour the beginning, middle and end of our journey? What is the frequency and duration of cultural and clinical interventions?
Confirming the responses to these questions is recorded on the Waka Oranga template.

**Wā: Time**

Planning the departure, sailing and arrival of the Waka Oranga requires time.
Sometimes unexpected changes mean time frames have to be brought forward or postponed. Acknowledging this is always possible is essential. Where possible however, time must be taken to ensure that all those “on board” Te Waka Oranga know their roles and while they may not be completely comfortable with their “paddling partner” they have come to accept, for the collective process, they will fulfil what is required of them. On board waka it is not uncommon for people to be seated alongside others they would not choose to be close to. This is because the balance of weight in the waka is crucial for the sailing. Similarly, on Te Waka Oranga this balance in order to ensure a safe enough journey needs to be negotiated.

Questions that must be answered here are:

When will we be ready for the next journey?
Estimates of how long it will take?
When will we conduct Māori culturally determined practices on the journey?
Documenting the answers occurs on the Waka Oranga template.

Wāhi: Place

The places of departure and of arrival are the focus in this section. The whānau value their places of cultural significance. Ways that these places can be brought into the planning of the healing journey are very important.

Pertinent questions here are:

Where are we now?
Where do we want to go?
Are we agreed or do we need to discuss this further to come to a shared understanding of our desired destination?
How do we make our place on Te Waka Oranga a healing place as we traverse towards our destination?
What are the signs we will recognise on our journey to the destination that alert us to being on the right track? What are the signs that alert us to being off track? How do we use our resources on board our Waka Oranga to adjust our trajectory if we need to?
How do we know we have arrived?
What are our practices that honour the beginning, the middle and the end of journeys?

Recording of the responses to these questions as part of Te Waka Oranga Taonga
means the process is visible and transparent.

This phase also ensures review of the journey occurs. For example the following questions can be addressed: In what ways did Te Waka Oranga enhance the hauora of the mokopuna and their whānau. What went well? What could have been done differently? This material is recorded in the wake of the Waka Oranga.

In summary, Te Waka Oranga is a framework for whānau and clinicians to work side by side, with transparent ways of working that recognise each others world views and give clear guidance about how to work together using the principles of Wairua, Tangata, Wā and Wāhi as navigational tools.

**Personal reflection**

While the framework has not been trialled as part of this study it is reasonable to reflect on my work with mokopuna with TBI and consider how my work could have occurred differently with use of Te Waka Oranga and the theoretical position of concomitant injury to wairua.

The short fictitious case summaries that form the head of each chapter in this thesis illustrate aspects of my work to date. What they show about my previous approach is that I have described and advocated elements of Te Ao Māori that seemed pertinent at the time I assessed each young person and their whānau. However, use of Te Waka Oranga would have enabled me to be systematic and comprehensive in my approach in a number of ways. Initially, I would have been able to describe a proposed Māori specific explanatory model of mokopuna TBI. Such that, in the context of this injury to the head, given that he tapu te upoko, a range of mātauranga resources which may not have been available to the whānau have the potential to come to the surface to address the cultural needs of the injury. I would have been able to describe to the whānau that a range of Māori specific resources have been identified in providing a cultural response to the wairua injury part of traumatic brain injury. I would have been able to navigate a deliberate Māori cultural formulation of the Traumatic Brain Injury using the four Pou: Tangata, Wā, Wāhi and Wairua. This process would have enabled repeated Māori formulations of the traumatic brain injury and response to Māori specific interventions over time. This mechanism would have ensured robust support by koroua and kuia as it advocates strongly that these members of the whānau be brought into direct involvement with interventions.

In addition, the framework would have been helpful in orientating discussion about Māori identity and the appropriateness of Māori interventions to strengthen wairua alongside other interventions to strengthen other aspects of recovery. I had not previously been aware of the cultural importance of names, particularly in the context of non-accidental brain injury.
and how they may convey both a contribution to the injury as well as an opportunity for a culturally determined healing process. Overall, I would have been able to have a much richer discussion about what the traumatic brain injury may mean to this particular whānau and to explore the importance of everyone in the whānau playing a part in the healing process as well as identifying others within the whānau who have particular skills to share.

The framework would have also assisted me greatly in communicating with non-Māori clinical colleagues about a comprehensive understanding of the traumatic brain injury from a Māori perspective. Being able to articulate the carefully considered methods by which it was developed would also assist with this approach being taken seriously rather than being seen as an luxury or of lesser value than established TBI rehabilitation practices. The framework would have assisted in facilitating whānau and the clinical team to work better together by providing a simple vehicle for their shared working and making explicit their world views and the impact of these views on each others practices. This process would have the potential to support better outcomes for the whānau as well as better job satisfaction and improved cultural competency for clinicians.

I am often asked to assess the mokopuna and their whānau some years after the injury. Using Te Waka Oranga to reflect on and re-frame what “journeys” have been traversed to date and what the current desired destination is and any sense of differences with current clinical services involved would be helpful.

The framework would also assist me in writing my reports. By including a Māori cultural formulation of the mokopuna’s traumatic brain injury, related recommendations would be communicated more effectively with the range of people involved. This way of working would have helped position me in a facilitatory role at the interface of the whānau world view and that of the professionals.

One of the criticisms that could be made of this framework is the idea that families are already carefully considered in rehabilitation treatment plan goal setting. However, the difference here is that this study has found that Māori whānau, rather than providing a generic type of support or being considered from a coping perspective, have been identified as playing a fundamental and active role in the provision of specific culturally determined interventions targeting a culturally determined aspect of the injury.

In addressing specific types of injury, the responses to the non-accidental TBI pūrākau assists in providing insights into other areas that may contribute to improved outcomes. These ideas such as “becoming tupuna”, the power of naming, the importance of dealing with blame in adaptive ways and that healing for the perpetrator would improve healing outcomes overall are worthy of further exploration.
Summary

This chapter has presented the theory and framework results of this rangahau, answering the second question proposed by this research; how could participants' contribution be developed into a practical framework for working with mokopuna with TBI and their whānau? The theory outlines how and why injury to wairua is important in mokopuna traumatic brain injury from a Te Ao Māori perspective. This theory thereby outlines a systematic Māori analysis of what TBI might mean providing a robust platform to inform intervention. Strengths and limitations of the theory have been described. The framework “Te Waka Oranga” is a practical tool developed on this platform to assist whānau and clinical teams to work better together in improving outcomes for mokopuna TBI and their whānau. A description of use of the framework followed. Possible use of Te Waka Oranga in practice was reflected on.

The final chapter of this thesis will provide a concluding discussion about the rangahau process and where these results may lead in future.
Ka ū te waka ki uta.

Chapter Seven: Conclusions and recommendations

Pepi is a 14 month old who survived a severe non-accidental traumatic brain injury at two months of age. Pepi’s whānau, experiencing complex feelings of shame, guilt, shock and horror have been supporting each other and their pepi at the hospital in Auckland, a long way from their home. They have a senior kuia who continues to advocate for clear communication between whānau and professionals. I am asked to work with the whānau to provide Māori neuropsychiatric perspectives, assessment and treatment recommendations alongside a specialist kaumatua. I need a comprehensive and transparent guide to assist this work with whānau and the clinical team, I recommend we trial use of Te Waka Oranga.

Introduction

This thesis has presented the first study to explain, using Rangahau Kaupapa Māori (Māori specific research methods), what a mokopuna traumatic brain injury (TBI) might mean for Māori who have a level of comfort in participating in marae wānanga. This study proposed the theory that for these Māori, injury to wairua also occurs in mokopuna traumatic brain injury. This theory then articulates the brain injury in cultural terms. This project is also the first to provide a practical means to respond to mokopuna TBI using this theoretical explanatory model. These outcomes align with both local and international findings that cultural aspects of TBI are an important and complex area. It extends work that describes the over-representation of TBI in Māori children and young people in a distinctly Māori way by uncovering a solution focussed interventional tool. Together these outcomes begin to address the gap in the literature about indigenous child and adolescent traumatic brain injury. The importance of cultural resources working alongside clinical resources in specific ways suggests a practical means likely to improve outcomes. The outcomes of this study are important because they demonstrate a clear role for whānau in responding to the wairua injury alongside the clinical team in a Māori space. While the methodology of this study is innovative it is firmly located in established Kaupapa Māori scholarship and therefore adds to the repertoire of Rangahau Kaupapa Māori practices already available.

This chapter reviews the aims of the study and steps taken to achieve those aims. It documents the extent to which the research can be regarded as successful and how the study design could be improved. The chapter also puts the findings into the wider context of global research in the area of culture and pediatric traumatic brain injury and makes
recommendations about how the results can be used. Steps taken to begin this next phase of the journey are outlined. Finally, the most important points of the work are summarised.

**Review of aims and success in achieving these: noho puku**

In what ways did this study achieve what it set out to do? How robust are the findings? What are the limitations? These questions and consideration have been foremost in the writing of this section, exemplifying again the practice of noho puku. This study had ambitious goals which involved use of innovative Rangahau Kaupapa Māori practices. The study began with two aims. The first of which was to find out what Māori people said when invited to response to the culturally defined notion, “he tapu te upoko”, introduced in the context of the topic of mokopuna traumatic brain injury, in a Māori specific setting. And secondly to develop a framework from this data. Given these aims decisions about methods were critical.

**Methods: bringing the ordinary into the foreground**

Reflections on the methods chosen and their contribution to the success of the research achieving it’s aims will now be described.

One theme that emerged in considering the methods as a whole was that of bringing an ordinary lived experience of being Māori into sharp relief. Asking permission from my own hapū and whānau felt like such a normal and expected thing to do. On reflection this is something I might have omitted to include in the writing up of the design at the outset. However, as the introspective writing period progressed the words and meaning of the whakatauki ‘Ko te mauri o Ngāpuhi he mea kua huna i te moana’ reminded me of the importance of recognising the essence contained in ordinary daily life. This guidance encouraged me to document the ordinary, less visible and therefore potentially marginalised aspects of being Māori. This continued to be an imperative that kept the rangahau process grounded adding to previous work by Helen Moewaka Barnes highlighting the importance of the ordinary (2000b). The related and interwoven practices of noho puku, whanaungatanga and kaitiakitanga were another example of this. These mechanisms which I had learnt to use in the Takarangi cultural competency training programme had become part of my daily routine (Matua Raki, 2010). As I embarked on the research design their ordinary quality eventually drew my attention to make them explicit. Their usage grew from initially providing direction of my personal practices as a clinician and then a kairangahau (researcher) to become practices that were used in all layers of the research process including working with the data. This was an unexpected and useful progression and I hope a useful tool that other kairangahau can utilise and test.

I joked with my relations that the rangahau was about finding reasons to be useful at
Home. Home being my tribal area of origin. As the rangahau progressed I came to realise that an important personal outcome of the research was the strengthening of my connection with where I am from, who I am, my Te Reo Māori (Māori language) and what I can contribute in my hapū and iwi. This project helped strengthen my relationship with my kaumātua in Te Kao. One of my kamātua who was a strong supporter of this research passed away during the course of the study and going home to his tangihanga (traditional funeral rituals) further strengthened my resolve to be more connected to home. One final somewhat ironic point in this section is that the translation for the word Māori, as an adjective, denotes aspects that are “normal, usual, ordinary” (H.W Williams, 1975).

Centrifugal thinking: he whakaaro Māori

Another useful practice was that of “centrifugal thinking”, translated here as whakaaro Māori (Māori thinking). I had both heard and read Professor Sir Mason Durie’s presentation of this idea. However, I had not been aware of the concept being operationalised in Rangahau Kaupapa Māori previously. The idea itself, which involves moving into larger and larger categories of ideas, resonated powerfully with my own experience of hearing the way ideas were discussed on marae both in this study and in general. Centrifugal thinking described what I was attempting to achieve; moving with the data from fine detail to broader concepts. Using this idea helped to enhance the success of my coding of the data. This process of oscillating between the detail and how the detail could be coded into larger concepts with the imperative being the development of robust big ideas exemplified a centrifugal drive. For me the concept of constant comparison from a Grounded Theory perspective came closest to describing this way of working. To my knowledge this is the first study to use this idea as part of a research design. Again, my hope is that other researchers will trial and critique this way of working.

Kaitiakitanga

The establishment of the Rōpū Kaitiaki was also extremely important and a mechanism without which this research could not have been appropriately or successfully conducted. Given the cultural importance of the head to Māori the expertise and guidance provided was essential to my sense of confidence in pursuing this delicate area of exploration.

Marae located rangahau: Whanaungatanga

The relationship with the participantating marae and the decision to locate the research in those places, governed by their rules and regulations made a significant contribution to the success of the study. The decision to consider marae themselves as
participants and to think of the korero (discussion) as the voice of each marae is a useful mechanism for future research. Choosing this method meant that I was able to rely on the dominance of the local tikanga and on my roles and responsibilities related to those prescribed by tikanga (lore). This decision also meant that being Māori was defined locally, not by rarified or exclusive constructs derived from other domains such as the academic sphere. This locational decision lead to recognition that one wānanga at each marae would not be sufficient to accomplish all the requirements necessary to meet the goals in an appropriate way. I decided that having only one wānanga at each marae was unworkable to meet the aims of this study. Firstly, this was too onerous and burdensome for the marae, given their other activities and demands. Indeed, the daily demands on marae and participating in a study such as this was identified early on as significant for marae. One way of enhancing what was done here was to consider having noho marae (literally, staying on marae) with participants sleeping on the marae and enhancing the richness of what is discussed by sharing the living space over several days. I have experienced many noho marae and the resultant intensity of the way the whakaaro builds under those circumstances. However, time, money and people resources prohibited that option on this occasion. The relatively short periods of several hours for each wānanga could be seen as a limitation of this study. However, this was balanced by the constraints on the marae of their other activities. The second round of wānanga became a crucial mechanism for enhancing the success of the rangahau because it reinforced the relationships and reciprocity. This process valued time spent together and upheld the mana (respect, reverence) of what was shared. It also provided time and space to provide the wānanga participants with the opportunity for them to critique the first layer of analysis. This reinforced the whanaungatanga aspects of the experience for both participants and kairangahau. The DVDs of the wānanga footage and final summaries being sent out to the marae wānanga organisers was another aspect that attempted to acknowledge the generosity of the marae and their people in contributing to the rangahau. One interesting aspect was that marae participants in the second round of wānanga asked about how their responses compared to other marae. They were interested in finding out more about the others experience. The summary sent out to marae wānanga representatives (Appendix 11) was integrated into the design from the outset, and in this way whanaungatanga was further reinforced. By maintaining confidentiality of material source the summary addressed this interest in the expressions from other marae wānanga in a manner that met both scientific and cultural ethical requirements.

At the beginning of this study trying to organise the marae wānanga was a reminder of how busy marae are. The assistance of a whānau member, Aunty Thelma Munro, who was well versed in organising marae wānanga was extremely helpful. In future I would
ensure someone with this subspecialist knowledge of marae liaison was involved in the study design from the outset. Some may argue that marae based methodology is limited because if there is a tangihanga then the research wānanga has to be rescheduled. I disagree that this is a limitation. The lives of marae and the ahi kā (those that keep them warm) responding to their vital roles in tikanga Māori such as tangihanga keeps the researcher humble and grounded in Te Ao Māori.

My ongoing relationship with the participant marae is another important outcome. I have continued to emphasise to participants that the data is theirs to use in ways that meet their needs and to remain in contact for any future support I could offer them. For marae that have Hauora (health clinics), such as Whakawhitī Ora Pai at Potahi Marae in Te Kao, there are ongoing discussions about ways to trial Te Waka Oranga.

Marae located rangahau: collective cultural capacity?

A potential limitation and a strength of this method in locating the research data gathering process on marae is the self selection bias at the point of entry to the study. On one hand this may have conferred a bias by influencing Māori with a certain level of confidence about being on marae to attend, limiting the applicability of the study. One the other hand, this mechanism conferred a collective gateway to the study and this informed the collective analysis of the findings, coding each marae as having one collective voice.

Participants’ decision to attend was likely based on a degree of comfort with that particular marae, their perceptions about who else might attend and a shared sense of collective capacity to attend to the culturally appropriate demands of the marae setting. Those who did not attend may have not done so because they did not feel so culturally capable. It is also possible those who did not attend made this decision based on their awareness that the appropriate people were attending. The local cultural hierarchies may also have determined who would be required to attend and who was not. These aspects of participation were not explicity explored. This method did not for example investigate the extent to which these decisions may have been actively discussed by participants leading up to the wānanga and what influence this may have had on who participated. However, it is likely that the presence of this potential cultural bias means the findings are more likely to resonate with those that have a degree of comfort with participating on marae. Evidence that a degree of marae participation is the case for more that 50% of Māori suggests the outcomes could be useful for the majority of Māori (Statistics New Zealand & Ministry of Culture and Heritage, 2003; Te Puni Kokiri, 2010).

It is interesting to speculate about the relationship between how this shared sense of Māori cultural competency, sufficient to participate in marae wānanga, might be related to whānau participating in clinical settings. It is possible that those who are most comfortable on
marae could be less comfortable in hospital settings because of increased cultural dissonance. Studies exploring this specific aspect of Māori cultural identity have not to my knowledge been published. International research using an acculturation measure, found a more traditional cultural orientation in Native Hawai’ians was associated with worse health outcomes in the context of Type 2 Diabetes (Kaholokula, et al., 2008). The authors hypothesise possible psychosocial variables including depression as mediating factors requiring further investigation (Kaholokula, et al., 2008). An additional possibility is elements of cultural dissonance provided some influence on the relationship of these variables. International TBI rehabilitation findings suggest that those families where English is a second language or who are in a cultural ‘minority’, as proxy measures of cultural dissonance, receive poorer service responses as reviewed in Chapter 2. The findings of this study suggest an approach that brings the cultures of whānau and clinicians together at a clearly articulated interface. This approach may mitigate cultural dissonance factors. These factors have been carefully considered in planning studies that test Te Waka Oranga.

Another consideration of these ideas is how the degree of comfort in collective participating in discussions about TBI on marae might illuminate aspects of shared Māori identity. How this might generalise to understanding how Māori participate collectively in TBI rehabilitation is an interesting proposition for future research. Overall, further exploration of the dimension of the comfort Māori people experience collectively on marae as a type of acculturation measure for Māori in TBI rehabilitation is promising.

**Methods: other challenges**

The technological demands of the methods chosen was a further challenge. Learning to use a video camera and means for recording sound and vision with a backup sound track took time and resources. Having built confidence with these research tools, these are skills which will prove invaluable for future projects. Qualitative research analysis programmes were another area where upskilling was needed over the course of the research. Ideally, I would have been proficient prior to starting this rangahau. A number of possibilities were reviewed. Dedoose was selected because of it’s ease of use and flexibility for coding and modifying levels of coding. Dedoose has a range of functions that allow mixed methods research which will also be helpful in future.

What was striking was that none of the participant marae dismissed the concept of “he tapu te upoko” as irrelevant to contemporary Māori life. Equally, none dismissed clinical knowledge, rather emphasising that clinicians need to know more about Te Ao Māori and working with whānau. The richness of what was shared produced an enormous amount of data. The size of the task of analysing this data was daunting. The impact of the amount of material that needed the first level of analysis meant that transcribing and reviewing
transcripts and footage took longer than expected. Choosing nine marae in an attempt to be as inclusive as possible while methodologically sound, created logistical challenges in time and energy required for analysis before the second round of wānanga began. This balance between time needed for analysis and not letting too much time pass between the first and second wānanga, risking loss of confidence or interest in the research, required careful planning given the constraint of needing to complete all the wānanga within one year.

**Theory building**

The methods described facilitated the collection of data with the view that this data inform a framework for intervention. However, in the early stages of the rangahau design it was not clear how the data would lead to the development of the framework. The idea of considering theory building came from one of my supervisors. At first this seemed to be an extraordinarily ambitious suggestion which did not sit easily with me. Would that be a culturally acceptable practice for me as a Māori clinician and researcher to engage in theory building? As I read more about Kaupapa Māori theory and theory building from other paradigms I became more comfortable and embraced this practice as intellectually exacting as well as practically necessary as a conduit by which the construction of framework could be clearly developed. Alongside this I reflected on the influential theoretical underpinnings of TBI rehabilitation practices such as those from social learning theory, cognitive theory and child development theories. The need for a culturally resonant Māori theory was apparent. Theory building is a practice I intend to pursue in bringing qualitative material into the realm of application in future. As far as I am aware this is the first time a specific Kaupapa Māori theory has been posited in this way in the context of mokopuna traumatic brain injury.

**What might the homogeneity of the outcomes mean?**

The theory of wairua injury in mokopuna traumatic brain injury and Te Waka Oranga seen together provide evidence that Māori who have sufficient comfort to participate in this sort of marae activity, have a cohesive view, or at least do not express disparate views, about mokopuna TBI leading to the need for culturally determined responses. The consistency of response across rural, remote and urban marae, albeit with local flavours of emphasis, was interesting and somewhat suprising. While consideration of the wide dimension of the experience of Māori identity has been documented for some time, it could be argued this was first robustly articulated in Durie’s seminal paper (1995b). Yet here are findings of significant homogeneity. The question of how to account for this finding can be raised and whether some aspect of methodological error may account for this is reasonable. It is possible that the marae based entry point contributed a self selection bias which influenced the consistency of the findings. I have also considered whether there was some
element of bias that masked differences or missing data that could have contributed to this finding. Having my data coding system and application of codes to the theory building peer reviewed has reassured me that there is no obvious error or bias in the coding process. Another possibility is the iwi and ngā hau e whā marae sampled shared some consistency of response because of the sampling method, where senior Māori from my whānau and the Rōpū Kaitiaki determined the marae participants via whakawhanaungatanga. It may be that other iwi groups not included may have differing views. This aspect requires further investigation during implementation of Te Waka Oranga to assess the relative variability or consistency of whānau responses to the application of the framework. It is possible this level of agreement of views was elicited in response to the subject matter of the tapu quality of the head. This suggests an interesting possibility, that wherever Māori are on the continuum of the dimension of cultural identity, that in the context of a mokopuna TBI a more uniform set of Māori values, beliefs, behaviours and needs comes to the fore.

The participants were explicitly not drawn from those whānau who identified themselves as having direct experience of mokopuna TBI. Despite this, the participants had a great deal to say on the topic. This is perhaps unsurprising given the epidemiology of Māori TBI. The high incidence of TBI in the Māori community, translating into a commonly occurring peripheral connection with whānau members with TBI, may be a contributing factor to the homogeneity of responses.

Te Waka Oranga: challenges of implementation

The implementation of this tool will be challenging. Some might argue that Māori patients and their whānau already receive comprehensive culturally responsive care and such a tool is unnecessary. They might cite Māori specific policies and cultural competence requirements and training. What participants in this study identified was their sense of a very limited knowledge and practice related to Māori within clinical environments. In my experience, one reason for their view might be that in clinical services Māori practices are compartmentalised into areas such as karakia conducted by Māori staff. Following this rather standardised generic clinical interventions take place. In that sense, once culturally specific practices are completed, if they are done at all, the cultural component and responsivity is completed. Māori patients and their whānau may unconsciously feel the need to fulfill the clinicians views of them, to maintain the status quo of the power relationship where they clearly rely on the clinicians’ good will. It is possible that this dynamic leads Māori whānau to leave their Māori qualities at the door, as it were and pick them up again on their way out of the service. Use of Te Waka Oranga would mean a change for these whānau who may be more familiar with the mind-set of “leaving it to the Doctors”, although that was not expressed as a preference by the participants in this study. It also means change for
clinical staff who are more familiar with being in control. That being said, there is also evidence that some responses to Māori in clinical settings have been shown to be racist (Harris, et al., 2006). Te Waka Oranga provides a clear mechanism for Māori practices to lead and be maintained throughout the episode of care. This approach not only includes but privileges this wealth of specific cultural knowledge into a realm which is almost entirely dominated by western medicine.

The richness and perceived relevance of Māori knowledge systems was a striking finding of this research. Māori knowledge is fully expressed every day in Māori settings, many of which are limited in their visibility to non-Māori and to some extent also elusive to some Māori because commonly the entry point is Te Reo Māori. The findings of this study reinforce the importance of both Māori and non-Māori health care systems continuing to support their staff to enhance their skills, knowledge and attitudes about mātauranga.

In the first instance whānau themselves may find use of Te Waka Oranga challenging. One reason for this is that they may find it hard to locate whānau members who hold specific levels of Māori cultural skills. This area of work, finding whānau with appropriate skills, is anticipated as a core aspect fulfilled by an appropriate whānau and or team member in facilitating the use of Te Waka Oranga. It is possible that Te Waka Oranga might be best received in services where the complexity and difficulty for the clinical team in developing a working relationship with whānau might mean there is increased willingness to trial such a tool, such as in non-accidental mokopuna TBI. What the outcomes of this study emphasise is that Māori culture is not a compartmentalised discipline, restricted to the scope of practice of a member of the multi-disciplinary or inter-disciplinary team. Rather, Māori culture is a vital aspect of care for consideration and action for all members of the group involved, whānau and professionals combined.

One interesting finding was that there were no significant differences identified in the wānanga responses to the age or developmental needs of the mokopuna in the three pūrākau (case studies). The cultural formulation approach was consistent across the responses to the three stories. It is possible that for some reason differences were considered but not identified by this method. One aspect that was identified related to the cause of traumatic brain injury in the mokopuna with non-accidental TBI pūrākau. Because of the causal features the participants emphasised the need to take on attributes of tupuna (ancestors) suggesting a cultural ‘stepping up’ required from the whānau in this complex situation. They also emphasised the importance of healing for the perpetrator. The critical importance of taking time to adequately address necessary processes was highlighted. These ideas are helpful in the future application of Te Waka Oranga in cases of mokopuna non-accidental TBI.

There are a number of settings where Te Waka Oranga’s use could be envisaged.
These can be grouped into Māori and non-Māori governed structures. The vast majority of current service structures have non-Māori governance, although they commonly have some sort of Māori policy. It is anticipated that barriers to implementation would be present in both. What might these barriers look like? The degree to which baseline trust and respectful reciprocal relationships exist is likely to present a potential barrier to the use of Te Waka Oranga. In Māori governed environments the degree to which the Māori workforce is free of hegemonic influences would be important in reducing barriers to implementation. In non-Māori governed structures dynamics of power relations within teams and how Māori and non-Māori staff perceive their areas of work and expertise are likely to influence the ease of implementation. The methodological rigour underpinning the theoretical base could motivate health professionals interested in use of the framework from an evidence based perspective. The tool itself is likely to significantly strengthen the relationships between whānau and clinical staff, the vitality of which has already been described as a determining factor in optimising TBI rehabilitation outcomes (Gordon, et al., 2006). Identifying clinical champions, who can influence wider systems, is likely to be a strategic way to modify barriers and facilitate uptake of this approach.

Te Waka Oranga could be used across a number of TBI rehabilitation realms. For example, in the early stages of traumatic brain injury treatment thereby structuring time and activities into manageable units. It could be used at later stages where short-term goals are being developed to enrich negotiation about arriving at goal destinations and to build cohesion towards these goals, defined by both whānau and professionals. In addition, Te Waka Oranga could be used in facilities where mokopuna and their whānau are residing for longer-term rehabilitative care to ensure a robust process that is whānau-centred.

It is likely that this framework may provide a useful approach for services that deal with particularly complex situations such as in working with whānau where non-accidental traumatic brain injury in mokopuna has been identified and in populations where significant prevalence of rangatahi Māori with TBI occurs such as youth offender units (H.W. Williams, Cordan, Mewse, Tonka, & Burgess, 2010).

While I have outlined a number of locations and contexts where Te Waka Oranga could be useful I want to emphasise the caution with which I intend to pursue testing of this framework. Initially, given the tool was developed with participants in marae wānanga, I will offer this approach on marae. A proposal to test this way of working has been developed where whānau in the high-potential area of my iwi affiliation will be recruited and randomised to either the Te Waka Oranga intervention arm or the treatment as usual (TAU) arm. Monthly marae meetings where information about TBI will be discussed are included in the TAU group to mitigate bias related to time spent on marae with the researcher. A range of outcome measures of child behaviour mood and anxiety as well as whānau member
depression will be used for both groups. Focus groups will also be used to uncover the professions and whānau experiences and preferences. The considerable support from iwi health providers ensures a cultural infrastructure supports the experience of Te Waka Oranga. The results from this proposed study alongside impressions of the impact of Te Waka Oranga from the wider community in this context will better inform the conditions under which this approach can safely be used.

**Rehabilitation: a problematic concept**

Another important finding is that for Māori the word rehabilitation was problematic. This study has found that the word rehabilitation itself was a barrier. Use of Māori words and phrases as part of Te Waka Oranga, such as ‘hoe tahi’ and ‘ngā hua o te haerenga’ are chosen for this very reason; they exemplify Māori whakaaro about health and healing. Interestingly, the word rehabilitation in the context of TBI was described as “unhelpful generally” by a senior clinician in the Rōpū Kaitiaki. This suggests that a wider discourse about the language that best describes what these types of activities and thought processes entail is warranted.

**Virtual rehabilitation**

Te Waka Oranga could be used to develop virtual rehabilitation resources for mokopuna with Traumatic Brain Injury. This is an area of future work that offers much inspiration. This is because it would mean that the whānau, including the mokopuna, could engage in constructing Te Waka Oranga and experience their efforts in virtual space, similar to a computer game, where essential elements of Māori defined healing could occur. Virtual rehabilitation games with generic content are already in use in some centres. None have been developed with Māori content specifically for Māori patients. A Māori defined experience for mokopuna and whānau would provide a choice, particularly useful for whānau whose first language is Te Reo Māori and whose preference is to conceptualise in Te Ao Māori.

**Dissemination of the results**

Developing a wider awareness of the rangahau process and the results has been a parallel process throughout with presentations at targeted local and international conferences actively sought and in train for the future. Further dissemination of the results will proceed with papers about both the methods and the outcomes planned for submission to peer review journals. A specific proposal for a pilot study with a group of patients and their whānau is in its early stages. One of the vital components of future study is anticipated to include a kahui (advisory group) of young people with TBI and their whānau to review the
proposed theory and to continue to guide refining Te Waka Oranga.

**Results within global context**

These results sit within the global context of diverse cultures where children and young people experience traumatic brain injury together with their families. They experience a variable dimension of understanding from health professionals about the families’ cultural beliefs and practices related to TBI. Published sources recording cultural beliefs about the head that might be relevant to traumatic brain injury are few. The Yoruba people of West Africa have a detailed belief system which links the source of creation with the mind, located in the “inner head”, as part of an overarching view of the universe being a tension between good and evil (*The Oxford companion to the mind*, 2004). This suggests that for the Yoruba peoples injury to the head may have different cultural significance and implications. Other examples of cultural beliefs that may also impact of ways of responding to a traumatic brain injury have been elusive. Researchers from other cultures might use this work as a platform to pursue investigations about beliefs pertinent to traumatic brain injury within their own culture. This type of exploration is needed to broaden a collective understanding of this area, and importantly, challenges the dominant paradigm that western science understandings and methods of research have all the valid answers.

This research adds to the existing body of knowledge about pediatric TBI in several ways. By using lived concepts from Te Ao Māori in the methods and analysis this research provides clear examples of culturally determined approaches in pediatric TBI research and practice. This exemplar may be useful for researchers and practitioner from other cultural groups, particularly other indigenous peoples, to explore their own culturally determined ways of working in this field.

**Te Reo Māori: he rongoa**

It is important to comment on the role of Te Reo Māori. While other frameworks have included words in Te Reo Māori they do not comment on the vibrancy or potency of the words themselves and the rich poetic, culturally profound meanings layered within them. One of the problems with using words from another culture is that for people who speak only English the English translation takes over the cultural meanings and nuances of words from the other language. This further marginalises the culture of origin’s meanings. In the process of this study I became acutely aware of this problem because participants frequently commented that Te Reo Māori was a powerful healing tool and that “if only” more clinicians could speak Te Reo Māori this would greatly enhance communication and the experience for the whānau as well as recovery. The power of all aspects of Te Reo Māori was something the wānanga reiterated. It was clear that participants considered use of Te Reo Māori was a
potent mechanism by which healing the wairua injury associated with TBI would occur. Te Reo was spoken of as a rongoa, a medicine. The importance of having kupu Māori (Māori words) maintain their integrity and rich meanings will be a carefully considered feature of Te Waka Oranga implementation. The role of koroua and kuia is an crucial element which would ensure fidelity in the use of Te Reo Māori, particularly as they would use the mita; the dialect and accent, of their own area.

**Conclusion**

Finally, this study has successfully achieved its aims and made a significant contribution to new knowledge to the area of indigenous child and adolescent traumatic brain injury in Aotearoa New Zealand. First, it has used innovative Rangahau Kaupapa Māori practices in novel ways, adding to the repertoire of methods. One interesting outcome suggests that exploring aspects of marae participation as a proxy measure of collective Māori identity is worth pursuing. This is a particularly intriguing idea given it can be measured relatively simply. Investigating this might begin to illuminate understanding the interactions of whānau as a group with health services, currently a poorly understood area. The use of marae as expressing the collective voice is an area that is promising for future rangahau. Another unexpected outcome was the homogeneity of the findings. Whether this demonstrates a hitherto unidentified bias in the method or whether this represents a uniformity of conceptualisation predicated on the tapu nature of the head or reflects the lived experience of the high Māori incidence of TBI is unclear. However, this finding suggests that a majority of Māori may find Te Waka Oranga resonates with their own beliefs.

Second, this study has produced a theory to guide intervention by articulating the injury in cultural terms. Injury to wairua concommitant with damage to physiological and anatomical structures is the central tenent of this theory. Te Waka Oranga, a draft practical tool to help whānau and clinicians work together at their interface is predicated on this theory. The value of having theory building in this territory is that it lays down a robust foundation for testing and trialling aspects of the theory, such as the framework developed here. It is hoped that aspects of this study's methodology, methods and theory in particular will be of use to other researchers exploring indigenous approaches to well-being in the context of TBI as well as other insults to the body that may be culturally salient.
## Glossary

<table>
<thead>
<tr>
<th>Term</th>
<th>Meaning</th>
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<tbody>
<tr>
<td>hā</td>
<td>breath</td>
</tr>
<tr>
<td>hapū</td>
<td>subtribe</td>
</tr>
<tr>
<td>hauora</td>
<td>Māori concept of holistic health</td>
</tr>
<tr>
<td>he</td>
<td>a or some</td>
</tr>
<tr>
<td>haerenga</td>
<td>journey</td>
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<tr>
<td>hoe</td>
<td>paddle</td>
</tr>
<tr>
<td>hoe tahi</td>
<td>paddle as one</td>
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<td>hui</td>
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<td>iwi</td>
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<td>guardian</td>
</tr>
<tr>
<td>karakia</td>
<td>prayer</td>
</tr>
<tr>
<td>kare-ā-roto</td>
<td>emotions</td>
</tr>
<tr>
<td>kaumatua</td>
<td>esteemed elder or either gender</td>
</tr>
<tr>
<td>kaupapa</td>
<td>subject, reason</td>
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<tr>
<td>kaupapa whānau</td>
<td>group of people who are connected because of a common cause</td>
</tr>
<tr>
<td>kawa</td>
<td>rules, can mean sour in a different context not used here</td>
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<tr>
<td>ki</td>
<td>a particle indicating towards something</td>
</tr>
<tr>
<td>kia</td>
<td>a particle indicating a purpose</td>
</tr>
<tr>
<td>koroua</td>
<td>grandfather, esteemed elder</td>
</tr>
<tr>
<td>kotiro</td>
<td>daughter</td>
</tr>
<tr>
<td>kuia</td>
<td>grandmother, esteemed female elder</td>
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<tr>
<td>mahunga</td>
<td>head</td>
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<tr>
<td>Māori</td>
<td>indigenous people of Aotearoa, New Zealand</td>
</tr>
<tr>
<td>marae</td>
<td>traditional Māori campus of related areas and buildings</td>
</tr>
<tr>
<td>mātauranga</td>
<td>sometimes translated as knowledge, knowledge systems</td>
</tr>
<tr>
<td>matenga</td>
<td>head</td>
</tr>
<tr>
<td>mita</td>
<td>dialect</td>
</tr>
<tr>
<td>mokopuna</td>
<td>grandchild</td>
</tr>
</tbody>
</table>
ngawari      easy, simple, relaxing
noho      stay, sit
noho marae      stay overnight, or for several nights on a marae
noho puku      self reflection
ora      wellbeing
oranganga      healing, health
Pākehā      non-Māori non-Pacific New Zealander
papa kainga      home
pepi      infant
Pou      pillar
pūkenga      skills
pūrākau      story
rangatahi      adolescent
rewa      ready
rongoa      medicine
Rotorua      town in Aotearoa New Zealand
rōpū      group
tai      in this context the ocean
taiohi      adolescent
taitamariki      children
tama      male child
tamariki      child
tane      male
tangata      human being, person
taonga      treasure
tapa      wall
tapu      sacred
te      the
Te Ao Māori      the Māori world
tere      fast
Te Reo Māori      the Māori language
Te Reo Rangatira      the language of chiefs, another way of saying the Māori language
tinorangatiratanga      self determination
tupuna      ancestor
tūroro      patient
tukutuku  a type of woven paneling
upoko  head
uta  in this context, the shore, the land
wā  time
wāhi  place
wairua  sometimes translated as the spiritual
dimension of wellbeing, profound
connection, uniquely Māori
waka  canoe, vessel, conveyance
wānanga  traditional fora for learning and
discussion
whai  follow, seek
whakairo  carving
whakapapa  genealogy
whā  four
whānau  extended family
whānau ora  wellbeing of the extended family system
whanaunga  relation, kindred
whanaungatanga  process of making relational links
whare  house
Appendix 1

Tuku Iho, He tapu Te upoko. From our ancestors the head is sacred.

He Anga Whakairi Tikanga mo te whakaora tamariki Maori i ngaukinohia te whara o te roro (TBI)

WHARANGI WHAKAMOHIO

Ko Parengarenga te wahapu
Ko Mareitu te maunga
Ko Awapoka te awa
Ko Te Reo Mihi me Potahi oku marae
Ko Ngati Kuri, Te Aupouri, Te Rarawa me Ngapuhi oku iwi
Ko Murray ratou Ko Yates oku whänau
Ko Hinemoa Elder toku ingoa

Tena koe. Ko Hinemoa Elder toku ingoa he rata ahau, mo te mate hinengaro tamariki me te tairohi, he mema hoki o te Royal College of Australian and New Zealand Psychiatrists. Ko tenei whāinga mātauranga e aro ana ki te rangahau mo taku tohu Kairangi i te whare Wänanga o Massey.

Te ahua o te mahi me tenei pōwhiri

Kei runga noa atu nga tatau o nga pëpi, tamariki me nga tairohi Mäori i tera o te rahiinga o te hunga e ngaukinohia ana te whara o te roro (TBI). He ai ki nga rangahau o tainehi tonu nei he raruraru tino nui tenei. Puta noa i te ao kei runga noa atu te pākia kinohia o te kohungahunga Maori e te TBI.

Ko nga whakakitenga o te rangahau whanake hauora o Otautahi, e kii ana he 30 orau o te iwi e pākia ana e te TBI kei waenga i nga tau 0 me te 25. He ai ki nga tatau a iwi, i roto i te rua tekau ma rima tau e tu mai nei, hau toru o nga tamariki o Aotearoa, ka Maori. He tohu tenei i te whiu kia haere
whakamua tonu nga mahi whakatu anga tikanga motuhake hei tiaki pepi, tamariki me te taiohi Maori e ngaukihohia nei te whara o te roro. ara te TBI.

Kahore he anga whakairi tikanga o naianei hei whakaora tamariki Maori, otira, tētahi i takea mai i roto i te tikanga Maori. He ai ki nga rangahau o te ao he mea tuturu ano te whai waahi atu o nga tikanga a iwi taketake ake hei whakaora i a ratou kua whara te roro. Ko ta tenei whakamātautau he whakatūi anga whakairinga tikanga whakaora i poua ki te tikanga Maori kia rite ai ki ta nga rangahautanga e tohe nei hei hiki ake i te hauora o tenei wāhanga o te iwi.

Te hunga ka tohia, ka whai waahi mai

Ka tu te rangahau nei i runga marae. Ko nga take o te hui e hangai ana ki nga tikanga e pa ana ki te roro, te hinengario, me te wairua. Ka whakahaeretia i roto i te reo Maori me te reo Pakeha. Ko rere te powhiri ki nga Kaumatua me nga Kuia, me era atu i roto i te marae, kia whai waahi mai.

E mowetiweti pea etahi ki nga korero e pa ana ki te whara o te roro . Ka tu he kaupapa hei awhina, hei tiaki i tenei hunga.

Nga tikanga whakahaere mahi

Ka toru ki te ono haora pea o te roa o enei hui marae, Ka hora he kai. Ka tu enei hui i waho i nga haora mahi, kia rahia atu ai te iwi e whai waahi mai.

Te momo tiaki i nga mohioranga nei.

Ko nga korero ka puta i te hui ka hopu a – rīpenetia, he wa ano pea ka whakaahuatia ki runga rīpena. Ko aata tono-a-tuhi atu nei to whakaae mai kia hopu a rīpenetia o korero. Ko nga korero ka puta i te hui, ka hina ote ki kaitahi kia noho tapu aua korero. Ko wewetetia e ahau nga korero i kohikohia nei he whanake upoko korero hei whakaara i te anga tikanga whakaora. Mo te roanga o te whakamatautau nei, ki tia kina nga korero ki etahi kaapata pupuri e raka ana, kei te Whare Wananga o Massey, i roto hoki i taku tari. Ina hiahia koe ki tetahi whakarapopototanga o te mahi nei waea mai koa, iāmera mai, aata inoi mai ranei i tetahi o nga hui. Ka noho tapu tonu to ingoa, a mehemca ka whakahuainia i runga i nga rīpena, e kore e puta i roto i nga tuhinga, purongo rangahau ranei. Ki te whakaahua a rīpenetia te hui, e kore e taea te arai to tupono mohiotia mai.

Nga Tika O Te Hunga Ka Uru Mai.

Kahore he here i runga i a koe ki te tango ake i tenei tono. Ina whakaae koe ki te uru mai, he tika tou:
Kua arotakehia kua whakaetia tenei kaupapa mahi e te Massey University Human Ethics Committee: Southern A, Application 09/48. Mehe hē maharahara tou mo tenei rangahau, whakapa atu ki a Professor Julie Boddy, Chair, Massey University Human Ethics Committee: Southern A waea 06 350 5799 x 2541, imera humanethicsoutha@massey.ac.nz.

<table>
<thead>
<tr>
<th>Dr Hinemoa Elder</th>
<th>Professor Mason Durie</th>
<th>Professor Chris Cunningham</th>
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<tbody>
<tr>
<td>Principal Investigator</td>
<td>Supervisor</td>
<td>Supervisor</td>
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<tr>
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<td>Research Centre for Māori Health &amp; Development</td>
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<tr>
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<td>Email <a href="mailto:Hinemoa@xtra.co.nz">Hinemoa@xtra.co.nz</a></td>
<td>Email <a href="mailto:m.h.durie@massey.ac.nz">m.h.durie@massey.ac.nz</a></td>
<td>Email <a href="mailto:c.w.cunningham@massey.ac.nz">c.w.cunningham@massey.ac.nz</a></td>
</tr>
</tbody>
</table>

Whakapa atu koa ki te kairangahau, te kaitiro ranei mena he patai au mo te mahi nei.
Tuku Iho, He tapu Te upoko. From our ancestors the head is sacred.

A Framework for the rehabilitation of tamariki Māori with traumatic brain injury (TBI)

INFORMATION SHEET

Ko Parengarenga te wahapu
Ko Mareitu te maunga
Ko Awapoka te awa
Ko Te Reo Mihi me Potahi oku marae
Ko Ngati Kuri, Te Aupouri, Te Rarawa me Ngapuhi oku iwi
Ko Murray raua Ko Yates oku whānau
Ko Hinemoa Elder toku ingoa

Tēnā koe. My name is Hinemoa Elder, I am a Child and Adolescent Psychiatrist and Fellow of the Royal College of Australian and New Zealand Psychiatrists. This study is contributing to my research towards a PhD which I am undertaking at Massey University.

I would like to invite you to participate in this study of Māori views of Traumatic Brain Injury and Rehabilitation.

Project Description and Invitation

Pepi, tamariki and taiohi Māori are over represented in populations with Traumatic Brain Injury (TBI). Recent research highlights the severity of the problem. Māori infants have one of the highest rates of TBI in the world.

Findings from the Christchurch Health and Development Study report an overall prevalence of TBI of approximately 30% for those between the ages of 0 and 25 years. Current population trends suggest that in the next twenty five years one third of children in New Zealand will be Māori. This
trend emphasises the ongoing need for a Māori pepi, tamariki, taiohi specific TBI rehabilitation framework.

There is currently no framework for the rehabilitation of Maori taitamariki, let alone one that is grounded in tikanga Maori. International research shows that culture is a key component in determining outcomes of brain injury rehabilitation. This study aims to develop a TBI rehabilitation frame work that is grounded in tikanga as the research suggests using this kind of framework would improves health outcomes for this population.

**Participant Identification and Recruitment**

The study takes place on marae. Hui will be held and discussion about tikanga related to the brain, hinengaro and wairua will be facilitated in both Te Reo Rangatira and English. Kaumatua, Kuia and other people of the marae are invited to participate.

Discussion about brain injury may make some participants feel distressed. Support for these people will be provided.

**Project Procedures**

The marae hui may take from three to six hours in duration, kai will be provided. These hui will take place outside working hours to enhance participation.

Te Roopu Kaitiaki, a group of experts in tikanga and neuroscience/neurorehabilitation will be brought together to assist the research process. I will be presenting your contributions to them for their reflection also.

A return hui will take place to bring back the contributions from the first hui to provide further time for reflection and checking that the ideas have been understood as you wished them to be.

**Data Management**

Information discussed in the hui will be audio taped and may be videotaped. Your permission for image recording will be sought in writing. Should your marae wish, a DVD copy of the hui will be made for the marae.

The data will be transcribed. The transcriber has signed a confidentiality declaration. I will use the information obtained to develop themes which will determine the rehabilitation framework. For the duration of the study the data will be kept in locked filing cabinets at Massey University and in my office. In order to access a summary of the project please ring or email me or ask me at one of the hui. Your name will not be recorded and if it is mentioned on tape will not be identified in the transcripts
or the research reports. It will not be possible for individual participants to withdraw from the study after the hui has taken place because individual contributions will be difficult to identify after that time. Should the hui be videotaped anonymity of identity cannot be offered.

**Participant's Rights**

You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- decline to answer any particular question;
- withdraw from the hui at any time;
- ask any questions about the study at any time during participation;
- provide information on the understanding that your name will not be used unless you give permission to the researcher;
- be given access to a summary of the project findings when it is concluded.

“This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 09/48. If you have any concerns about the ethics of this research, please contact Professor Julie Boddy, Chair, Massey University Human Ethics Committee: Southern A telephone 06 350 5799 x 2541, email humanethicsouta@massey.ac.nz.”

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<td><a href="mailto:C.W.Cunningham@massey.ac.nz">C.W.Cunningham@massey.ac.nz</a></td>
</tr>
</tbody>
</table>

Please contact the researcher and/or supervisor(s) if you have any questions about the project.
Appendix 2

Tuku iho, he tapu te upoko. From our ancestors the head is sacred.
He Anga Whakairinga Kaupapa mo te whakaora tamariki Maori i whara kino te roro
(TBI)

HE PUKA WHAKAAENGA KAIWHAKAURU - TAKITAHI

Kua pānuihia e au te whärangi whakamōhioranga, kua whakamaramatia nga take o te kaupapa ki ahau. Kua whakautu paitia aku patai, kei te marama hoki au e taea ano he patai a te wa e hiahia ai ahau.

(TOHUA MAI KOIA NGA WAAHI E WHA I RARO IHO NEI KA HAINA AI.)
E whakaae ana ahau/kahore ahau e whakaae ana kia whakaahuatia aku korero.

E whakaae ana ahau ki te uru atu ki tenei whainga mataurangta i raro i nga tohutohu kua takoto i roto i te whärangi whakamohio.

Ra:

Tāmoko:

Ingoa – tuhia:
Tuku iho, he tapu te upoko. From our ancestors the head is sacred.

A Framework for the rehabilitation of tamariki Māori with Traumatic Brain Injury (TBI)

CONSENT FORM FOR HUI PARTICIPANTS

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

[PLEASE MARK THE FOLLOWING OPTIONS AND SIGN]

I agree/do not agree to the interview being image recorded.

I agree to participate in this study under the conditions set out in the Information Sheet.

Signature: ________________________________ Date: ________________________________

Full Name - ________________________________
printed
28 September 2009

Ms Hinemoa Elder
P O Box 334
Oneroa
Waiheke Island
AUCKLAND

Dear Hinemoa

Re: HEC: Southern A Application – 09/48
Tuku iho, he tapu te upoko: A framework for the rehabilitation of Māori tamariki
with Traumatic Brain Injury (TBI)

Thank you for your letter dated 25 September 2009.

On behalf of the Massey University Human Ethics Committee: Southern A, I am pleased to advise you that the ethics of your application are now approved. Approval is for three years. If this project has not been completed within three years from the date of this letter, reapproval must be requested.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

Yours sincerely

[Signature]

Associate Professor Hugh Morton, Acting Chair
Massey University Human Ethics Committee: Southern A

cc Professor Chris Cunningham, Director
Research Centre for Māori Health & Development
WELLINGTON

Professor Mason Durie
AVC (Māori and Pasifika)
PN734
## Appendix 4

<table>
<thead>
<tr>
<th>Marae</th>
<th>1st wānanga</th>
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<tr>
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<td>Te Aupouri</td>
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<td>Iwi marae, remote</td>
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Nau mai haere mai!
Ki Rauru Marae, Ruatoria, 22th Whiringa-a-nuku, 10am, 2010
Te Kaupapa o te rā:
“Tuku iho, he tapu te upoko”
This is a doctoral study by Dr. Hinemoa Elder
(Te Aupouri, Ngati Kuri, Te Rarawa, Ngāpuhi)
This is the return hui for this kaupapa. Key ideas from our first wānanga on 19th Piripi will be reported back.
Appendix 6

Semi-structured questions and introductory statement:

“This wānanga has been called to encourage discussion about te roro, te hinengaro, me te wairua in relation to tamariki/mokopuna with traumatic brain injury and their whānau.

As Māori we have high rates of traumatic brain injury in our tamariki/mokopuna”.

• What are the stories, waiata, karakia that we can share that could help us understand more about how the brain, mind, and wairua work together in healing after an injury in a tamariki/mokopuna?
• What are your ideas about what needs to happen in whānau to promote healing following traumatic brain injury?
• In what ways does it matter what else is going on at the time a tamariki sustained a TBI?
• What can be done to protect tamariki/mokopuna at those times?
• What sort of injuries need traditional Māori healing in order to promote the best outcomes? How can we incorporate that kind of understanding into rehabilitation for tamariki/mokopuna?
• If we were doing a really good job of rehabilitation for tamariki/mokopuna and their whānau, what would that look like?
• What are some ideas about what sets the roro, hinengaro and wairua up to work best in harmony?
• What would you value in the outcomes after brain injury for tamariki/mokopuna, some people might value return to school, return to being able to do certain things?
• In what ways does the cause of the injury impact on how we need to work with tamariki/mokopuna and whānau after brain injury?
• What does rehabilitation mean to you?
Appendix 7

Transcriber’s Confidentiality Agreement

Researchers must obtain a signed confidentiality agreement from transcribers who will process audio recordings which contain personal information. This should cover agreement to not disclose, retain or copy information.

Tuku iho, he tapu te upoko. From our ancestors the head is sacred. A Framework for the rehabilitation of tamariki Maori with Traumatic Brain Injury (TBI)

TRANSCRIBER’S CONFIDENTIALITY AGREEMENT

[Signature]

Date: 28.01.2010

Te Kunenga ki Pārehou
Research Centre for Māori Health & Development
PO Box 706, Wellington 6140, New Zealand  T +64 4 801 5700 extn 0027  F +64 4 380 0626
http://rph.massey.ac.nz
Format for Transcriber's Confidentiality Agreement

Researchers must obtain a signed confidentiality agreement from transcribers who will process audio recordings which contain personal information. This should cover agreement to not disclose, retain or copy information.

Prepare your Transcriber's Confidentiality Agreement based on the format below.

Project Title

TRANSCRIBER'S CONFIDENTIALITY AGREEMENT

I __________________________ (Full Name - printed) agree to transcribe the recordings provided to me.

I agree to keep confidential all the information provided to me.

I will not make any copies of the transcripts or keep any record of them, other than those required for the project.

Signature: __________________________  Date: ___________
Appendix 8

Pūrākau (stories)

1. Tama is a 3 month old pepi. He was brought to hospital by a whānau member as he wasn’t breathing properly, he wasn’t opening his eyes or moving at all. He needed to be treated in Intensive Care. The doctors found he had a break in his skull, bleeding in his brain and damage to the brain itself. They called it a severe brain injury. Other tests showed he had partially healed broken leg bones and a broken arm, at different stages of healing. This was evidence he had been hit at different times. He left the hospital with long term physical problems with weakness on his left side and visual problems. His mothers new partner was convicted of physically abusing the baby.

   (Discussed at Te Mahurehure, Owae and Tapu te Ranga marae)

2. Tamahine is an 8 year old girl who fell down some concrete steps at school. She seemed confused after the fall, the teacher noticed she was holding her head. She was taken to the family doctor by her whanau. The doctor diagnosed a mild traumatic brain injury because of her confusion. She had disrupted sleep for several days and seemed a bit withdrawn, she was fidgety, irritable and was lacking in confidence and found it hard to get on with her friends when she went back to school the following week. Several years later, when she started high school she found studying very difficult and continued to struggle with making friends.

   (Discussed at Pukemokimoki, Rauru and Potahi marae)

3. Rangatahi is a 17 year old who had a serious knock to the head in a car accident. He was a passenger and wasn’t wearing a seatbelt. Two people died at the scene of the accident. He was in hospital for several weeks. When he left the hospital he lived in a rehabilitation unit for almost a year.

   (Discussed at Araiteuru, Tutanekai and Piritahi marae)
## Appendix 9

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Comments on the research
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Te Waka Oranga

Wāhi whai oranga

Clinical goals

Wāhi

Place

Pūkenga / kare ā roto

Skills / Emotions

Wā

Time

Ngā hua o te haerenga

Findings of the journey
Appendix 11

Tuku iho, he tapu te upoko, from our ancestors the head is sacred.

Māori theory building and framework for mokopuna with Traumatic Brain Injury (TBI) and whānau.

Summary written for marae participants

Dr Hinemoa Elder (19.11.11)

This is the first study to propose and operationalise a Māori theory of traumatic brain injury in mokopuna. This theoretical hypothesis proposes that traumatic brain injury damages not only the brain itself but also the wairua, a uniquely Māori dimension of wellbeing characterized by profound connection to the universe. The framework, Te Waka Oranga, provides a Māori space for both whānau and clinical staff to work together identifying pathways to strengthen wairua as well as other aspects of Traumatic Brain Injury recovery.

These outcomes were developed after 18 wānanga on 9 marae, remote, rural and urban, across NZ Aotearoa in 2010 followed by detailed analysis of the data. Initial analysis took the form of noho puku (self reflection), whanaungatanga (connection with others) and kaitiakitanga (guardianship support). The first round of wānanga, attended by 79 people, identified seven central ideas:

Wairua is fundamental and attended to as a priority, Whānau are the functional unit of healing, Whānau experience the clinical world as an alien culture, Mātauranga Māori has a wealth of resources specific to mokopuna Traumatic Brain injury, Māori Identity is about connection, Places have an important healing role because they define identity, and Other trauma is remembered within whakapapa when Traumatic Brain Injury discussion is invited.

This distillation of ideas was fed back to the participating marae in a second round of wānanga, attended by 56 people. Each wānanga were then asked to respond to one of three pūrākau (stories). These were pūrākau about a pepi (infant), tamariki (child) or taiohi (adolescent) with a Traumatic Brain Injury. The pūrākau were based on common features of traumatic brain injury in these age groups. The wānanga were asked to solve the problems inherent in the pūrākau using the ideas they had generated in the first wānanga. This lead to what I have called Māori cultural formulation of mokopuna traumatic brain injury using four key elements, or Pou, to navigate the formulation. These are Wairua, Tangata (people), Wā (time) and Wāhi (place). The transcripts were then further analysed using “dedoose”, an online research tool, with the purpose of developing categories that informed the development of this theoretical position. From there the framework was constructed.

The participating marae were; Potahi (Te Kao), Araiteuru (Otepoti), Te Mahurehure (Tamaki Makaurau), Rauru (Ruatoria), Tutanekai (Owhata), Pukemokimoki (Ahuriri), Owae (Waitara), Tapu Te Ranga (Poneke), Piritahi (Waiheke).
The Theory of Wairua Injury in Mokopuna Traumatic Brain Injury (TBI)

This theoretical position proposes that wairua is injured in mokopuna traumatic brain injury alongside injury to the anatomical structures and physiology of the brain. Wairua is defined in this theory as a uniquely Māori experience of profound connection with all aspects of the universe. Because wairua is a connecting and communicating element with all aspects of the universe the nature of the wairua injury travels through the wairua connections back in time through whānau and whakapapa. It also travels forward in time towards descendants of the mokopuna. The wairua’s function here is to bring cultural specific resources to aid the healing processes required. In this theoretical space the experience of being Māori is defined as being part of a whakapapa.

This theory proposes that Māori whānau have latent cultural resources (beliefs, attributions and practices) that are relevant to traumatic brain injury, which they may or may not be aware of. When mokopuna traumatic brain injury happens these resources are activated. This mātauranga consists of two key aspects. Firstly, memories of events that have occurred within the whakapapa that may have contributed to the current injury are brought to mind. Secondly mātauranga about practices specific to healing the wairua injury part of traumatic brain injury becomes available. The suggestion is that the current wairua injury is also an opportunity to address other trauma within the whakapapa. This is different from the Whare Tapa Whā model in a number of ways. The primary distinction here is that here wairua is privileged.

Why does this happen? This happens because in Te Ao Māori (the Māori world view) "he tapu te upoko"; the head is the most sacred part of the body. Awareness of the head’s status is commonly held mātauranga, and is triggered in the context of the traumatic brain injury.

How do we know this mātauranga is held in whakapapa? We know because the mātauranga is shared through being passed down from generations of tupuna in many forms; written, practiced and remembered in waiata, oriori, moteatea, karakia, spoken and relived in memories and pūrākau, carved in whakairo (carving) and created in tukutuku (woven panels) and on marae. Practices that are activated from the whakapapa storehouse of mātauranga are contained within Te Reo Rangatira me ōna tikanga (the Māori language and protocols). By being in Te Reo Rangatira and structured as part of tikanga Māori, the mātauranga held within whakapapa determines that these practices have a direct and potent effect on attending to the wairua needs of the mokopuna their whānau, hapu and iwi. The sound and vibrational qualities of Te Reo Rangatira is highlighted as an essential feature of this healing potential. Combining healing practices in Te Reo Rangatira such as oriori with specialised forms of touch such as mirimiri and romiromi is proposed to further enhance healing opportunities.
Medical services’ attitudes and active validation of the whānau is a proposed dimensional mediating factor. This determines the nature of the relationship between whānau participation in both mātauranga practices and clinical recommendations. When medical services express their respect and understanding of Māori whānau mātauranga this strengthens the whānau ability to more fully participate in their own Māori defined healing processes as well as those recommended by the clinical staff. When the medical services have limited ability to understand and support the need for whānau to fully access mātauranga this compromises the whānau capacity to fully address their culturally defined healing needs as well as what is recommended by the clinicians. This aspect underlines the importance of the influence of clinical services in this situation.

This proposed theory is postulated to operate for Māori people who have some connection to their marae in contemporary NZ society. Of importance here is that despite the awareness of a diverse experience of being Māori, 55-70% in recent surveys of Māori reported attendance on marae “often” or “very often” (Survey of attitudes, values and beliefs towards the Māori language. Te Puni Kokiri, 2010. A measure of culture; cultural experiences and cultural spending. Statistics NZ and Ministry of Heritage and Culture, 2003). This suggests that the theoretical model proposed here has the potential appeal to a majority of Māori. Possible limitations of this theory have been reduced in a number of ways including use of a Rōpū Kaitiaki and the diversity of marae included.

This theoretical position might also predict outcomes in other situations involving injury or insult to the head and brain. This conceptualisation may also have relevance for people from other indigenous cultures such as a Tangata Maoli, indigenous Hawai’ians, given similarities in language and cultural beliefs.

**Te Waka Oranga. A framework to assist whānau and clinicians working together in mokopuna Traumatic Brain Injury (TBI)**

The framework takes the shape of a waka. This iconic Māori symbol has been chosen because it is a Māori mode of transport; it embodies and houses Māori mātauranga that traverses intergenerational time and space. Unlike other Māori frameworks it makes movement and change explicit. Te Waka Oranga privileges the Māori worldview and invites other worldviews to “come aboard”. It enables the whānau and clinicians to work together at the interface of their world-views.

This framework is used in two stages. Firstly, “Hoe tahi” (Paddle together as one). This stage establishes ways of working together on Te Waka Oranga. Secondly, “Te Haerenga o Te Waka Oranga” (The Journey of the Waka Oranga) occurs. This involves the launching, sailing and arriving of Te Waka Oranga.

This framework involves completing a template that can be personalized to reflect the preferences of the mokopuna. Each template provides space for documenting and
prompting discussion using the elements of Māori cultural formulation of TBI and guided by the seven core ideas generated by the wānanga and the theory building. The framework makes explicit the Māori practices that are specific to addressing the needs of wairua injury alongside the clinician recommendations to address other aspects of TBI.

Initial trialing and refinement of this framework is anticipated for situations of complexity such as non-accidental traumatic brain injury.

This approach could be further developed into a virtual rehabilitation activity.

This theory and framework have been reviewed by the hapū at Te Kao and the Rōpū Kaitiaki (Naida Glavish, Amster Reedy, Professor Richard Faull, Professor Sir Mason Durie, Dr Greg Finucane and Associate Professor Juan Carlos Arango Lasprilla) as well as other key stakeholders.

Please do not hesitate to contact me with any feedback.

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