Kaupapa Māori Evaluation

Transforming Health Literacy

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KARAKIA

Te Kawa Rokihau

Maiea te tupua
Maiea te tawhito
Maiea te kāhui o ngā ariki
Maiea tawhiwhi ki ngā atua
ōi ka takina te mauri
Ko te mauri i takea mai i a Rongomaraeroa e
Tenei te mauri te whakapiki
Tenei te mauri te whakakake
Te mauri tū, te mauri tapu
Te mauri nō whea nōu e Rangotaketake e
He ngakau tapatahi
He ngakau papaku
He ngakau whakaiti
Te ngakau o tama e rongo e
Kia tau te rongomau,
kia āiō te noho
Ko tematau ka rehe, ko te mauī ka rehe
Tukuna atu tama kia tiritiri
i te toi whenua o te mātauranga
Purutia kia ū, purutia kia mau/
He kura huna ka kapohia
i te ringa o teretere pūmahara
Purutia kia ū, purutia kia mau/
Ka tupu ko te pūkenga, ko te wānanga,
Ko te taura, ko te tauira
He ora te whakapiri e Ngāti Porou Hauora e
Kia puta ēnei tauira hei iho pūmanawa,
Hei whakamaunga kanohi
He putanga ariki nōu e Rongo e
Uhi wero, tau mai te mauri
Haumi ē, hui ē, taiki ē!

Dedicated to my

Great Great Grandmother

Ramari Waiariki (nee Heremia)

1879–1965

Grandmother

Rawinia Carlson (nee Waiariki)

1924–2000

ABSTRACT

This thesis set out to evaluate the effectiveness of a cardiovascular disease medicines health literacy intervention. Kaupapa Māori evaluation was the guiding approach for gaining insights about the intervention from patients/whānau and Ngāti Porou Hauora health practitioners directly involved in the intervention as well as the wider Ngāti Porou community. Beyond this research setting, I sought to broaden the insights into health literacy approaches through Māori and international Indigenous key informant interviews, synthesising their insights with analyses of the evaluation data. In addition, the study sought to ground its understandings of health literacy interventions and approaches with Indigenous communities in other colonial contexts by collaboratively designing and testing an evaluation framework. As well as the focus on health literacy as a construct, I aimed to broaden understandings around the praxis of kaupapa Māori evaluation in the context of an iwi-centred approach.

The key findings of the strands of the study are effective health literacy, with sub-themes for Ngāti Porou context and importance of whanaungatanga; kaupapa Māori evaluation – transformational praxis; reclamation of health literacy and contributions to the formation of Indigenous health literacy. To bring about change, we need to deepen health literacy's scope to examine practices embedded in broader social narratives and cultural agency that recognise issues of equity, equality, and empowerment. Health literacy needs to be understood and enacted as a situated social and cultural construction that is negotiated, fluid, and shaped by people, whānau communities, and the complex array of other stakeholders. I propose transforming health literacy praxis at all levels – requiring the re-orientation and re-configuration of power relations that is

congruent with current debates and discussions about decolonisation. Decolonising health literacy will involve revamped decision-making and recruitment processes grounded in Indigenous world views, tino rangatiratanga and mana motuhake. More specifically, transformation of health literacy will involve investing in cultural safety and competency training, applying new standards of practice, and ensuring internal and external Māori involvement at all levels of engagement.

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I would like to thank Ngāti Porou Hauora staff and the parent project's research team for your time and guidance. Thank you to the funders who supported this research. Ngā mihi matakuikui ki a koutou katoa: Health Research Council (Māori Doctoral PhD Scholarship); Ngā Pae o te Māramatanga (Doctoral Bridging Grant, Conference Attendance Grant); Māori Education Trust (Ti Maru Māori Trust Prestigious Scholarship, Eric Hall McCormick Memorial Scholarship); Massey University (Pūrehuroa Awards); Ministry of Health (Hauora Māori Post Graduate Scholarship); MAI ki Tamaki He Manawa

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Thank you to my whānau and friends. A big mihi to my parents and grandparents, who support me in their own unique ways. Thank you to my darlings, for your aroha, kisses, and hugs – George, Wiremu, Ōkaire, Maggie and Tawatihitihi o te Rawhitiroa.

Nā Manaakitanga Teah Anna Lee Carlson

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GLOSSARY

These translations have been sourced from personal communications and online and hard copy dictionaries. Many are complex and warrant much deeper reading to fully appreciate their meaning and usage. “Because language and culture are interwoven, meaning is more than the translation of words” (Moewaka Barnes, 2008, p. 147). The words and meanings are presented specific to the context of and usage within the research. This includes words, dialects, and meanings used by the participants of this research, representing whānau, hapū, and iwi context(s).

ʻAi Pono	Good ancestral food
Aʻo aku, aʻo mai	Reciprocal learning
Ahua	Energy
Āhuatanga	Tradition, way, aspect, likeness, circumstance
Aloha kekahi i kekahi	Caring for one another, showing respect
Aorangi	Ancestoral Mountain of Ngāti Porou
Aotearoa	New Zealand, “Land of the Long White Cloud”
Aro	Take interest, face towards
Aroha	Love, concern, compassion
Aromātai	Evaluation
Atua	Gods
Awa	River
Hapū	Sub-nation(s) that share common ancestor
Hauora	Be fit, well, healthy, vigorous, in good spirits
Hikurangi	Ancestoral mountain of Ngāti Porou
Hinengaro	Mental

Ho’oponopono	Conflict resolution
Hui	Meeting, to gather, congregate, assemble
Iwi	Nation, confederation of sub-tribes, often refers to a group of people who descend from a common ancestor and occupy a specific territory
Kai	Food
Kaiāwhina	Community support worker
Kaitiakitanga	Acknowledgment of the people as caretakers of the environment
Kanohi ki te kanohi	Face-to-face
Kanohi kitea	Face-to-face connections
Karakia	Incantation, prayer
Karanga	Ceremonial chant of summons, welcome or introduction performed by women
Kataraoera	Castor oil
Kaumātua	Cultural elder, person of status
Kaupapa Māori	Māori approach, topic, philosophy, ideology, strategy
Kaupapa	Movement, topic, policy, plan, issue
Kawa	Protocol, ceremony
Koha	Reciprocity, gift, contribution
Kōrero	Contribution, discussion, tell, say, address, speak, talk, conversation
Kotahitanga	Interdependence, expression, realisation of unity
Ma’e ma’e	Pure spirit
Maia	Courage, boldness, purpose, resistance, leadership, ambition, grit
Makawakawa pūkaki	Place of significance located north of Uawa, Ngāti Porou
Mālama ‘āina	Care for the land, it will grow healthy food
Māmā	Mum, mother

Mana motuhake	Autonomy, an authority that derives from the land and is of the land
Mana whenua	Power from the land
Mana	Essence, life force, status and prestige. Mana is a supernatural force in a person, place, or object
Manaaki	Support, reciprocity, blessing
Manaakitanga	Hospitality, kindness, generosity, support, care
Manawa	Heart
Mangakino	Place of significance locted north of Uawa, Ngāti Porou
Mangatokerau awa	River/stream locted north of Uawa, Ngāti Porou
Mangatokerau	Place of significance located north of Uawa, Ngāti Porou
Manuhiri	Visitors
Māori	Indigenous peoples of Aotearoa
Marae	Meeting grounds, often used to include the complex of buildings around the Marae atea
Mārenatonga	Marriage
Matai	Gaze intensely, longingly
Matakaoa	Region near Te Araroa, Ngāti Porou
Mātāmua	Eldest
Mātauranga Māori	The body of knowledge originating from Māori ancestors, including Māori world view and perspectives, Māori creativity and cultural practices
Mātauranga	Knowledge, wisdom, understanding, skill, education
Mātauranga-a-iwi	Knowledge of iwi
Matenga	Death
Māui-Tikitiki-a-Taranga	Eponymous ancestor
Maunga	Mountain

Mauri ora	Healing and wellbeing
Mauri	Spiritual essence, special nature, the essential quality and vitality of a being or entity
Moana	Sea, extensive body of water, ocean, lake
Mōhio	Knowledge
Moko; moko-mokopuna	Grandchild(ren), next generations
Motu	Country
Nehi	Nurse
Ngā purere whakamaharahara	Memory strategies
Ngahere	Bush, forest
Ngakau Tapatahi	Integrity
Ngāti Porou Hauora	Iwi Health organisation
Ngāti Porou	Nation affiliated with the East Coast region of New Zealand
Ngāti poroutanga	Ngāti Porou culture
Noa	to be free from the extensions of tapu, ordinary, unrestricted, void
Nukutaimemeha	Māui’s canoe
Ora	To be alive, healthy, healed
Pakari	Collaboration, partnership
Pākehā	Non-Māori
Pakeke	Cultural advisor, Māori elder, providing cultural advice
Pāpā	Dad, father
Paripoupou puke	Hill located north of Uawa, Ngāti Porou
Poharatanga	Influences of poverty
Pohautea	Place of significance northern region of Ngāti Porou
Pono	Truth and sincerity
Poroporoāki	Farewell
Pōtikirua	Northern marker of Ngāti Porou territory

Pūkaki	Streams
Puku	Stomach
Pule	Prayer and appreciation
Pūmotu	Elements
Pūrākau	Ancient legends
Rahuimanuka	Place of significance northern region of Ngāti Porou
Rangatiratanga	Self-agency, Chief, person of status, status of a person
Rangitukia	Region south of the East Cape, Ngāti Porou
Rohe	Iwi territory
Rohenga tīpuna	Shared ancestors, history and location
Rongoā	Medicine
Tairāwhiti	Gisborne Region
Takiwā	Home area
Takohanga	Responsibility for understanding
Tāmaki Makaurau	Auckland
Tamariki	Children
Tangata whenua	People of the land
Tangi	To cry, to weep, Māori death rituals
Taniwha kōmanawa	Place of significance located north of Uawa, Ngāti Porou
Taniwha	Water spirit, monster, powerful creature,
Taonga tuku iho	Heritage, heirloom, something handed down, cultural property
Taonga	Gift
Tapu	Sacred state/condition
Tauiwi	Non-Māori
Taumautanga	Experience, engagement
Te Aitanga a Hauiti	Nation on the East Coast, North Island, New Zealand

Te Ao Māori	The Māori world
Te Araroa	Township northern end of Ngāti Porou territory
Te hua me te rautaki	Effectiveness and efficiency
Te ia o te kaupapa	Context specific and fit for purpose
Te Ika-a-Māui	The North Island of New Zealand
Te Kāwai Ora	Māori Adult Literacy Working Party
Te Onepoto	Place of significance northern region of Ngāti Porou
Te Pipiwharauroa	Māori language newspaper
Te Puia Springs	A small settlement on the East Coast, Ngāti Porou
Te Rarawa	Tribal group north of the Hokianga area
Te raupapa whare ora	Capacity and capability building
Te Reo Māori	The Māori language
Te reo me ōna tikanga o Ngāti Porou	Ngāti Porou Māori philosophy, knowledge, practice, and identity
Te Runanganui o Ngāti Porou	Ngāti Porou iwi governance entity
Te tai ao	Environment
Te Tiriti o Waitangi	The Treaty of Waitangi
Te ū o te kaha	Strengths based
Te Whānau a Ruataupare	Sub-nation of Ngāti Porou
Te Whānau-ā-Apanui	Nation affiliated with narrow coastal strip between the Raukūmara Range and the eastern Bay of Plenty of New Zealand
Tika	Proper, fair
Tikanga Māori	Tikanga specific to Māori and their cultural customs
Tikanga	Customary system, correct procedure, code, convention, custom, method of practice
Tikitiki	Small town in Waiapu Valley on the north bank of the Waiapu River Ngāti Porou
Tikitiki-o-rangi	Realm of heaven

Tinana	Physical
Tino rangatiratanga	Self-determination and positive Māori development
Tīpuna; tūpuna	Ancestors, grandparents
Titiro whakarongo . . . kōrero	Look and listen (and then maybe speak)
Tohu	Qualification, sign, symbol
Tohunga	Ritual expert, skilled person, healer
Toka-a-Taiau	Southern marker of Ngāti Porou territory
Tūhononga	Connection
Tūpuna; tīpuna	Ancestors, grandparents
Tūrangatira	Engagement through presence
Tūrangawaewae	Meet them on their own ground
Uawa	Tolaga Bay
Upoko	Head
Waiapu awa	Ancestral river of Ngāti Porou
Waiapu	Place of significance northern region of Ngāti Porou
Waiata	Song, singing
Waikato-Tainui	Nation affiliated with the Waikato region in the western central region of New Zealand
Wairepo	Swamp
Wairua	Life, spirit, soul
Wairuatanga	Sacred relationship to the gods and the cosmos, spiritual belongingness
Waka	Canoe
Whaikōrero	Speeches
Whakaaro	Thoughts
Whakaharatau	Practices
Whakahautanga	Self-mastery
Whakahua	Access
Whakairo	Carvings

Whakamahi	Use, shift in practice
Whakapapa	Genealogical lines of descent
Whakapono	Beliefs
Whakarongo	Listen, hear, obey
Whakataukī	Proverb
Whakawhanake	To develop, improve
Whānau	Family group, extended family, relationship
Whanaunga	Kin, relative, cousin
Whanaungatanga	Relationship, kinship, collective, sense of family connection – a relationship through shared experiences and working together that provides people with a sense of belonging
Whānautanga	Birth
Whangaikena	Place of significance northern region of Ngāti Porou
Whare	Home, house
Wharenui	Meeting house on marae
Wheako whaiaro	Experience
Whenua	Land, country, territory, ground
Whitiwhiti	To change, turn, exchange, transfer

PREFACE

> Identity at any meaningful level cannot be manufactured or manipulated; it is as much genetic imprint as formative experience. No matter what destructive processes we have gone through, eventually the taniwha stirs in all of us, and we can only be who we are.
>
> (Merata Mita in Dennis & Bierenga, 1996, p. 54)

For Māori, doctoral research is often a deeply personal experience. I have developed alongside my research, as a Māori woman, researcher, and evaluator. My research journey has been trying at times. I have faced enrolment issues, changed institutions/supervisors, relinquished one scholarship and attained another, proposed/re-proposed, amended ethics applications, lost involvement from an organisation, reduced participants, had personal health issues, had relationships end, changed my whole immediate whānau structure and had a newborn, who took me on a ride of a year and a half of sleep deprivation. My journey has not been straightforward, but I have learned from every resubmission and new start I have had to make, and my values and goals of serving my people and my community and contributing towards meaningful actionable transformation have never changed. Alongside the challenges, my PhD journey has been very rewarding. I have met amazing, dedicated people and made lifelong friendships. I have been humbled and honoured to present my research at various marae and Māori organisations, presented papers at conferences, and travelled from one end of Aotearoa to the other and to O’ahu, Hawai’i.

Introduction

Cardiovascular diseases (CVD), including angina, myocardial infarction, stroke, and transient ischemic attacks, are significant causes of illness and mortality among Māori (Indigenous peoples of Aotearoa [New Zealand]). Patients[1] and their whānau (family) play a major role in managing heart disease and stroke. To self-manage long-term conditions effectively, people must be able to access, comprehend, and act on information for health. This process is called health literacy (Berkman, Davis, & McCormack, 2010; Rudd, 2012).

Strengthening Health Literacy Among Indigenous People

In 2009, a tripartite partnership between the National Health Medical Research Council (Australia), Canadian Institutes of Health Research, and the Health Research Council of New Zealand funded an international collaboration named *Strengthening Health Literacy Among Indigenous People Living with Cardiovascular Disease, Their Families, and Healthcare Providers*. The project was funded by the International Collaborative Indigenous Health Research Partnership grant (ICIHRP), which brought together Indigenous health services and universities in Canada, Australia, and Aotearoa. The principal investigators on this project were all Indigenous and included Dr Sue Crengle (Waitaha, Kati Mamoe, Kai Tahu) from Aotearoa, Ian Anderson (Palawa Trowerna from the Pyemairrenner mob in Tasmania) from Australia, and Dr Janet Smylie (Métis Nation

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[1] The term 'patient' was used in this thesis for ease of understanding for national and international audiences. It is apparent that this term has limitations as people have expertise across positions and are much more fluid than patient/health practitioner (professional), lay person/expert and passive/active categories.

of Ontario with Métis roots in Saskatchewan), a researcher and general practitioner (GP) in Canada.

Cardiovascular Disease Medicines Health Literacy Intervention

The Aotearoa branch of the research project is known as the *Cardiovascular Disease Medicines Health Literacy Intervention* (parent project). It was developed and implemented by a team of Māori health researchers and Māori health providers. The intervention targeted Māori patients and their whānau, drawing on kaupapa Māori (Māori approach) theory and praxis to effect change amongst this population. The aims of the parent project included the following:

- To develop a culturally appropriate health literacy intervention that focuses on CVD medications and on communicating with health practitioners about medication use to meet evidence-based care standards/targets.
- To implement the intervention in the “real-world” context of five Indigenous primary care providers: two in Aotearoa, one in Australia, and one service with two different sites in Canada.
- To understand the impact of the intervention in the broader context of the health services and to identify other factors that may have an impact on the effect of the intervention (case study).
- To identify issues associated with sustainability in each site and transferability to other sites (case study).

The objectives of the intervention focused on increasing knowledge of CVD medications, promoting changes in health literacy practices, creating more empowered interactions between affected Māori and health practitioners, and providing training in health literacy for service staff.

Evaluation of Cardiovascular Disease Medicines Health Literacy Intervention

This doctoral research evaluated the effectiveness of the *Cardiovascular Disease Medicines Health Literacy Intervention* for Māori who were involved and explored the contribution kaupapa Māori theorising may offer to the evaluation of health literacy activities. The evaluation involved a two-phase process. Phase one consisted of collecting qualitative data from semi-structured interviews and phone contact with patients, whānau, and health practitioners involved in the intervention. Phase two involved the development of a kaupapa Māori health literacy evaluation framework shaped by insights from semi-structured interviews with key informants (selected Māori health literacy experts) and Ngāti Porou Hauora staff (research advisory group), the Māori health provider implementing the intervention. The Ngāti Porou Hauora research advisory group had input into the evaluation framework and the consultation processes and methodology and helped define the expectations of the intervention from the perspective of the organisation.

My aims and objectives were as follows:

1. To carry out a kaupapa Māori evaluation of the effectiveness of the *Cardiovascular Disease Medicines Health Literacy Intervention* by
    - gaining insights into perceptions, practices, and experiences of the intervention through semi-structured interviews and weekly phone contact with six patients and whānau and
    - gaining insights into perceptions, practices, and experiences of the intervention through semi-structured interviews with three health practitioners.

2. To develop wider learnings in relation to health literacy interventions with Māori and Indigenous communities by
    - collaboratively designing and testing an evaluation framework with Ngāti Porou Hauora,
    - gaining insights into health literacy approaches through key informant interviews with six health literacy informants, and
    - synthesising the data and seeking input and feedback from Māori providers.

I worked collaboratively with the evaluation participants in designing and testing the evaluation framework for Ngāti Porou Hauora. Additional perspectives were gathered from interviews with local and international key informants on the topic of health literacy. These understandings were synthesised and grounded through input and feedback from the research advisory group. I aimed for a shared power base that limited hierarchy. The research advisory group, staff, and patients/whānau participants were invited to be part of the research process through hui (meetings), interviews, phone contact, and email.

The Chapters

This thesis comprises ten chapters. Chapters one and two provide the context for the research. The six findings chapters (four–nine) are broken into two sections: section one covers the thematic findings drawn from participant data. Section two consist of published papers submitted to New Zealand and international peer-reviewed journals, as well as chapter nine, which describes the Indigenous co-design of a health literacy framework. Together, these chapters further cover the research objectives and contribute to the overall research aim.

In chapter one, I provide a literature review on the topic areas covered in the thesis, contextualising the theoretical and practical knowledge around kaupapa Māori theory/research and evaluation. I then introduce the context in which the research was conducted with the iwi (nation) Ngāti Porou, and Ngāti Porou Hauora, the intervention provider, and the areas covered in the research: health literacy, CVD, and medication use.

Chapter two introduces who I am, describes my doctoral journey in more detail, and outlines my responsibilities regarding the research and the relationships involved. I then detail my framework of practice, drawing on Māori values and principles and mapping out my methodological foundations and collaborative research approach.

Chapter three provides an overview of the research aims and objectives, relationship to the parent project, data design, and data collection. I then provide a detailed account of the process used in developing the kaupapa Māori evaluation framework with Ngāti Porou Hauora.

Chapter four presents thematic findings from the kaupapa Māori evaluation of the *Cardiovascular Disease Medicines Health Literacy Intervention*, providing various insights into what effective health literacy means from the perspective of Māori patients and Māori health practitioners directly involved in the intervention and more broadly for Māori and Indigenous key informants.

I have produced several academic papers for peer-reviewed publication. The following five chapters of section two reveal those efforts.

Chapter five is my first published paper, co-authored with my supervisors, Professor Helen Moewaka Barnes and Professor Tim McCreanor. We open with a discussion of my collaborative journey through the kaupapa Māori health literacy evaluation project. The chapter details how the kaupapa Māori research principles of kanohi kitea (face-to-face connections), collaboration, titiro whakarongo … kōrero (Look and listen and then maybe speak), contextual practice, and community priorities have been implemented in my research, highlighting that kaupapa Māori evaluation is about developing relationships with our communities to pursue understanding and knowledge together. I examine the nature of such collaboration, particularly how to negotiate equitable input and power differentials and engagement opportunities. The examination of inequities in power is further developed in the next three chapters.

Carlson, T., Moewaka Barnes, H., & McCreanor, T. (2017). Kaupapa Māori evaluation: A collaborative journey. *Evaluation Matters—He Take To Te Aromatawai Journal*. 1 (4) 1-33.

Chapter six is co-authored with my supervisors and health literacy expert Susan Reid. It begins by outlining health literacy and its evolution and practice, focussing particularly on patient– practitioner relationships and healthcare relations generally. This research illustrates how distal understanding of the interpersonal dynamics of health literacy are vital to understanding how it could be made more useful to Māori communities.

Carlson, T., Moewaka Barnes, H., Reid, S., & McCreanor, T. (2016). Whanaungatanga: A space to be ourselves. *Journal of Indigenous Wellbeing Te Mauri – Pimatisiwin*. 2 (2) 44-59.

Chapter seven is also co-authored with my supervisors and explores how we can take the relational understanding and practice of health literacy described in chapter six and analyse the effectiveness of the intervention. The findings highlight that the responsibility for improving health literacy lies with everybody in making substantial systemic change. This understanding provides the basis of the kaupapa Māori health literacy evaluation framework presented.

Carlson, T. (submitted). Health literacy in action: Kaupapa Māori evaluation of cardiovascular disease medicines health literacy intervention. *AlterNative: An International Journal of Indigenous Peoples.*

Chapter eight centres on reclaiming health literacy as a practice, apparent in the earliest historical accounts, that we as Māori have been enacting through our ways of knowing and understanding for over a thousand years. I propose decolonising health literacy by reclaiming it as a shared practice amongst Māori to be applied in contemporary settings of Ngāti Porou. The research process centred on people – patients, health practitioners, iwi representatives, Ngāti Porou Hauora staff and governance members, and key informants (health practitioners working specifically in interventions that involve health literacy and Indigenous health literacy practitioners). The chapter examines what effectiveness means in the Ngāti Porou context regarding health literacy, action areas, and goals.

Carlson, T. (submitted). The power to define: Decolonising health literacy. *Public Health Journal: Special issue: Health of Indigenous peoples.*

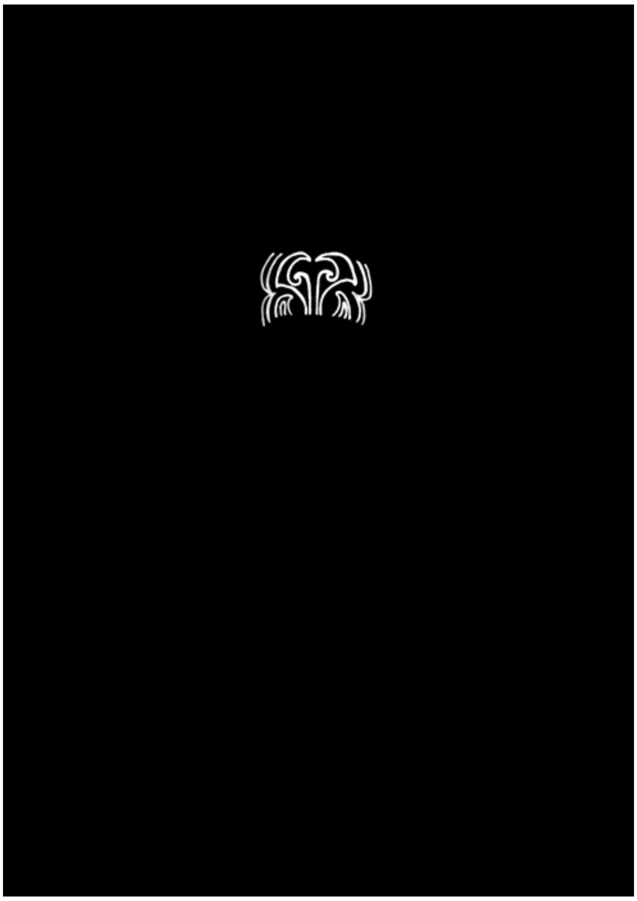
Chapter Nine explores a kaupapa Māori co-design process to develop health literacy interventions and approaches within Indigenous communities. I invited conference attendees at the World Indigenous Peoples' Conference on Education (WIPC: E) to participate in a workshop on developing a health literacy evaluative framework exploring values and principles, action areas, and criteria. In collaboration, we reclaim health literacy in the pursuit of health and wellbeing for the communities we serve. This was an important journey, as it enabled me to broaden my analysis of Indigenous knowledge and understanding in the context of health literacy and directly informed the development of an Indigenous health literacy framework. I then synthesise findings from the qualitative data from the thesis and explore Indigenous global perspectives for conceptualising the decolonisation of health literacy.

Carlson, T. (19 May 2014). *Indigenous Evaluation: A Kaupapa Māori Health Literacy Intervention.* Paper presented at the 2014 World Indigenous Peoples' Conference on Education. Kapiʻolani Community College: Oʻahu in the Hawaiʻi Archipelago.

Chapter ten examines the central conceptualisation of Indigenous knowing to solidify our unique, comprehensive notions of power, connection and responsibility to others and the environment. I bring the key findings from these data chapters to synthesise a framework drawing on mātauranga-a-iwi and Indigenous perspectives. I also provide final reflections on health literacy as a key focus of this doctoral thesis and my practices as a kaupapa Māori evaluator.

Thesis imagery – Images are presented at the beginning of each chapter in an attempt to illustrate my practice as a kaupapa Māori researcher and evaluator. My work aims to illustrate the importance of the Indigenous voice and control with respect to the delivery of health services and in the design and implementation of health literacy, kaupapa Māori evaluation, and medications. The images provide a running commentary throughout the thesis, conceptualising kaupapa Māori practice, inspiration, evaluation, ethics, and research management. I begin with setting the scene.

CHAPTER ONE: SETTING THE SCENE



Teah Carlson
Painting my gaze – who I am, what I have learnt, and what I see
2017
Liquid chalk on black card
637 × 415 mm
Private collection, Auckland

I am an artist, activist, and academic, and I draw on these
identities to express, connect, and articulate Indigenous
solidarity, self-determination, and hope.
I begin with whakapapa, the lines of descent.
I ask what do you see?

I see me.

Indigenous

In reviewing literature, the term "Indigenous" can be referred to as two distinct processes, first as a process of coloniality – the forced positioning of Indigenous peoples in a certain social class in the course of colonial power, in relationship to Pākehā, in relationship to non-Indigenous peoples as a collective tool. Second, self-identification is related to Indigenous movements and political ideologies, an ethic group for and in itself. The word "Indigenous" has its origins in Latin – indigena meaning "sprung from the land," and indu meaning "in, within." In other words, it relates to descent and the lands.

Linguistically, the meaning of the term "Indigenous" changes depending on the context in which it is utilised – it relates to the way the speakers, writers, communicators of a language contextualise it. Therefore, it becomes less an issue of what a word "means," and more an issue of defining the meaning for its use in specific political matters when it becomes necessary to do so, while simultaneously recognising that such defining is merely functional and not all-inclusive.

No categorisation of Indigenous peoples is absolute, except perhaps when it comes to the issue of control. For the most part, the term "Indigenous peoples" is used today to describe a group that has had ultimate control of their lands taken by later arrivals; they are subject to the domination of others. Used in this sense, descent is less important than political perception.

In this thesis, I refer to "Indigenous/Indigenous peoples" as first peoples of the land, I do acknowledge that other terms could be used as peoples have their own names to define themselves such as first peoples, aboriginal peoples, and native peoples. However, I recognise and acknowledge there is inherent political value in having global terminology of Indigenous peoples, a label of solidarity – an aid towards the anti-colonial, counter narrative, decolonising battle. These considerations/processes enable and enact a political analysis within all our work as kaupapa Māori researchers and evaluators (Cram, 2016).

Kaupapa Māori

Kaupapa Māori as a means of creating, maintaining, and sharing knowledge has its conceptual origins in history that date back over a thousand years (Smith & Reid, 2000). Within the "Western" academy, kaupapa Māori theoretical foundations emerged from the post-World War II era and mark a conscientised resistance to prevailing research theory and practice that viewed Māori through the lens of the dominant culture. This tended to produce results that were often irrelevant, of little practical benefit, or actively disempowering to Māori communities. Out of this consciousness came motivation for change, which led to the emergence of key political movements toward Māori tino rangatiratanga (self-determination). One of the emerging areas that utilised and developed kaupapa Māori theory as a revolutionary standpoint occurred within the discipline of education. Smith's (1997) contribution was instrumental in the development of kaupapa Māori theory as he linked "kaupapa Māori" with "theory" and opened up space for Māori epistemological foundations to be further expressed and debated within academia (Kerr, 2012a). Kaupapa Māori theory has provided a space for Māori and encouraged Indigenous peoples elsewhere to reclaim their own theories and research practices (Moewaka Barnes, 2000b; Pihama, 2001; Smith, 1999a). The very nature of kaupapa Māori theory is organic; it does not have a set formula, being central to the diverse needs and aspirations of the communities they serve. However, there are broad principles that enable it to develop (Pihama, 2017; Smith, 2014).

- **Distinctive to Aotearoa** – uniquely Māori, locates Māori in a colonial context in relation to Pākehā/non-Māori as a collective tool.
- **Mātauranga Māori** – knowledge that is created from Māori paradigms for the needs and aspirations of Māori communities that go beyond any particular academic discipline.
- **Self-determining** – kaupapa Māori must be defined and controlled by Māori – we control our definitions of what kaupapa Māori theory means.
- **Transformational** – should be considered a tool for change. Research should be conducted for a particular purpose that prompts change in the actions and practice of it in our daily lives.
- **Multiple expressions** of kaupapa Māori theory exist at a whānau, hapū (sub-nation), and iwi level.
- **Systemic and structural** – Acknowledges that many determinants of health and wellbeing exist beyond the control of the affected individuals. Societal institutions, laws, and cultural norms are critical to how disparities in health and wellbeing are framed, interpreted, and addressed.

The broad principles remain wide ranging to encompass its scope of influence, countering the attraction to provide a framework of engagement; it can never fit within the current flawed system of Western epistemology (Pihama, 2017). The links between theory and research are reciprocally interconnected. Theory grounds and guides the research by providing justification and premise, whereas research is the tool, action, and method in which researchers conduct themselves (Mataira, 2003).

Kaupapa Māori research has the ability to reclaim Te Ao Māori (the Māori world) and support Māori individuals and communities, including both those who are researched and those who are researchers (Edwards, McManus, & McCreanor, 2005). As a Māori researcher, it is important to go beyond the recognition of colonisation to acknowledge its continuation by actively working towards decolonising research practices, approaches, and methods critical to kaupapa Māori (Pihama, Cram, & Walker, 2002a; Smith, 1999a). Once a decolonising space is created, it enables opportunities for social and systemic change, where Māori can strive towards tino rangatiratanga and mana motuhake (autonomy) (Cram & Lenihan, 2000; Walker, 1996).

Walker, Eketone, & Gibbs (2006) describe kaupapa Māori fundamentally as a philosophy, then a research strategy that can produce reliable and valid data when applied correctly. Like any other research, kaupapa Māori research can be poorly conducted, and much depends on the researcher (Walker et al., 2006). However, kaupapa Māori research may accord equitable weight to acceptance by the Māori community and the academic community (Walker et al., 2006). Likewise, researcher control tends to be less important in kaupapa Māori research as it may entail greater negotiation over the guardianship of research data with the community involved (Walker et al., 2006).

Walker et al. (2006) acknowledged that kaupapa Māori research can be viewed as having a narrow focus that may not benefit all Māori. However, they argue that "kaupapa Māori research has shown itself as a radical, emancipatory, empowerment-oriented strategy and collaborative-based process, and when it is used systematically it can produce excellent research which can lead to improved policy, practice, and individual outcomes for Māori people” (p. 343).

Evaluation

Western practices of evaluation focus on the systematic determination of the quality, value, or significance of something (Social Policy Research and Evaluation Unit [Superu], 2017). Evaluation theory is built on a dual foundation of accountability and systematic enquiry. The need and desire for accountability presents a need for evaluation. The importance of accounting for actions or resources used in the conduct of programmes or interventions is a vital component of the functioning of any government or private organisation. Accountability is not a limiting activity, rather, it is designed to improve and better programmes, organisations, and – in turn – society. The social inquiry basis originates from a concern for employing a systematic and justifiable set of methods for determining accountability (Scriven, 2003). While accountability provides the rationale, it is primarily from a social inquiry basis that evaluation models have been derived (Christie & Alkin, 2008). Theory has moved the programme evaluation field from perceiving its function in terms of assessment in a top-down managerial approach (Tyler, 1942) towards approaches that seek to affect policy and practice for the betterment of people and communities (House & Howe, 2001; Scriven, 2003).

Scriven (2001) describes the breadth and range of evaluation as something that is both simpler and more complex than their individual summaries. Evaluation is simpler at a meta-level – community-level awareness but complex in action as it involves “a pervasive multi-function, multi role, multi-player enterprise" (Scriven, 2001, p. 28). However, this description does not capture the complex and diverse nature of culture and politics in evaluation. The epistemologies of people involved in evaluations often differ because of their political and cultural contexts, lived experiences, histories, and knowledge. Patton (1990) described evaluation as a political activity; whether it is acknowledged or made invisible, it is a process of judgement, examination, and assessment, presenting a version/dimension of a varied reality or truths.

Evaluation theory is predominantly prescriptive, offering approaches, models, and frameworks for determining what is regarded as good and effective evaluation practice. According to Alkin and Christie (2008, 2009), evaluation theory can be divided into three areas: (a) use of the evaluation effort – concern for how the information will be used and focuses on who will use the information (for example, Patton, 1990); (b) values the evaluation is based on – the process of evaluators placing value on data (for example, Tyler, 1942); and (c) methods used in an evaluation – process of generalising knowledge and findings (for example, Scriven, 2003). They explain further that these three types are based on a tradition of social inquiry and the motivation for accountability and control (Christie & Alkin, 2008). In practice, evaluation can be recognised as being goals based or goals free. Goals based means any type of evaluation that focuses on the knowledge of and reference to aims and objectives of a programme/approach/intervention (Scriven, 2001). Goals-free evaluation avoids learning the stated aims and objectives, instead observing and measuring actual impacts (planned or unplanned) (Alkin, 2009). This research utilises both approaches by being goals based and assessing the effectiveness of an intervention and by being goals free, broadening the scope to encompass wider learnings of the contextualised space in which the intervention was conducted.

Kaupapa Māori Evaluation

Kaupapa Māori evaluation is grounded in kaupapa Māori research and theory (Cram & Lenihan, 2000; Kerr, 2012a; Moewaka Barnes, 2009). Theory is an integral part of the evaluative discipline as it can illustrate the lens in which it is viewed, its purpose, criteria, and boundaries (Kerr, 2012a; Scriven, 2003). Arising out of kaupapa Māori theory came the kaupapa Māori research paradigm, which utilises a wide range of research methods, including evaluation (Pihama et al., 2002a). Kaupapa Māori evaluation can be described as seeking, exposing, and highlighting the practised and lived realities of Māori (Pihama, Cram, & Walker, 2002b) using Māori forms of enquiry and accountability measures and criteria. This understanding and knowing is then refined and developed through a collective and collaborative process (Cram & Lenihan, 2000; Jackson, 2000).

Kaupapa Māori evaluation practitioners describe processes of exploration, innovation, and explanation (Cram & Lenihan, 2000; Kawakami, Aton, Cram, Lai, & Porima, 2007), pursuing information and knowledge formed through the lens of Te Ao Māori (Kerr, 2012b). As a reflective and analytical process, kaupapa Māori evaluation is about determining the merit, worth, and value of something against a collective good, for instance how a programme may align with the goal of tino rangatiratanga (Kerr, 2012b). Reflection may highlight strengths and the potential for change and assist in the development of pathways forward. This can be done by making assessments and judgements within a kaupapa Māori evaluative framework (Masters-Awatere, 2015).

Kaupapa Māori evaluation can provide evidence needed to assist an organisation, programme, project, or initiative to assess set aims and objectives, determine the degree of achievement or value, provide feedback, gain insight into prior or existing initiatives, allow for reflection, and determine the next steps to take (Cram & Lenihan, 2000). Kaupapa Māori evaluation often involves an on-going relationship, depending on the level of collaboration and partnership between the stakeholders and the evaluator (Cram & Lenihan, 2000).

The interpretation and practice of kaupapa Māori varies across disciplines and contexts, and its methodologies are fundamentally complex, subjective, and evolving (Bevan-Brown, 1998; Levy, 2007; Smith, 2012; Te Awekotuku, 1991; Walker, 1996). Moreover, stakeholders, participants, and researchers are all explicitly located within whānau, hapū, and iwi realities (Walker, 1996).

Collaboration is considered an important and vital element of kaupapa Māori evaluation because it is founded on tino rangatiratanga and mana motuhake and more practically set within a complex contextual environment with varying interests and concerns (Joseph, Tahana, Kilgour, Mika, Rakena, & Jefferies, 2016). Within collaborative processes, it is important to consider each stakeholder group’s ecological, social, political, and historical context; this may include recognition that Māori and iwi organisations often evolve from a response to a need in the community.

A recent development in the field of kaupapa Māori evaluation is Masters-Awatere’s (2015) conceptualisation of culturally confluent evaluation. Culturally confluent evaluation involves bringing Indigenous epistemology, ontology, and methodology together with generic evaluative approaches to form a new pathway that is reflective and transparent. Cultural confluence is about being honest about the complexity of history, the subsequent messiness of evaluation and celebrating the strengths of both so that convergence can occur (Masters-Awatere, 2015). As a concept, it captured my visions for my research and aligned with many of my experiences. The concept of cultural confluence is a way of opening engagement channels between two paradigms that seek to inform transformative and inclusive changes in our communities, our organisations, and our health system.

When reviewing the literature on kaupapa Māori theory in evaluation, I chose to focus on scholars who were instrumental in the development of kaupapa Māori theory and/or used kaupapa Māori praxis in their research. Scholars included Graham Smith (1997), Linda Tuhiwai Smith (1999b), Moewaka Barnes (2000b), Pihama (2001), Walker (1996), Irwin (1994), and Bishop (1996). Key principles discussed in relation to kaupapa Māori praxis in evaluation included Te Ao Māori, tino rangatiratanga, taonga tuku iho (heritage), whānau, and kaupapa (movement). In the following sections, I provide an overview of each of these.

Te Ao Māori

Although the definitions and descriptions of Māori knowledge vary, it is generally, in a variety of ways, grounded in Māori world views, cosmology, philosophies, language, and culture, all of which are valid in their own right (Marsden, 1992; Mead, 2003). Henry and Pene (2001) considered that Māori philosophical beliefs and social practices were founded on whanaungatanga – the collective; kotahitanga – interdependence; wairuatanga – a sacred relationship to the gods and the cosmos; and kaitiakitanga –

acknowledgment of the people as caretakers of the environment for future generations. Pihama (2001) emphasised that kaupapa Māori could not be understood without comprehending mātauranga Māori (Māori knowledge) and the ways in which Māori engage knowledge and ways of knowing. In kaupapa Māori evaluation, all the proceeding principles – tino rangatiratanga, tikanga (customary system), whānau, and kaupapa – are grounded in Te Ao Māori and derive and evolve and are sustained within this world.

Tino Rangatiratanga

Kaupapa Māori is explicitly located within the wider context of Māori self-determination and autonomy over cultural wellbeing (Bishop & Glynn, 2003; Smith, 1999b). In evaluation, tino rangatiratanga focuses on the revival of space for Māori within the research paradigm via shared control and participation (Smith, 1999a). Kerr (2012b) outlined in her research framework that this may include control of the evaluation theory, research aims, design, process, and dissemination. The level to which this is interpreted and practised is a contentious topic nationally and internationally (Bishop, 1996; Cram & Lenihan, 2000; Cram, McCreanor, Smith, Nairn, & Johnstone, 2006). Kaupapa Māori theorists call for a high degree of Māori control in evaluation premised on Māori rights as partners with the Crown under the Te Tiriti o Waitangi (The Treaty of Waitangi) (Cram, 2009; Cram et al., 2006; Pihama et al., 2002a). The principle of Māori control or ownership, when applied to evaluation, is somewhat complicated within the context of being accountable to external funders and government organisations. It is vital that the development of initiatives and their evaluation, from the very inception, includes processes that ensure that accountability measures align with the kaupapa of those involved at whānau, hapū, and iwi levels (Kerr, 2012b).

Taonga Tuku Iho

The cultural aspirations principle acknowledges the strong emotional and spiritual factor in kaupapa Māori, which is introduced to support the commitment of tino rangatiratanga (Pihama, 2001; Smith, 1997). Māori control over the research agenda ensures Māori cultural norms will be embedded in the research, legitimising and validating kaupapa Māori as the research ethic and practice. Most kaupapa Māori theorists recognise and refer to cultural aspirations in their work. Linda Tuhiwai Smith (1999a) referred to “taonga tuku iho” in terms of supporting the commitment of Māori through te reo Māori (the Māori language), mātauranga Māori, tikanga Māori (Māori customs) and āhuatanga Māori (Māori tradition). Walker (1996) referred to “living in our own world,” asserting the position of Māori as valid and legitimate. Irwin (1994) stated that kaupapa Māori research needs to be culturally relevant and appropriate, and Moewaka Barnes (2000b) defined cultural aspirations as a “normative” process.

Whānau

Whānau can be described as the fundamental kinship arrangement that supports a common cause intrinsically related to but not limited to whakapapa (ancestral links) (Durie, 1994b; Walker, 1996). Kaupapa Māori theorists refer to the fundamental importance of the relationship of the whānau, identifying the need to be unified around collective responsibility and shared vision (Kerr, 2011). Within kaupapa Māori evaluation, whānau can be interpreted as a principle that strengthens the commitments whānau members have towards each other while also providing structure within social hierarchy (Hirini, 1998). The functional basis of whānau within evaluation is a way of organising a research group, incorporating ethical procedures, “giving voice” to the different aspects of the Māori community, and debating ideas and issues that have an impact of the research project (Smith, 1999a). Practitioners need to prioritise the development and maintenance of appropriate relationships. Relationships may include kaumātua (cultural elder) or community leaders being invited to be a part of the process and having kanohi ki te kanohi (face-to-face) meetings as well as appointing cultural supervisors or a whānau support group. Linda Tuhiwai Smith (1999a) stressed that these relationships are paramount to the success of research projects and detailed research and evaluation protocols that are important in governing relationships; these include respect, listening, and being hospitable, cautious, and humble. Moewaka Barnes (2009) and Kerr (2012b) stated that kaupapa Māori evaluations that prioritise collaborative relationships with negotiated and shared goals will facilitate the best outcomes for Māori. Kerr (2012b) also acknowledged that, in some circumstances, these may include national and international relationships for the development and sharing of new knowledge that will benefit Māori.

Kaupapa

Graham Smith (1997) presented the principle of kaupapa in his early research as a theory of change. Smith stated that this theory emerged out of the Māori community itself and is generalised under the label of kaupapa Māori. The theory of change provides a basis for transformative praxis to be utilised. Kaupapa Māori theorists call for “Māori to develop initiatives for change that are located within distinctly Māori frameworks” (Pihama, 2001, p. 139). Kaupapa is about bringing together action and reflection, theory and practice, utilising a participatory and democratic process, in pursuit of transformative solutions to issues of oppression and every structure that maintains oppression. It focuses on participation and change, using a range of methods depending on the issues and the context, in a cyclical process where each revolution consists of planning action, implementing change, and evaluating the results (Cram, 2012; Moewaka Barnes, 2000b). The action research process can provide a working framework to be developed where future problems and directions can be managed. In evaluation, not only would kaupapa aim to assist Māori transformation but evaluators would also be fully cognisant to the value of koha (reciprocity) (Moewaka Barnes, 2009). Kerr (2012b) identified that, within evaluation, koha can exercised in variable ways; however, more often it leads to capability and capacity-building outcomes. Evaluation in kaupapa Māori praxis often leads to whakapapa-based relationships or recognition of whakapapa connection before the evaluation process, which not only adds to the credibility and accountability of the evaluation, but also are more likely to endure after the official evaluation process period (Kerr, 2012b). The process of reciprocity can also invite continuing practitioners contributions to a Māori group or community well beyond the end of the evaluation (Aotearoa New Zealand Evaluation Association [ANZEA] & Social Policy Evaluation and Research Committee, 2008).

Health Literacy

The concept of health literacy emerged from the health education and nursing research literature written in the 1970s in the USA. Key papers included Stanton (1979), Waltzkin and Stoeckle (1972), Villiers (1983), and Bucklin Mohammed (1964). Initially, the literature placed responsibility for health literacy on patients. In 1985, interest in health literacy began to grow with the publication of the book *Teaching Patients with Low Literacy Skills* (Doak, Doak, & Root, 1985). During the 1990s, health literacy became an important determinant of health following the release of the results of the International Adult Literacy Survey (IALS) (Darcovich et al., 1997). The report uncovered widespread difficulties with literacy skills relevant to healthcare, specifically reading and writing

(Kirsch, Jungeblut, Jenkins, & Kolstat, 2002; Mancuso, 2009). Ten years later, the international Adult Literacy and Life Skills Survey (ALLS) was conducted, which included a specific health literacy domain. According to the ALLS, 57% of Australians, 55% of Canadians, and 60% of New Zealanders had low health literacy skills (ABC Canada Literacy Foundation, 2005; Australian Bureau of Statistics, 2008). Subsequent research established health literacy, at both individual and population levels, as a key determinant of health status, health outcomes, and compliance with treatment (Gazmararian et al., 2006; Nutbeam, 2008; Parker, 2000).

Being able to make informed and appropriate health decisions is an important part of managing CVD patients' ever-changing health situations. In Aotearoa, health literacy has been defined as "the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions" (Ministry of Health, 2010). Health literacy is not only about increasing patient knowledge around their healthcare; it is about enabling patients to navigate and interact within the health system. Health literacy includes the individual's expectations about health and wellbeing, the patient's sense of entitlement to good healthcare and healthcare providers, their understanding of health promotion and medications, and their ability to fill out medical forms and communicate with health practitioners (Kickbusch, Wait, & Maag, 2005). Perrin stated that,

> Health information alone will not be useful to people who do not feel they have the power to act. Other complementary strategies are needed, such as community development and participatory health education . . . The healthcare system also needs to acknowledge the lack of power which many people feel, and to explore ways in which it can assist people in taking more control over their lives and their health (Perrin, 1998, p. 28).

Key to the development of the concept of health literacy and the ways in which it is understood has been the contribution made by Nutbeam (2000, 2008, 2009), who distinguished between basic/functional health literacy – skills of reading and writing; communicative interactive health literacy – skills used to actively participate in everyday activities and apply new information to changing circumstances; and critical health literacy – critically analyse information and use it to gain greater control over circumstances and situations (Nutbeam, 2009).

A systematic review by Sørensen et al. (2012) provided an overview of existing health literacy definitions and conceptual models. Sørensen and colleagues developed a thorough empirical review on the dimensions of health literacy and proposed a model integrating medical and public health views. In summary, the dimensions of health literacy included skills and abilities (knowledge, competence, and motivation), actions (access, understand, appraise, and apply), objectives (promote, function, appropriate, empower, build capacity, build knowledge, build skill, reduce risk, make sound decisions, engage, and communicate), place/settings (healthcare, disease prevention, health promotion), time/life course (cognitive, psychosocial development, previous and current experiences), level/continuum (individual to population), determinants (personal, situational, social, environmental), and impact/outcomes (health service, cost, behaviour, outcomes, participation, and equity).

The integrated model of health literacy indicates that, as a concept and intervention, health literacy is preoccupied with understanding how it functions and interacts within a system rather than a critical analysis of the invisible values and principles it promotes. In relation to equipping health literacy to better serve the needs of Indigenous peoples living in colonised settings, more emphasis needs to be placed on what goals, visions, and outcomes are envisioned for health literacy and questions such as “whose agenda and value are we striving for?”

The *Kōrero Mārama Health Literacy and Māori 2006 Report* (Ministry of Health, 2010) indicated that 56.2% of adult New Zealanders have poor health literacy skills. This means a majority of New Zealanders are limited in their ability to obtain, process, and comprehend basic health information and services to make an informed and appropriate health decision (Ministry of Health, 2010). Māori have much lower health literacy skill levels than non-Māori, regardless of age, gender, education, work status, household income, and location. Specifically, 80% of Māori males and 75% of Māori females have poor health literacy skills. Māori who live in rural environments have, on average, the poorest health literacy skills, followed by Māori who live in urban environments (Ministry of Health, 2010). Māori aged between 16 and 24 years and between 50 and 65 years have the poorest health literacy relative to that of other New Zealanders. Māori also have the lowest health literacy levels across all labour force types, with Māori who are unemployed or looking for work being in the worst health literacy position (Ministry of Health, 2010).

A pharmaceutical literacy survey was conducted with Pākehā (non-Māori), Māori, and Tokelauan groups in Aotearoa (Norris, Simpson, Bird, & Kirifi, 2001). Each ethnic group was asked to define selected pharmaceutical terms. Overall, the level of understanding was low across all groups, with only 37.1% of responses coded as correct. On average, Pākehā were able to define more than five words, followed by Māori – with just over three correct words, and, lastly, Tokelauan – with fewer than two words. The low overall level of understanding and high level of incorrect definitions suggest that patients' poor comprehension means terms used in everyday medical settings are not being understood. However, suggested solutions were based on health practitioners using plain/clear language with patients rather than focusing on increasing patient knowledge and skills.

A systematic review (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011) explored whether low health literacy was directly related to poor health outcomes, including poor use of healthcare services, cost, and age factors. Results indicated a strong correlation between low health literacy levels and poor health outcomes in relation to increased use of emergency services and hospitalisations and low use of preventive services such as screening and immunisations. Low health literacy levels indicated patients with poorer skills in taking medications, less likelihood of identifying their medications and interpreting health messages, and poorer interpretation of medication labels. Evidence in relation to racial disparities and low health literacy levels was viewed as emerging, but this was not conclusive as studies measured different outcomes (Berkman et al., 2011). A recent systematic review by Mantwill, Monestel-Umaña, and Schulz (2015) stated that health literacy is an important intervening factor to consider when reducing health disparities; however, the exact nature of predictors remain unclear. An important finding of the review was that the literature was still dominated by the functional dimensions of health literacy, and more focus is needed on the systematic, critical, and interactive domains of health literacy (Mantwill et al., 2015).

Direct measures of reading word and word recognition, such as the Rapid Estimate of Adult Literacy in Medicine (REALM) (Baker, Williams, Parker, Gazmararian, & Nurss, 1999; T C Davis, Michielutte, Askov, Williams, & Weiss, 1998), as well as screening questions about reading ability (Chew, Bradley, & Boyko, 2004; Morris, MacLean, Chew, & Littenberg, 2006), were developed to assess literacy skills in health settings. Results from these measures indicated a correlation between a person's level of literacy and their health status. Patients with low scores on these tests were found to have poorer health outcomes linked to their health condition, low health knowledge, and higher rates of morbidity (DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004; Gazmararian, Williams, Peel, & Baker, 2003; Sudore et al., 2006). Research in this domain continues to develop and expand internationally (Sudore et al., 2006). However, critics have highlighted the limitations of these psychometric measures. The original focus on reading and writing is too narrow to capture the wide range of cognitive and social skills that individuals might need in order to navigate health services (Greenberg, 2001; Nutbeam, 2008).

Chinn (2011) identified that we are now in the "second wave" of health literacy research, with the field being influenced by sophisticated understandings of pedagogical theories relating to multiple schema, for example, a patient's knowledge of the world (contextual schema) and a patient's knowledge of how documents are organised (textual schema) (Workbase Education Trust, 2011). The realities of a disease system are changing from the one-way scripted discussion of doctors/nurses providing tools and mechanisms to patients who listen and follow instructions in order to return to health to the emancipation of both roles. The patient role has become more of a consumer/client and the medical doctor/nurse as an all-round social health operator. This change has meant that the second wave of health literacy development has had to recognise issues of equity, equality, and empowerment when dealing with the realities of the disease system (de Leeuw, 2012).

Studies by Catford (2011), de Leeuw (2011), and Sparks (2011) suggest we are on the brink of a “third wave” of health literacy development. Established notions of health literacy suggest that skills required to navigate the system are traditionally associated with patient advocacy and empowerment, but the third wave of health literacy literature suggests that health system literacy should be the responsibility of health services and the complex of policy, funding, and decision making that supports them. The third wave is defined as the skills and understanding required to access, comprehend, and interact with social and political determinants of health and their social discourse. This requires an appreciation of the political ecosystem in health promotion, which can include the political cultural agendas of the day. These findings are consistent with the World Health Organisation (WHO) report on Social Determinants of Health (CSDH, 2008), where health system literacy is an intrinsic part of the social fabric, enhancing our capacity to build and maintain supportive environments for health.

The health effects of having low health literacy levels are significant, as patients are less likely to have knowledge about their illness and their medications, are less able to self-manage their long-term illness, are less likely to use screening and prevention services, and are more likely to be hospitalized (Knight, 2007). Research indicates that increasing health literacy levels goes beyond individual capacities; it is intertwined with the health and educational systems and social and cultural factors.

In 2015, the Ministry of Health published *A Framework for Health Lite*racy (Ministry of Health, 2015b). This framework identifies the four groups involved in health literacy in Aotearoa; health system, health organisations, health workforce, and patients and whānau. The framework is based on the second category, where health literacy is defined as an interactive practice, and provides some ways that the four parties can create a paradigm shift from the first category to the second, enabling health literacy to be a critical focus at all levels of the health system (Ministry of Health, 2015b). In the framework, it is the role of the health system and health organisations to reduce the health literacy demands placed on patients and whānau and the role of health practitioners and patients and whānau to build health literacy.

Healthcare Experience

The health system derives from a particular scientific knowledge base that corresponds with the biomedical model of health and illness (Lyons & Chamberlain, 2006). Medical practitioners work in a number of fields and healthcare settings and have diverse roles, such as GPs, nurses, occupational therapists, midwives, and psychologists. For patients with chronic diseases, relationships with medical practitioners are an important and vital component of treatment outcomes (McCreanor & Nairn, 2002a, 2002b; Ministry of Health, 2010; Winefield, 1992). For this reason, it is important that the patient–health practitioners encounter is successful. Factors contributing to the success of the relationship include offering both biomedical and alternative options, finding treatment options that best match the social and cultural context of the person, the ability of the person to retain information, good communication, and the patient feeling satisfied that issues were addressed in accordance with their needs and expectations (McCreanor & Nairn, 2002a, 2002b; Ministry of Health, 2010).

According to the Waikato Medical Care Survey (WaiMedCa) (McAvoy, Davis, Raymont, & Gribben, 1994) , the National Primary Medical Care Survey (NatMedCa) (Crengle, Lay-Yee, Davis, & Pearson, 2005), and Jansen, Bacal & Buetow (2011), when comparing Māori and non-Māori experiences of general practice, Māori demonstrated differential usage of primary healthcare. Specifically, Māori presented with higher health needs; presented for treatment late; were less likely to be offered choices at their general practice, to be seen on time, or to be seen within their preferred time frame; and had shorter consultation times and lower referral rates than non-Māori. These studies indicated that Māori did not receive the same standard of care as other New Zealanders. Additionally, in the New Zealand Health Survey (Gerritsen, Stefanogiannis, & Galloway, 2008), 4.5% of Māori surveyed reported unfair treatment compared with 1.5% of non-Māori, and Māori were almost 10 times more likely to experience multiple types of discrimination than non-Māori (Harris et al., 2006a). The table below from the *Tatau Kahukura Māori Health 2015 Chart Book*, presents indicators that look at the use of health services, with a focus on primary healthcare providers.

Table 1
Unmet need for primary healthcare indicators for adults aged 15 and over

Indicator (self-reported)	**Māori**	**Non-Māori**	**Difference (%)**
Experienced one or more types of unmet need	38	27.4	139
Unable to get appointment at usual medical centre within 24 hours	20.7	16	129
Unmet need for GP services due to cost	22.4	15.1	148
Unmet need for GP services due to lack of transport	5.8	2.6	223
Unmet need for after-hours services due to cost (self-reported)	12.9	6.6	195
Unmet need for after-hours services due to lack of transport	2.7	1	270

Notes: Amended from Ministry of Health, 2015c, p.54. Figures are age-standardised to the total Māori population as recorded in the 2001 census.
GP = general practitioner.

Māori adults were more likely than non-Māori adults to experience one or more types of unmet need for primary healthcare in 2013/2014. Māori adults were 1.2 times more likely to report an unmet need in terms of getting an appointment at their usual medical centre within 24 hours than non-Māori adults. Māori adults were nearly more than one-and-a-half times more likely to experience an unmet need for GP services due to cost than non-Māori adults. Lack of transport was more than twice as likely to be a barrier to accessing GP services for Māori adults compared with non-Māori adults. Cost was almost twice as likely to be a barrier to accessing after-hours services for Māori adults than for non-Māori adults. Lack of transport was 2.7 times as likely to be a barrier to accessing after-hours services for Māori adults than for non-Māori adults.

Māori with Cardiovascular Disease

Significant health inequalities exist in Aotearoa for Māori (Gracey & King, 2009; King, Smith, & Gracey, 2009; Ministry of Health, 2012, 2017); Māori have significantly higher rates of "all-cause mortality" and are more likely to die before the age of 65 years than are non-Māori (King et al., 2009; Robson & Harris, 2007). Life expectancy has consistently increased in Aotearoa since the 1950s; however, there remains a 7.1-year gap between Māori and non-Māori (Ministry of Health, 2015c). Moreover, the amenable mortality rate, which measures premature deaths from causes the health system could have prevented, had been reducing between 2000 and 2013; however, disparities between ethnicities remain, with Māori having 2.7 times higher ratings than the non-Māori population (Ministry of Health, 2017).

Given the appalling rates of CVD among Māori, more needs to be done to address the prevalence of preventable and premature morbidity and mortality. Brown et al. (2010) summarised the urgency and need for collective action:

> . . . Every day spent waiting to find voice is another day that bears witness to preventable death. The price of our collective failure continues to be borne by the most vulnerable: the impoverished, the marginalised, the oppressed and those who have had their systems of control and authority undermined by colonisation and its intergenerational impacts (Brown, et al., 2010, p. 265).

The *Tatau Kahukura Māori Health 2015 Chart Book* reported that ischemic heart disease (IHD), a major cause of CVD deaths, was the leading cause of death for Māori males and the second cause of death for Māori females (Ministry of Health, 2015c).

Table 2
Disease rates for Māori compared with non-Māori

Disease	**Māori (per 100,000)**	**Non-Māori (per 100,000)**	**Difference (%)**
Total CVD mortality	286.8	132.4	217
CVD hospitalisations	3,186.4	1,938.6	164
Stroke mortality	48.2	30.9	156
Stroke hospitalisation	365.7	207.6	176
Heart failure mortality	5.2	2.2	236
Heart failure hospitalisations	547.5	136.4	400
Rheumatic heart disease mortality	5.4	1	540
Rheumatic heart disease hospitalisation	38.7	8	484
Ischemic heart disease mortality	154.6	72.1	214
Ischemic heart disease hospitalisations	872.7	667	131

Notes: Amended from Ministry of Health, 2015c, p 30. Figures are age-standardised to the total Māori population as recorded in the 2001 census.
CVD = cardiovascular.

Table 2 shows that the total CVD mortality for Māori was over two times higher than that for non-Māori. Māori were more than one-and-a-half times more likely to be hospitalised for CVD than non-Māori. Stroke mortality was one-and-a-half times higher, and the stroke hospitalisation rate was more than one-and-a-half times higher for Māori than for non-Māori. The heart failure mortality rate for Māori was more than twice as high as the rate for non-Māori. Māori were four times more likely to be hospitalised for heart failure than non-Māori. The rheumatic heart disease mortality rate for Māori was 5.4 times more than that for non-Māori, and Māori were 4.8 times more likely to be hospitalised for rheumatic heart disease than non-Māori. IHD accounts for over half of all CVD mortality. The IHD mortality rate for Māori was more than twice that of non-Māori, and Māori were 1.3 times as likely to be hospitalised for IHD than non-Māori.

Ngāti Porou Hauora regional population mortality statistics indicated that CVD and diabetes were the leading causes of death in 2007–2011 and were key contributors to potentially avoidable hospital admissions (Tan, 2016). Many cardiovascular deaths were premature and preventable and contributed to amenable mortality rates. Since 2008, CVD risk assessment rates have also been recorded in primary health organisations, including Ngāti Porou Hauora, to increase the offer of preventive support services. The 2015–2016 target rate for CVD risk assessment was set at 90% of eligible patients having their risk assessed and noted in patient records. As mentioned in a later section (Ngāti Porou Hauora p. 80), Ngāti Porou Hauora exceeded the rate and reached 93% and maintained a high level of performance, often outperforming Tairāwhiti (Gisborne region) and the rest of the nation (Tan, 2016).

Age-specific death rates from CVD have been declining in Aotearoa but remain significantly higher than corresponding rates in similar developed countries, such as Australia and Canada (Hay, 1999). Improving all CVD outcomes for Māori and removing inequalities between Māori and non-Māori is an important and urgent health priority

(Ministry of Health, 2017). Disparities in CVD health outcomes in Aotearoa continue to negatively affect the health of Māori individuals and their whānau.

In reviewing the literature, explanations of CVD health inequalities can be broadly placed into four categories; however, these categories overlap, and research is not limited to the presented categories. The categories are resource-dependent characteristics such as socio-economic status and asset ownership (Blakely, Tobias, Atkinson, Yeh, & Huang, 2007; Chan et al., 2008; Harper, Lynch, & Smith, 2011; Kaplan & Keil, 1993; Korda, Clements, & Kelman, 2009; Riddell & North, 2003); non-resource-dependent characteristics, including psychological, cultural, and racial factors (Anderson & Whyte, 2008; Blakely et al., 2007; Brown et al., 2010; Feinstein, 1993; Gracey & King, 2009; Harper et al., 2011; King et al., 2009); inequalities arising from different experiences over a “life span” such as diet, smoking, exercise, and body mass index (Davey-Smith, 2000; Feinstein, 1993; Harper et al., 2011; Mullins, Blatt, Gbarayor, Hui-Wen, & Baquet, 2005); and, finally, inequalities arising from differences in access to and utilisation of formal health services (Ellison-Loschmann & Pearce, 2006; Feinstein, 1993; Harper et al., 2011; Mullins et al., 2005; Riddell et al., 2008; Thornley et al., 2011).

The relationship between socio-economic position and the prevalence of CVD is strong and consistent (Brown et al., 2010). The principle measures of socio-economic status are education, occupation, and income, or combinations of these. During 40 years of research, there has been a consistent inverse correlation between CVD, primarily coronary heart disease, and many of the indicators of low socio-economic status. Evidence for this relation has been derived from prevalence, prospective, and retrospective cohort studies (Brown et al., 2010; Harper et al., 2011; Korda et al., 2009).

Research on socio-economic inequalities in CVD indicates there has been a decrease in cardiovascular mortality across all socio-economic groups; this decline has been greatest among those of higher socio-economic status (Brown et al., 2010; Harper et al., 2011; Korda et al., 2009). As a result, socio-economic inequalities in CVD have widened, with CVD increasingly associated with the poor and impoverished (Riddell & North, 2003).

In Aotearoa, Māori are disproportionately represented in lower socio-economic strata (Ministry of Health, 2017); this relatively poor socio-economic position of Māori means that being Māori is strongly related to explanations for socio-economic inequalities in CVD. While socio-economic position fundamentally determines Māori inequalities in CVD, this explanation is fragmented. Socio-economic explanations alone are inadequate, since they do not take into account the factors that lead to marginalisation of Māori and unequal distribution of socio-economic resources by ethnicity in the first place (Harris et al., 2006b).

While medical advances in the management of CVD have halved age-specific mortality rates over the past 30 years, age-standardised mortality rates for coronary heart disease have fallen at a slower pace for Māori than for non-Māori (Sharpe & Wilkins, 2004; Webster & Heeley, 2010). The increased prevalence of risk factors for CVD, such as obesity (Stamler, 1993), high blood pressure (Sorel, 1992), smoking (Borman, 1999), and diabetes (Stern, 1984), are all prevalent risk factors among the Māori population (Webster & Heeley, 2010). Psycho-social measures also act as mediators in the relationship between socio-economic position and CVD, including lack of social support (Bunker et al., 2003; Hemingway & Marmot, 1999), depression (Bunker et al., 2003; Hemingway & Marmot, 1999; Marmot & Wilkinson, 2006), and stress (Dowd, Simanek,

& Aiello, 2009; Marmot & Wilkinson, 2006). However, the interplay between the risk factors is complex; for example, smoking – the most influential modifiable risk behaviour – is more prevalent among those on lower incomes; however, Tobias and colleges suggest that the contribution smoking makes to ethnic disparities in mortality is probably less than 10% (Tobias, Blakely, Matheson, Rasanathan, & Atkinson, 2009). Socio-economic factors contribute an additional 32–39% (Tobias et al., 2009).

Access to medical care is also an important factor when considering the prevalence of CVD among Māori. Research reveals that poor access to and quality of healthcare services for those living in deprived circumstances may contribute to inequalities in health (Cormack, Robson, Purdie, Ratima, & Brown, 2005; Payne & Saul, 1997; Pell, 2000). In Aotearoa, factors related to patient and service interactions that contribute to poorer health outcomes for Māori CVD patients and their whānau include inadequate levels of prescribing effective therapies (Riddell, Jackson, Wells, Broad, & Bannink, 2007; Riddell et al., 2008), inadequate follow-up of individuals with known elevated risk (Riddell et al., 2007; Riddell & North, 2003), and a lack of quality communication between patients and healthcare practitioners (Jansen et al., 2011; McCreanor & Nairn, 2002a, 2002b).

Prevention and Management of Cardiovascular Disease

Internationally, CVD is the most prevalent cause of death and one of the most preventable causes of mortality (Miner-Williams, 2017). Healthy nutrition, exercise, smoking cessation, and effective medications are key strategies of primary and secondary prevention. Explicit evidenced-based CVD management guidelines (New Zealand Guidelines Group, 2009), health provider education (Abbott, Davison, & Moore, 2008), and computerised decision-support tools (Bannink, Wells, Broad, Riddell, & Jackson, 2006; Riddell et al., 2007; Wells et al., 2008) have been implemented to assist health practitioners and health services to provide high-quality CVD care (Crengle, 2009). However, literature on the effectiveness of these approaches within a culturally specific domain indicates that such approaches are not effective in creating positive health outcomes for Indigenous people. Brown et al. (2010) stated that any CVD initiatives that are devised must acknowledge and reflect the unique needs of Indigenous people, their families, and their communities.

Research on culturally targeted health interventions (De Jesus, 2010; McAuley et al., 2003; Moewaka Barnes, 2009; Simmons, Rush, & Crook, 2008) suggested the introduction of target-specific strategies that address racial and ethnic health inequalities increases the effectiveness of the intervention. Target-specific strategies may include Māori-specific intervention programmes that convey health information through a Māori lens. Literature on interventions that are developed for specific groups rather than assumed to be universally applicable in Aotearoa is limited. The research by McAuley et al. (2003) on the implementation of a successful lifestyle intervention to reduce the risk of type 2 diabetes mellitus and CVD identified that non-target-specific interventions have low Māori participation and ultimately are less effective for Māori than for non-Māori. Moewaka Barnes' (2000a) research found that alcohol interventions that are not tailored for Māori have low Māori participation rates and have less impact on Māori health outcomes than non-Māori health outcomes.

Although Māori are frequently identified as being most at risk and having the highest prevalence of CVD, few studies, initiatives, or projects have involved Māori solutions and community engagement and action. Many argue that effective delivery of and information on Māori healthcare should incorporate Māori health perspectives and to be delivered by Māori (Rada, 1997; Ropiha, 1993). Durie (1993a, 1994a, 2001) stated that successful pathways to Māori development need to be based on Māori social structures, Māori delivery systems, and Māori cultural health contexts.

The way in which health initiatives are developed is vital to their success and sustainability within the chosen Māori community (Cormack et al., 2005). Health initiatives have a high chance of succeeding if their inception, development, principles, adaption, ownership, and endorsement include active community participation, consultation, and approval and are moulded to the community context (Cormack et al., 2005; Cram, 2007). Other Māori-specific approaches can include integrating Māori expertise and advice, locating the initiative in Māori settings, incorporating te reo Māori, and – if appropriate – including Māori healing and the option of integrating Māori rongoā (medicines) (Cormack et al., 2005; Durie, 1994a). It is also vital that aims and objectives are realistically achievable within the contextual environment. Durie (1993b) and Kerr et al. (2010) argued that substantial gains for Māori need to be placed in perspective, as it may take decades for the effectiveness of long-term objectives and strategies to be demonstrated (Kerr, Penney, Moewaka Barnes, & McCreanor, 2010).

The management of CVD requires long-term care, in which the patient is required to perform the majority of their healthcare management, including taking daily medication, monitoring and recording health information, and making and attending appointments (Ministry of Health, 2010). To navigate the health system, manage medications, and be effective self-managers of chronic diseases, patients and their whānau need a complex array of skills, knowledge, and psycho-social factors (Dyck, Kontos, Angus, & McKeever, 2005; Field, Ziebland, McPherson, & Lehman, 2006; Gordon, Smith, & Dhillon, 2007; M. Reid, Clark, Murdoch, Morrison, Capewell, & McMurray, 2006; Sorensen, Stokes, Purdie, Woodward, & Roberts, 2006). Knowledge about CVD risk factors and medications is essential to self-management. Literature on patient knowledge and understanding of medications and their use is limited, as the majority of research explores CVD risk factors (Choinière, Lafontaine, & Edwards, 2000; Frijling et al., 2004; New Zealand Guidelines Group, 2003, 2009) and understanding of CVD risk assessment (Homko et al., 2008; Mooney & Franks, 2009; Wagner, Lacey, Abbott, de Groot, & Chyun, 2006). Literature in this area states that risk factors and assessment processes should specifically target population groups that have a high burden of CVD to ensure the benefits of risk screening and subsequent management.

While literature on CVD risk factor prevalence among Māori (Arlidge, 2004; Ellison-Loschmann & Pearce, 2006; Harwood, 2010; McAuley et al., 2003; Ministry of Health, 2010; Sharpe & Wilkins, 2004) states that CVD risk factor prevalence, including smoking, obesity, and low socio-economic status, among Māori is high, no literature has been located on medication knowledge in Indigenous communities. My master's study focused on medication use and understanding in Māori households with chronic illnesses (Carlson, 2010). Since the completion of my master's thesis, I have been involved in the publication of several journal articles on the socialisation and understanding of medications in Māori households. Articles include Nikora, Hodgetts, Carlson, and Rua (2011), which explored meanings given to medications in four Māori households; Hodgetts, Nikora, Rua, & Carlson (2011), which explored Māori people's access to medications, specifically how Māori men obtain medications; Hodgetts, Chamberlain, et al. (2011), which explored the spatial, material, and relational practices involved in the everyday use of medications in domestic settings; and Nikora, Hodgetts, Carlson, Tongi, and Li (2010), which explored how interactions between household members affect medicine-taking practices of elders and their families from three cultural groups: Māori, Tongan, and Chinese. Findings demonstrated how medication knowledge and understanding is embedded in the patients' social, cultural, and environmental contexts in which medications are obtained, used, and understood (Hodgetts, Chamberlain, et al., 2011; Nikora et al., 2011). Medications were more than curative potions; they became implicated in experiences of illness, self, relationships, home, and care (Hodgetts, Nikora, et al., 2011). In the study of Māori households (Nikora, et al., 2011), the context of medication use and understanding was understood within cultural practices that incorporated five key themes: tapu and noa: cultural hygienic practices; ngā purere whakamaharahara: memory strategies; manaakitanga: paying heed to the dignity of others; poharatanga: influences of poverty; and rangatiratanga: self-agency (Carlson, 2010; Hodgetts, 2011).

The use and understanding of medications in Māori households is determined by a series of processes associated with culture and the socialisation of medications influencing how medications are obtained, administered, routinised, stored, and embedded in filial relationships. Findings from Carlson (2010), Hodgetts, Chamberlain, et al., (2011), Hodgetts, Nikora, et al., (2011), and Nikora et al. (2011) indicate that the management of chronic illnesses and medications are significantly influenced by the relational practices that surround the medications; these include relationships with the patient's GP, pharmacist, whānau, and the community. Therefore, Māori healthcare needs to consider Māori-specific social and cultural practices in the "health journey" of Māori patients (Carlson, 2010; Hodgetts, Chamberlain et al., 2011; Hodgetts, Nikora et al., 2011; Nikora, 2011).

Medication Use

Medications are one of the most widely used medical technologies, both for treating illness and for sustaining health. They also carry a significant cost to the healthcare system. New Zealand’s Pharmaceutical Management Agency, PHARMAC, reports the community drug bill for the year June 2015–June 2016 at $NZ800 million (Pharmaceutical Management Agency, 2016). The range of PHARMAC subsidies on medications is widening every year, with 44.4 million funded prescription items filled increased (3%), with 15 new medicines funded since the 2014–2015 report (Pharmaceutical Management Agency, 2016).

Overall use of heart disease treatments continues to rise, although the cost is falling. This is due to generic competition leading to continued price reductions for the most-used heart drugs. Statins continue to be very widely prescribed – with 1.2 million atorvastatin prescriptions (fifth-most prescribed medicine) and 650,000 simvastatin prescriptions (Pharmaceutical Management Agency, 2016). Within the top 20 expenditure groups for medications, three were specifically allocated for CVD medications; these are presented in Table 3.

Table 3
PHARMAC expenditure on cardiovascular disease medication

CVD medication	**Total cost ($NZ, millions)**
Lipid-modifying agents used for raised cholesterol levels (CV risk)	17.49
Agents affecting the renin–angiotensin system used for raised BP (CVD risk)	14.70
Beta-adrenoceptor blockers used to treat heart disease and high BP	14.70
Total cost	**46.89**

Note: Amended from the Pharmaceutical Management Agency, 2016, p. 2.
BP = blood pressure; CV = cardiovascular; CVD = cardiovascular disease.

As Table 3 illustrates, PHARMAC dedicated at least $NZ46.89 million for subsidies on CVD-associated medications, 6% of the total PHARMAC budget. With a proportion of funding being dedicated to CVD medications, more research into understanding patient behaviours and use of prescribed medications is needed.

Considerable research has been devoted to medicines in medicalised contexts considering, for example, issues such as adverse drug reactions, side effects, and compliance (Barter & Cormack, 1996; Campbell, McCosh, & Reinken, 1983; Carrick, Mitchell, Powell, & Lloyd, 2004; Conrad, 1985; Ingersoll & Cohen, 2008). Despite studies showing that medicines are not taken as intended (Schoen, Downey, & Osborn, 2003), we know little about what people know about their medications, where they get their information from, and how knowledge affects the use of medications. It is vital that research supports the foundations of Māori cultural contexts to collate and investigate the findings in the context of Māori lived practices, covering not only cultural frameworks but also everyday lived cultural practices and what these look like (Durie, 2004).

Limited work has focused specifically on knowledge and use of medications. Research by Dowell and Hudson (1997) and the New Zealand National Advisory Committee on Health and Disability (2007) revealed the range of understandings and practices people have in relation to medication, such as a varied knowledge base around the role of medication in people's treatment regimens, discontinuing medication when they felt well, stockpiling medication for future use, or sharing medications with others who have similar conditions or symptoms.

Although more than 200 variables have been studied in relation to medication use, none could be considered consistently predictive of compliance behaviours (Vermeire, Hearnshaw, Van Royen, & Denekens, 2001). Rather than being a static or fixed phenomenon, compliance is better considered as a fluctuating choice that is rationalised in the context of everyday life (Chia, Schlenk, & Dunbar-Jacob, 2006; Vermeire et al., 2001; Wilson, Hutchinson, & Holzemer, 2002). Compliance in relation to prescribed medications is an ever-present and complex problem. This is particularly concerning for those with CVD, as they may have multiple symptoms, take high dosages of medication, face long-term treatment, and take multiple medications (Wilson et al., 2002).

Aotearoa research by Thornley and colleagues (2011) found that four of ten patients were not taking statin medication regularly one year after having an acute coronary event. Explanations for low dispensing rates of medications included physician prescribing and misclassified diagnosis. No Indigenous-specific data on compliance with CVD medications have been located, although Indigenous peoples are commonly described as "less compliant" than non-Indigenous (Crengle, 2009). McCreanor and colleagues (2002a) discussed this notion of being less compliant through research with

Tauiwi (non-Māori) GPs. Through the process of critical discursive analysis, Tauiwi GP bias was brought to the forefront, identifying a shared understanding that Māori patients' non-compliance was related to their behaviour and culture, "with the caveat that without compliance doctors cannot be held accountable for outcomes" (McCreanor, 2002a, p. 5). These accounts are cause for grave concern and have serious implications for Māori health outcomes. As Penney, Moewaka Barnes, & McCreanor (2011) demonstrated, these notions of non-compliance may be in direct contradiction with Māori lived realities.

The qualitative study by Penney et al. (2011) on Māori medical compliance investigated the treatment journey of Māori with IHD. The research explored clinicians' and patients' accounts of their interactions with each other and investigated issues of compliance. The views of both groups differed; clinicians generally described Māori patients as non-compliant in relation to their health, whereas Māori patients had contrasting views. Clinician explanations for non-compliance ranged from Māori patients having financial restraints and being self-destructive and ignorant to patients being wilful and ignorant. In contrast, accounts from Māori patients indicated they were willing, attentive, and proactive patients (Penney et al., 2011). Findings indicated that the cultural competence levels of clinicians need to increase, reducing barriers to care experienced by Māori. Therefore, it is imperative that the social and cultural context of medication users and their carers should be central to clinical engagement (Vermeire et al., 2001).

Ngāti Porou

The people of Ngāti Porou are descendants of Māui-Tikitiki-a-Taranga (eponymous ancestor). When he fished up Te Ika-a-Māui (The North Island), two rocks appeared; he named these two rocks Hikurangi and Aorangi after two maunga (mountains) that stood in his homeland of Hawaikii. It was Hikurangi that raised his waka (canoe), Nukutaimemeha, out of the water, and it rests on Hikurangi to this day.

Today, the tribal structure of Ngāti Porou consists of approximately 58 hapū and 50 marae (meeting grounds), with a total membership of 72,000 people (Statistics New Zealand, 2013). Within Ngāti Porou boundaries, which span from Toka-a-Taiau to Pōtikirua, the participants in this research were from the area north of the Waiapu awa (river). Their whakapapa links them to Ngāti Porou ki Pōtikirua ki Whangaikena, Whangaikena ki Waiapu, Pohautea ki Te Onepoto, and Te Onepoto ki Rahuimanuka (regions/areas of Ngāti Porou). The area is known as Rangitukia, which means to break through to heaven; this is the acknowledgement of the terrestrial space. When you journey up the awa to Tikitiki, this area is known as Tikitiki-o-rangi, another form of heaven. You can then make your way onto Hikurangi, the most prominent maunga on the coast; this is known as the celestial heaven. The names of these places are an acknowledgement and appreciation of the creator for giving us these lands; this is mana whenua (power from the land).

Figure 1: Ngāti Porou tribal area

Descriptions of settlement life in the 1800s and early 1900s in the Rangitukia and Matakaoa regions portray lands thick in vegetation and divided by natural formations – awa and maunga (Mahuika, 2010). According to Soutar (2011, p. 1), the tribal area is about 400,000 hectares. “The land back then was anybody’s and everybody’s. There weren’t any exclusive boundaries between the families . . . there was a tremendous community spirit” (Karaka, 2000, p. 3). Communities were small, and everyone had a role and work to do; every decision and action was for purpose, for survival. Hapū existed as “amorphous” entities without set boundaries or size (Rangiheuea, 2010). Each hapū carried tūpuna (ancestral) names, and most were associated with a marae, as they are today.

The ngahere (bush), moana (sea), awa, pūkaki (streams), and wairepo (swamps) were places of resource, sustenance, and rongoā. Whānau knew what could be consumed, what was poison, and what healed. Whānau knew the lands well; they walked them every day to hunt for kai (food) and gather supplies. Knowledge and everyday living was guided by tikanga (customary system), founded by an understanding of the totality of the environment. The health and wellbeing of the people was based on common sense and an intimate connection with the environment. The Waiapu awa was (and is) the source of life, and the health and wellbeing of the awa was (and is) intimately connected to the people, providing kai and spiritual sustenance. When the awa flooded, it was a sign that tapu (sacred state/condition) had been breached, a violation of sacredness, and atua (gods) were offended (Karaka, 2000). When the waters were clear and flowing, life was in balance. The wellbeing of the people was based on a value system that was shared by all.

Ngāti Porou Health Services

In the nineteenth century, the Crown began funding some health services for Māori. However, these services were founded in Western bio-medical sciences, which marginalised Ngāti Porou knowledge and practice and were ineffective against many diseases; the people continued to rely on traditional practices (Mahuika, 2010). Ngāti Porou suffered significantly compared with Pākehā from diseases of poverty such as tuberculosis (TB) and typhoid (Mahuika, 2010). At this time, a new generation of leaders, the Young Māori Party, was formed. Āpirana Ngata was a key figure in the party, the first Māori to gain a degree from a New Zealand university. Ngata strived for bicultural relationships with the Western government that were based on reciprocity; combining

Māori ethics with Pākehā notions of equality and justice (Walker, 2006). Ngata was a visionary of his time, dedicating his life to protecting and developing Māori land, supporting and advancing Māori farming, arts, language, education, and tribal government, and preserving Māori culture. Ngata worked tirelessly through traditional tribal structures, traveling the motu (country) on horseback from hui to hui bringing new messages of education, ventilation in marae, and health and hygiene measures (Walker, 2006). In 1885, the government established the Cook and Waiapu hospital boards to manage the provision of hospital services in the East Coast region. In 1900, Māori of the region were suffering from many sicknesses and diseases. Typhoid and TB hit Māori in epidemic proportions. TB huts became a common sight in communities, as there was little government help and many people turned to tohunga (ritual expert) for help. "It is an utter disgrace what has happened to our people. Tauiwi brought in diseases that killed off whole families, like typhoid, TB, and influenza" (Tangaere, 1999, p. 30). In 1907, Te Puia Springs hospital was opened to provide healthcare for most of the region, and – in 1929 – a six-bed hospital was opened in Te Araroa (Te Runanganui o Ngāti Porou, 2017). Around this time, there was a push from the government to undermine and eventually outlaw the customary medical practices of tohunga (Tangaere, 1999). The detraction was made official when the Crown passed the Tohunga Suppression Act in 1907.

In 1910, the first nurse to be based on the East Coast was Nurse Banks. She was named Nehi Kataraoera, "Nurse castor oil," after her tendency to provide all her patients, willing or not, with castor oil (Mahuika, 2010). In 1912, the Crown sponsored Horouta and Takitimu Māori Councils to oversee the development and running of primary healthcare programs on the East Coast. The Councils were the authorised vehicle for regulating public health issues such as sanitation. However, insufficient funding meant the two councils were unable to provide an effective service to the public and ceased operation by 1945. The influenza pandemic struck Aotearoa in 1918, killing over 8,000 people, 2,000 of whom were Māori, in two months. Māori suffered greatly, with fatalities over seven times that of Pākehā (Lange, 1999). In 1935, medical officer Harold Turbott conducted a survey of the Waiapu Valley. He found that Māori in the area had six times the influenza rate and ten times the TB rate of Pākehā (Te Runanganui o Ngāti Porou, 2017). Up until the 1970s, there was very limited Ngāti Porou representation on the boards. In 1988, the Director General of Health characterised the government health policies and the development and implementation of national health services as mono-cultural (Mahuika, 2010).

Since the 1920s, research has highlighted that ethnic disparities between Māori (including Ngāti Porou) and Tauiwi have been the most consistent and compelling inequities in health (Robson & Harris, 2007). Perhaps unsurprisingly, Ngāti Porou has been a site of much research and policy innovation over the years, yet only scant attempts have been made to understand the impacts and outcomes from these efforts.

Ngāti Porou Hauora

Ngāti Porou Hauora was recognised by District Health Boards (DHB) New Zealand as a leader in community health services (District Health Boards New Zealand, 2009). Whānau and hapū of Ngāti Porou established Ngāti Porou Hauora in 1994 in response to health challenges and barriers faced by people in the region. Key drivers for the formation were poor health outcomes, limited access to health services, a determination to retain rural health services, a need to build a local Māori workforce, and a strong wish to develop innovative and locally relevant services. One of the organisation’s aims was to deliver health in a holistic manner and consistent with the vision and values of Ngāti Porou that reflected Ngāti Poroutanga (Ngāti Porou culture) (Te Runanganui o Ngāti Porou, 2012). In 1999, the health facilities and assets of the area health board were transferred to Ngāti Porou Hauora. In 2002, the organisation became a primary health organisation, which – fortunately – required little structural change as the Primary Health Care Strategy supported the key drivers of Ngāti Porou Hauora (District Health Boards New Zealand, 2009). The organisation has built a strong health contract base over the past 23 years, with six community healthcare clinics and one rural hospital. To date, Ngāti Porou Hauora holds special area doctor status, which means services are free of charge to all community members, and offers a subsidised fee at their two Tairāwhiti-based clinics.

The population served by Ngāti Porou Hauora is predominantly rural Māori, regarded as the most socio-economically deprived in Aotearoa, ranked at NZ deprivation decile 9 and 10. According to Statistics New Zealand Census (2013), Māori made up 70% of the population in Ngāti Porou. Ngāti Porou Hauora has the highest proportion of enrolled Māori patients (88%) of all primary health organisations’ enrolments (15%) in Aotearoa.

The region is made up of coastal and inland regions, with coastal residents living in highly rural areas. Ninety percent of the population live in deprived areas, compared with just over 50% for Tairāwhiti DHB region and 20% for Aotearoa. On average, households in the region earn less ($38,700 – equalized household income, census 2013) than the average income level of Aotearoa ($57,800). The Ngāti Porou region has the highest overall mortality[2] rate in Aotearoa (66% over the national rate and 17% above the Tairāwhiti rate). The Māori mortality rate is 12% above the national rate. The avoidable death rate[3] in the region is disturbing: it is the highest rate in the country, at 107%, and is 10% higher than the Tairāwhiti rate. For Māori in the region, the avoidable death rate is 34% higher than the national rate. The premature mortality rate[4] is even more disturbing, at 129% higher than the rest of Aotearoa and 48% higher than Tairāwhiti. The rate for Māori was 15% higher than that for Tairāwhiti and 37% higher than the national rates. These statistics show that Ngāti Porou is the highest need area in Aotearoa with the worst "perpetuating" exacerbated inequities (Te Kani, 2016).

The Ngāti Porou Hauora Health Dashboard (2016) report compiled a set of domains from sources including Ministry of Health, Tairāwhiti DHB, primary health organisations, and Statistics New Zealand, providing a trend analysis of service coverage and utilization and a health profile of the population served by Ngāti Porou Hauora. The report detailed intermediate performance outcomes showing that Ngāti Porou Hauora was performing on par with Tairāwhiti DHB. This included improvement in CVD risk assessment from 78% in 2013 to 93% in 2015, exceeding the 90% target range and outperforming

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[2] Overall mortality rate is the probability of dying across all ages, based on national mortality data, recording deaths by place, time, and cause. NZ mortality data is sourced from the deaths registered by Births, Deaths and Marriages (Whānautanga, matenga, mārenatanga) systems of deaths, with the underlying cause of death coded by the Ministry of Health.

[3] Avoidable mortality is defined as premature deaths before the age of 75 years that could potentially be avoided, given effective and timely healthcare. That is, early deaths from causes (diseases or injuries) for which effective healthcare interventions exist and are accessible to New Zealanders in need (including actions to address the social determinants of health) or through preventive and curative interventions at an individual level (Ministry of Health, 2016).

[4] "Amenable mortality is a subset of avoidable mortality and is restricted to death from conditions that are amenable to health care at all levels" (Tan, 2016, p. 31), including primary prevention, early detection, and treatment and improved treatment and medical care (Tan, 2016).

Tairāwhiti and Aotearoa. In terms of rates of avoidable admission to hospital, Ngāti Porou rohe (iwi territory) were 21% higher than the rest of Aotearoa and 7% higher than Tairāwhiti. The use of ambulance services[5] in Ngāti Porou region was slightly higher, at 8%, than Tairāwhiti and 46% higher than the national rate. These statistics paint a picture of an organisation working hard to tackle "perpetuating inequalities."

In addressing the deficits in health outcomes/services for Ngāti Porou, whānau look to Ngāti Porou Hauora to lead/co-lead the implementation of appropriate alternatives to address this situation. This includes, as one "small" example, implementing the outcomes of the *Cardiovascular Disease Medicines Health Literacy Intervention* and the *Kaupapa Māori Health Literacy Evaluation* in which this research is located. Moreover, from 2010, the *Ngāti Porou Hauora Strategic Plan* (2014) has included "improved health literacy" as an indicator of having developed Te Hau Ora services: responsive to communities' needs, accessible, and empowering communities to take responsibility for their health. The parent project is the first project that will help Ngāti Porou Hauora measure how it is performing against that indicator.

The dashboard report (2016) was a "bitter pill to swallow" for the iwi (Ngāti Porou Hauora, 2016, p. 1). "This is not a legacy that I want to be a part of going forward" Rose Kahaki – Ngāti Porou Hauora Chief Executive, said (Leilua, 2016). Ngāti Porou Hauora financial health is fragile: Running at a deficit, the organisation relies on financial top ups from Te Runanganui o Ngāti Porou to bridge funding from their post-treaty settlement

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[5] Adjusted for differences in population age structures.

money (Te Runanganui o Ngāti Porou, 2016). A proposal for the future is for the "Crown to invest in Ngāti Porou via the accord which was part of the Ngāti Porou treaty settlement Agreement" (Te Runanganui o Ngāti Porou, 2016, p. 19). The health accord is a movement towards seeking crown commitment to investing in an innovative model of care and support infrastructure that will increase the life expectancy and health of the population it serves in comparison with national health standards. Given the push for Crown support and moving forward with practices of mana motuhake for Te Runanganui o Ngāti Porou, more specifically Ngāti Porou Hauora, consideration of kaupapa Māori health literacy seems the next logical step.

Ngāti Porou Literacy

Te reo Māori is a unique form of communication that has formed in relation to the natural and social environments and to the cosmos – a taonga (gift) of Aotearoa. Embedded in te reo Māori are the memories of the world as Māori understand it, forming the basis of all that we knew and hoped to be; therefore, it was essential in transferring knowledge. In the 1800s, Māori began to learn to read and write at a rapid pace, providing another proliferating means to communicate through letter writing, story writing, and newspaper articles (Spolsky, 2003). "Māori were prodigious readers and writers in te reo Māori and English" (Māori Adult Literacy Working Party, 2001, p. 2). Māori were in fact more literate in te reo Māori than Pākehā were in English (McRae, 1997). In 1847, the Native Education Act was passed, leading to the suppression of te reo me ōna tikanga. At this time, the English language displaced Māori as a first language.

> Our storytelling began to be disempowered the day the stranger began recording our stories, writing them down. From that day on, the stories started to change, they became a passive collection of words and phrases, sentence and paragraphs, pages of misinterpreted coding, derivative imagery, superficial characters and shallow portrayals. To the stranger from the west, mere collections of fantasy and myth (Mita, 2000, p. 10).

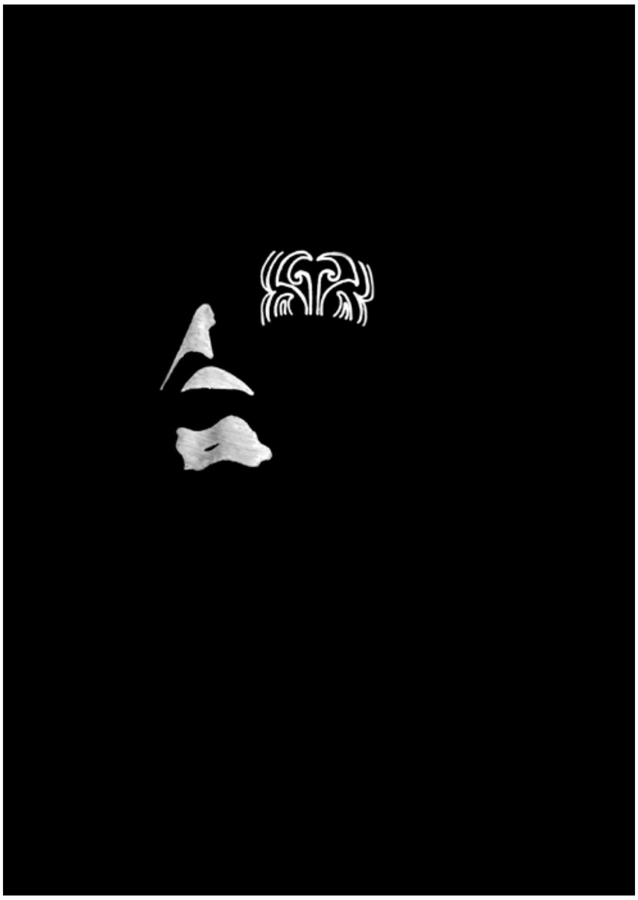
Literacy has always been a cornerstone practice of Ngāti Porou culture, with many prolific authors such as Katerina Mataira, Arapera Blank, Henare Mokena Kohere, and Mohi Turei, to name a few. Reweti Kohere was also the editor of Te Pipiwharauroa (Māori language newspaper) for many years (Te Runanganui o Ngāti Porou, 2017). The content included letters of articulated emotion, political statements, words to waiata (songs), retentions of whakapapa, and oral histories. Māori literacy of the 1800s provided important insights into the world views of the writers, showing dialectical and orthographic diversity (McRae, 1997).

Te Kāwai Ora – the Māori Adult Literacy Working Party (2001) – described literacy as an essential factor in building whānau, hapū, and iwi. Rawiri (2005) stated that Indigenous literacies of Māori are made secondary to Pākehā ideologies of literacy. Whānau, hapū, and iwi are at the heart of the social, political, and economic foundations of Aotearoa and have the right to determine and construct their own meanings and practices of literacy for their own purposes (Māori Adult Literacy Working Party, 2001). Rawiri (2005) supported this view, stating that Indigenous peoples have the right to define literacies as fundamentally social and political practices – defining what is valid and valued in society. I extend this description to include practices/concepts of health literacy – understanding it as a concept situated around whānau, hapū, and iwi. Literacy such as health literacy functions in a fundamental, relational, and critical way, founded on communication, expression, and connection encompassing holistic cultural, social, and physical understanding (Rawiri, 2005).

Summary

Kaupapa Māori theory locates this research in a structured way as a means of framing a pathway for analysis, determining the intent, structure, and broad aims/goals/aspirations of this research. Covered in the chapter is literature on the research topic areas, introducing the history of Western health literacy and the various ways it has evolved in definition and as a concept. Next, I provide a statistical picture on the prevalence of CVD in Aotearoa, specifically in the Ngāti Porou region, and the prevention and management of the disease, including medication use. Literature is then presented on contextual health services, health and literacy information on the Ngāti Porou region, iwi, and hauora. The Ngāti Porou context is unique to Aotearoa as a region diverse in geography, community, demographics, and income.

The following chapter serves as a description of how I perceive the world and how that perception impacts on my research practice, drive to conduct and complete this research, and the methodological practice in which the research is centred.

[6]

The strokes have changed to reflect the different frequencies I hear.
I ask, what do you hear?
I hear Kia Kaha Ngā Iwi.

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[6] Teah Carlson, Painting my gaze – who I am, what I have learnt, and what I see, 2017
Liquid chalk on black card, 637 × 415 mm, Private collection, Auckland

Kia Kaha Ngā Iwi

Kia kaha ngā iwi, pūpuritia
Ngā purapura i mahue mai rā
Ko ngaro rātou mā, ngā rangatira,
Hei mātoro mō te rangatahi
Kāore he tirohanga kē, e te iwi,
Ko ngā marae hei awhi mai
I taku Māoritanga, mana motuhake,
Hei pou tokomanawa.
He rau aroha nō tua whakarere
Nō aku tīpuna e.

Be strong, o tribes, and retain
those things bequeathed to us.
They, our leaders, are no longer with us
to help the younger generation.
However, one need look no further
because the marae are here to give help
to support my Māoritanga, my cultural identity.
They are my tower of strength.
tokens of affection from time immemorial,
from my ancestors.

Excerpt composed: Te Kumeroa Ngoingoi Pewhairangi, 1967

To me, this waiata is about resistance and challenges Western ways of thinking and being. It speaks of the importance of whakapapa, which encourages us to regard wisdom and knowledge as collective, with each new life building upon the layer before it. Wisdom is not about perfection or getting things right; it is about applying tūpuna knowledge to our generational context in light of our own needs and development. This understanding guides me to strive not for perfection but instead for the wellbeing of my people, to account for their complexities and diversity. These imperatives are the drivers for the return of decision-making power to the affected individuals and groups and reflect the context of colonisation, where tino rangatiratanga and mana motuhake remain a critical aspiration for Indigenous people.

Nanny Ngoi was close to our whānau. My dad, Joe, and her son, Terewai, were best mates and still are. Nanny Ngoi and Pāpā Ben looked after our whānau in the shearing sheds, and there was always hot kai and a bed for us in their home. My mum loved Nanny dearly, as she was welcomed with open arms and heart into the whānau. As a Pākehā woman in a Māori setting, mum always remembers her manaaki.

Whānau, then, has guided me throughout. It was clear to me that, within a kaupapa Māori and participatory approach, I needed to find my way of working based on who I was and how I wanted to proceed and guided by the key principle of whanaungatanga.

Beginings of the research

In this chapter, I outline the development of the research from its conception and explain the focus and importance of whanaungatanga – centring myself in the research. Next, I explore method theories and describe how they have informed the research methods. I then detail my research practice, covering principles of mātauranga, whakarongo, maia, ngakau tapatahi, whakahautanga, and whakapono.

As outlined in chapter one, I have been involved in research on medication use within whānau since my summer studentship year in 2008, when I investigated the public meanings of medications, their safety and risk, and social processes involved in their use. This research explored the use and practices of medications and informed strategies for enhancing the safety and efficacy of medication use. The studentship provided the basis for my master's thesis, where my focus was firmly on Māori households, investigating social processes surrounding medication use in Māori households with member(s) who have a chronic illness.

In 2009, my masters' supervisor forwarded me an advertisement seeking a PhD student interested in the development of an intervention to increase patient and whānau health literacy. They were looking for someone with experience in Māori health, interventions to improve health outcomes for Māori, kaupapa Māori research theory, and qualitative methods. I applied for the position and later learnt that one of the two Māori organisations in the study was my iwi healthcare organisation, Ngāti Porou Hauora. As I was living in Auckland, I saw this as an opportunity to travel home and maintain connections with my whānau and iwi. I saw the potential to implement actionable change for my people, especially those in isolated, rural parts of the East Coast.

Many parts of the research focus and process were predetermined. The parent project discussed in chapter one, *Strengthening Health Literacy Among Indigenous People Living with Cardiovascular Disease, Their Families, and Health Care Providers*, was funded by the Health Research Council and included a PhD stipend and associated costs. This included inheriting the term 'patient' from the parent project, categorising recipients of care into a passive/lay person descriptions.

The research project leaders anticipated that the PhD would involve the development of case studies in two Māori health service providers: one based in Auckland and the other based outside Auckland.

I initially had some concerns about health literacy, as it is largely grounded in Western approaches and literature, and I was concerned about what that would mean in relation to a kaupapa Māori approach. I wondered why health literacy was the focus and why it was based on health practitioners and patients and their whānau, rather than systematic changes and organisational impacts.

I wrote these questions and assumptions down in my research journal.

1) What role does health literacy play in terms of engagement with whānau? Who defines health literacy and what it means?

2) Are medications the right forms of treatment for patients? Medications are perceived as the assumed pathway; no mention of alternative therapies?
3) The parent project outlines patients' compliance with taking their CVD medications as one of their goals. I question whether patient compliance is a suitable goal? Do we want compliant patients – or ones that make fully informed decisions, utilising critical analysis skills?
4) Will health literacy improve compliance – just because patients may learn more about their CVD medications, does that mean they will change behaviour?
5) Do short-term interventions work? What are the long-term goals for this project? What considerations have been made for long-term funding and investment?
6) The parent project utilises the phrase "culturally appropriate" when describing the intervention they want to develop, but I wonder if we can we appropriate culture? Or can we act/interact in safe ways that honour diversity.

These questions have remained with me throughout the research process and guided my discussions with patients, health practitioners, and key informants.

Whanaungatanga

In kaupapa Māori evaluation, there is more to collaboration than working together; it is constituted as a way of knowing that is fundamentally different; letting go of the control, the expectations and needs of the self to seek connection, unity, and engagement – whanaungatanga. Collaboration can be sought through engagement practices of empowering relationships, shared activities with shared goals and purpose, agreed principles of operation, collaborative decision making, reciprocal accountability, and equal power, status, responsibilities, and rights. My collaborative journey through the kaupapa Māori evaluation relationships went deeper than evaluation partnership or collaboration, as I was both an insider – iwi member – and an outsider – evaluator.

Whanaungatanga and my whānau place in the community afforded me the privilege of making my research what it is today. However, dominant systems (Western science) determine what is regarded as legitimate. Although increasingly contested, this has been driven by the idea of an unbiased objective seeking truth (Jones, 1997). This notion positions the researcher as an outsider, an observer removed from the subject's space and "able to observe without being implicated in the scene" (Smith, 2012, p. 138). Thus, conventional empirical research is often at odds with first-person narratives and experiences. However, this view has been challenged considerably in the social science domain. Feminist scholars argued over three decades ago that the use of third person was a patriarchal strategy intended to create an impression of a "god trick," where the researcher appears to be everywhere and nowhere, thus creating the perception of objective truth in research (Haraway, 1988). The unique perspective of the researcher inevitability makes a difference to the research; as an insider–outsider, I viewed my position as one of possibility and opportunity (Kerstetter, 2012). I did not ever view myself as being either an insider or an outsider at different points in time; rather, my position enabled me to be both at the same time (West, Stewart, Foster, & Usher, 2013). I will always be intimately connected to land and feel a sense of responsibility and obligation to my iwi, but I can also reflect and step back and critically analyse situations and context, allowing my skills as a researcher and evaluator to come to the fore.

In treading the path of kaupapa Māori research, whakapapa, whānau, and whanaungatanga have played an important part in the research journey in terms of my research agenda, which is to contribute and serve my community in positive and actionable ways.

Ko Wai Au?

He uri mokopuna tenei no Te whānau ā Apanui, Ngāti Porou me Waikato-Tainui hoki. My whakapapa is derived from my Pākehā māmā (mum) and a Māori pāpā (dad). My māmā has English, Scottish, and French ancestry. My pāpā is Māori, Swedish, English, and Scottish. I grew up in two worlds – this is my strength and my lens.

I grew up in a small Māori community, Mangatokerau, on the East Coast, Ngāti Porou. Mangatokerau is so small it has no shops and just a few whare (houses). The boundaries encompass taniwha kōmanawa, mangakino, and makawakawa pūkaki, meeting the mangatokerau awa in between Hikurangi and Paripoupou puke, within Te Aitanga a Hauiti, Te Whānau a Ruataupare and Ngāti Porou hapū and iwi. An essential part of growing up on the Coast was living with and on the land – growing, hunting, storing, gathering, and sharing kai. My whānau taught me the importance of manaaki (support, reciprocity, care), aroha (love, concern, compassion), and connecting to people – whānau, whanaunga (kin), and all other forms of life.

As a child growing up in a shearing gang, our life was never dull and always changing. Travelling the world and meeting new people, there were often parties, alcohol, and other drugs. As the mātāmua (eldest), I grew up fast and took on adult responsibilities at a young age. Rising to this responsibility, I learnt to be adaptable and inventive. I developed a keen sense of analysis and did not hesitate to question parents, teachers, whānau, and the law. Looking back, my questions were about understanding the world philosophically, exploring the fundamental nature of the reality I lived in, and the unseen. I wanted to learn to understand myself and where I fitted, so that I could be a part of something greater than myself and have a role and a purpose. I wanted to be part of a solution, a movement that served the community and strengthened the marginalised, oppressed, and disadvantaged. It has been a long journey to discover that I do not have to search for this purpose. The role has been handed to me; it is written in the stories in my whakapapa and is a part of me.

I have worked in hapū and iwi settings, as a social care worker, youth worker, researcher, and evaluator. As a kaupapa Māori evaluator, I see myself as a translator between the community, stakeholders, organisations, and academia. I locate myself in a space embedded in responsibility and accountability, seeking equity and justice in unjust places. Today, I envision a future where evaluation is Māori led and mātauranga Māori is the vehicle that is situated as normal and dominates; a future where Māori methods prevail and we support everyone in a pathway of hauora (health and wellbeing).

Method Theories

As discussed earlier kaupapa Māori evaluation brings together action, research and theory utilising a participatory and self-determining process. Here, I cover a number of approaches that have informed my research. I outline my methodological approach, drawing on Māori scholarship and collaborative research approaches.

The research process is concerned with attaining and retaining knowledge in light of its use and usability. It is about building on what we know, and broadening understanding to make decisions and developments. Research is about control and power (Te Awekotuku, 1991):

> Social science research is specifically focused on people, and is particularly pertinent to political management and political planning; subsequently, the risk mismanagement or manipulation of either the information or the informants, may occur – only a code of ethics, scrupulously observed, can prevent this. However, it must be acknowledged that there can be no such thing as value-free social or political research either, despite many claims to the contrary, for humans are human, but there should be a commitment to the truth as it is discovered (Te Awekotuku, 1991, p. 13).

Using appropriate methodologies provides insight into participants' understanding of their positions. It is not only about giving voice; it is about theorising, thinking about systems and processes with a view to action and change that is beneficial to all. Individual actions are patterned by broader social and cultural structures (Boyatzis, 1998) and, to understand those structures, we can look at micro-level actions. For example, we can explore patient–health practitioners encounters to see the replication of broader social and cultural structures of power (Walker et al., 2006).

The research utilised qualitative methodologies, drawing together collective narratives that together captured ideas, knowledge, and understandings at a particular time. One of the complexities of qualitative data lies in its interpretive nature (Ziebland & McPherson, 2006). Developing a convincing account is not a straightforward process. I acknowledge there were limitations to this process, but this did not discount the validation of the findings. Rather, the awareness contextualised the conclusions that were made in order to build understanding and highlight areas for further inquiry (Meyrick, 2006).

When designing this study, I engaged in thematic analysis because it provided me with the ability to code and analyse data, both using in-depth exploration and systematically linking key themes, theories, and concepts to the broader research questions (Braun & Clarke, 2014; Patton, 1990). Thematic analysis is an accessible and theoretically fluid approach to analysing data that encompasses two broad perspectives. Thematic analysis enables the user to utilise the method as part of their theoretical and epistemological position, or, utilised independently of theoretical foundations. I have utilised thematic analysis in the latter sense as a tool encapsulated within kaupapa Māori theoretical foundations.

Linda Tuhiwai Smith (1999a), Graham Smith (1997), Mason Durie (2005), Ngahuia Te Awekotuku (1991), Anaru Eketone (2008), and other Māori scholars have explored the ways in which collaboration, partnership, and consultation manifest in the kaupapa Māori research space. Collaboration is an important aspect of research involving communities, particularly Māori communities – in this case, an isolated, rural Māori community of people largely aged 50 years and over. Collaboration means relationships, connection, reciprocity, involvement of relevant stakeholders, and open-ended invitations to participate in whatever capacity and form communities decide. It also entails eliciting support and supervision to undertake research in ethical and culturally safe ways (Health Research Council of New Zealand, 2010).

As a theory of change (Smith, 1997), kaupapa Māori provides a basis for action research processes to be taken up. This aligns with the action research methodology in that it utilises a participatory process in pursuit of practical solutions to issues of pressing concern. Action research focuses on participation and change, using mixed methods, depending on the issues and the context, in a cyclical process where each revolution consists of planning action, implementing change, and evaluating the results.

Brazilian educator Paulo Freire advocated for participatory processes in which people are not objects or recipients of political, organisational, and systematic processes but, rather, actors in history, able to name their problems and their solutions to transform themselves in the process of changing oppressive circumstances (Freire, 2005). According to Freire, social change occurs when people listen to each other, engage in participatory dialogue, make connections, and construct pathways for change. He suggests that, through engagement, we can learn from one another's perspective and discover new ways of looking at problems (Freire, 2005).

Collaborative Research Methods

The conventional tools of reference groups, focus groups, consultation meetings, policy development, and intervention logic models have been a dominant feature for service delivery conversation for a long time (Sanders & Stappers, 2008). Although these processes and models have served some good and created value, they also have the potential to grow into a paternalistic view – growing dependency rather than capacity. Such approaches often come from a set of values that equate to sympathy for others and validation of our own ideas rather than those of the people we actually serve. As a result, we often gather data within context, analyse it out of context, make a judgement from an expert perspective, and develop an intervention approach resulting in a logical pathway of working out how to solve social problems. This involves expert voice rather than the voices of the participants', and this voice often carries a tone of sympathy.

While my methodology is located within a kaupapa Māori lens, my strategy in utilising elements of action research, participatory action research, community-based action participatory research, co-operative inquiry, and co-design to collaboratively create visualisations of aspirations of health and wellbeing emerged from an interest in how we (kaupapa Māori evaluators) align with practices and movements towards tino rangatiratanga and mana motuhake through engaging in participatory decision making.

My doctoral study aligned with elements of co-design as I utilised techniques and tools derived from service design and values-based practice processes such as having an aspirational approach towards creating meaningful consumer/patient input, collaborative practice, creative activities, problem solving, and innovation practice. However, my research departs from the method when the aspiration of "co" assumes an equal input on the part of the participants/consumers. My approach was about offering components of co-design and co-creation pathways as an option to develop the framework; it was about the invitation to participate and collaborate for participants to determine the extent of engagement and participation in the method. The framework was about always keeping the process transparent, communicating developmental steps, remaining open for feedback and input as it became available to them.

The term "action research" was coined in 1948 by Kurt Lewin, who proposed cyclical steps of looking (gathering information), thinking (interpreting and explaining), and acting (resolving issues and problems), and then repeating the process. A core principle is critical reflection – exploring how and why things happen and making changes in the research process. Action research is broadly understood in two dimensions, as either an individual (practitioner) reflective process,[7] or a "systematic collection of information

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[7] Closely related to reflective practice, a term coined by Schon (1983).

that is designed to bring about social change" (Bogdan & Biklen, 1992, p. 223). The action research process can provide a working framework to be developed, whereby future problems and directions can be managed (Mathie & Greene, 1997).

As a participatory process, action research involves researchers working collaboratively with participants such as whānau, hapū, iwi, and organisations to develop, apply, and evaluate evidence-informed actions that address problems they have highlighted (Cram, 2012). Action research emerged in response to the broad generalisations of positivist research, which made no attempt to recognise the subjective, complex, diverse, cultural, and community lived realities. Descriptions of kaupapa Māori research and action research highlight community voice, collective understanding of issues, developing participant definitions, processes, actions, and outcomes. Action research can complement kaupapa Māori research by adding a reflective cycle that aligns with kaupapa Māori (Kerr et al., 2010).

Participatory action research is a form of action research that makes participant involvement explicit and takes a participatory empowerment approach to social change. Premised on the notion that local communities ought to be full partners in the processes, participatory action research is concerned with knowledge creation and social change and breaks down the distinctions between the researcher and the researched (Cahill, 2007). The method embodies an interactive process of change, where institutions and communities become transformed as people who participate in changing them become transformed. When participatory action research is combined with the overlay of colonisation, the question of who is in control or how control is relinquished through participation and who benefits or becomes empowered through this research, becomes critical.

Community-based participatory action research is closely related to action research and is “mainly used to conduct research with communities that are underserved by health services and seeing the outcomes of this in the health disparities experiences by people in these communities” (Cram, 2012, p. 2). The method is based on the premise that it begins with an interest in issues from a collective – group, organisation, or community. Community members are recognised as experts in relation to the issue or occurrence, which allows the meaning and usefulness of research to be informed by participants’ everyday experiences and understanding. As a process of inquiry, the approach is based on a set of social values that enable participation of all people, acknowledge people’s rights to equality, provide pathways away from oppression and debilitating conditions, and draw on people’s strengths and potentiality (Stringer, 2007).

Co-operative inquiry (collaborative inquiry) is also closely related to action research, with the main premise being about research done “with” rather than “on” people (Heron & Reason, 1997). Heron and Reason (1997) extend this by describing four different ways of knowing: propositional (conceptual), experiential (felt), presentational (symbolised), and practical (actions). In the health and social science field, forms of knowing favour propositional knowing and understanding, expressed in statements and theories, which have become the dominant foreground of understanding and inquiry (Heron & Reason, 1997). Less attention is given to forms of knowing that are experiential: face-to-face engagement, and knowing through connection, empathy, and resonance. One extension of experiential knowing is presentational knowing: expression through imagery, narration, drawing, sculpture, movement and dance and which is largely underdeveloped in academic research. However, in Indigenous spaces, experiential, presentational, and practical (skills and competencies) are very much a part of expressions of knowing. Additionally, in their enactment, these forms of knowing are embedded in connections and relationships and with them come all the rights and obligations they imply.

One approach gaining momentum in the public health service field is the method of co-design, also known as co-creation/construction/production. Co-design challenges existing quality-improvement practices commonly utilised in the public health system. In Aotearoa, DHBs, public hospitals, and local councils claim to utilise the method that employs similar principles and practices to co-operative inquiry, participatory action research, and kaupapa Māori research (Boyd, McKernon, Mullin, & Old, 2012). Power sharing and acknowledgement, community engagement, and action-focused and strengths-based practices focus on developing participant definitions, processes, actions, and outcomes (Kerr et al., 2010). As a result, participatory action research and kaupapa Māori research both draw attention to areas of strategic importance by revealing real and pressing issues for the communities and participants concerned.

My doctoral study aligned with elements of co-design, as I utilised techniques and tools derived from service design and values-based practice (formative evaluation), such as having an aspirational approach towards creating meaningful consumer/patient input, collaborative practice, creative activities, problem solving, and innovation practice.

Researcher Practice

As well as the method theories mentioned, I was guided by principles of practice, which are embedded in kaupapa Māori theory/research.

Indigenous ways of being embody relational practices, interwoven and understood in the realms of the natural environment and cosmos. Indigenous knowledge contains distinctive forms – spoken, written, and seen; has its own customs and traditions; and has localised context and meaning (Jones & Jenkins, 2011). There is no standard, universal Indigenous perspective on knowledge and understanding (Smith, 2012); the power of Indigenous approaches lies in the ability to embrace diversity (Battiste, 2008). All research is both political and moral: "In a world such as ours, to practice social science is, first of all, to practice the politics of truth" (Mills, 1969, p. 78). While numerous theoretical frameworks exist within positivist domains, few encompass Indigenous subjugated knowledge (Denzin & Lincoln, 2008). Western methodological approaches to conducting research have been applied to Indigenous peoples' knowledge and understandings the world over, attempting to objectify Indigenous philosophy, epistemologies, and politics into Eurocentric theoretical frameworks furthering colonial power and agendas. These practices marginalise, oppress, and subjugate Indigenous ways of being and knowing, ensuring the universalising of objective truth, and what remains is the "other" – Indigenous theory is cast as inferior (Connell, 2007).

Globally, Indigenous peoples, including Māori, have resisted exploitation, assimilation, and violent removal from their lands, resources, and systems of understanding – warranting suspicion of research, knowledge acquisition, and Western science (Health Research Council of New Zealand, 2010; Ramsden, 1994; Smith, 1999a). The work of many Indigenous scholars in the re-visioning and re-grounding of research continues to expand, with a focus on research that is ethical, performative, healing, transformative, and decolonising because it has been everything but that.

This section is an attempt to contribute towards methodological enquiry and praxis premised on emancipatory and empowering practice. Painting my gaze is about conceptualising what kaupapa Māori practice, evaluation, ethics, approaches, and research management looks like to me. Drawing from the work of key scholars (for example, to cite just a few: Linda Tuhiwai Smith [1999a, 1999b], Pihama [2001], Pihama et al., [2002a], Cram [2005], Cram & Lenihan [2000], Moewaka Barnes [2000b, 2009], Masters-Awatere [2015], Baxter [2012], Eketone [2008]), I attempt to bring my practice and subjective gaze to the fore by exploring the components of my conceptualisation/visualisation.

Mātauranga

Mātauranga means to be enlightened or illuminated. It is concerned with applying experience, knowledge, and judgement to enlighten and assist a situation. To honour collaborative processes, I had to be wise about my time, commitment, travel, and expenses. Ensuring that I could meet the proposed aims and objectives in a manner that was acceptable and effective for the people involved was important to the kaupapa Māori evaluation. I presented my limitations to stakeholders and participants upfront. One of these was my location; I lived in Auckland and was committed to attending parent project interactions with the community and Ngāti Porou Hauora (553 km away), as well as all research advisory group meetings. During the research, my whānau committed to indirect involvement in the research as members of the communities on the Coast. My aunty, uncle, and cousins made it a priority to attend marae and community events on my behalf. They were approached by participants who identified their connection to me as the researcher. Once these connections were made, my aunty and uncle would attend tangi and drop off kai to homes; they became my “kanohi kitea” – the face that is seen in the community (Smith, 1999a).

Whakarongo

Whakarongo – Listen with your whole being. In the context of my research, communication was not simply about talking and listening; it was much broader. It meant being available, accessible, flexible, and responsive. It was about valuing being heard and being able to listen. As it is written in an old whakataukī, “Whakarongo, whakarongo, whakarongo” (Listen with your upoko [head], manawa [heart], and puku [stomach]). In Te Ao Māori, it is understood that it takes more than ears to listen; we listen with our head or mind to make logical sense of what we hear and set this against our experiences and understanding of the world. We hear with our heart, which provides an emotional connection to what resonates with us. Lastly, we hear with our puku, listening to our intuition and foresight. If we provide environments and spaces where listening on all levels can take place, we can start building our knowledge capacities and our transformative endeavours.

Maia

Maia relates to courage, boldness, purpose, resistance, leadership, ambition, and grit. The vision for this component is honouring the collective priorities of Indigenous communities that we serve to support and advancing Indigenous aspirations. Support and advancement means that the authority of the evaluation/research should reside with Indigenous peoples in terms of leadership, decision making, resource control, methods, and distribution of outcomes through drawing on democratic processes (Borell, 2017). At times I felt torn between the agendas of the stakeholders. However, my whakapapa gave me the courage to resist temptations to give up and provided grounding in times of turmoil. As an iwi member, I felt obligated to my people and responsible for the kōrero (contributions) they shared with me. I felt it was my responsibility to prioritise their voice in this research because they will be directly affected by the outcomes.

Ngakau Tapatahi

Ngakau Tapatahi – Integrity – builds on concepts of tika and pono by adding an overarching expectation of ethical and moral conduct. For me, this involved being as transparent as possible with my participants, being clear about my intentions, and inviting them to collaborate in the whole research process, from shaping the research questions, methodological practices, and analysis through to dissemination – in the form of publications and reports. This approach helped ensure I had something useful to contribute and could align with my participants' aspirations and visions, although it could not protect me from getting things wrong and making assumptions and did not guarantee the relationships would be a success. What was important was continuously keeping an open door, involving participants and stakeholders at all stages, and striving towards reducing power differentials in the relationships (Cram, 2001).

Whakahautanga

Whakahautanga – self-mastery – is the ability to modify behaviour and actions for a desirable effect and speaks to the interdependency of wisdom and self-mastery.

Whakahautanga emphasises the importance of understanding who you are in order to best engage and connect with others. It is about being industrious, having perspective, being willing to collaborate, and showing humility, engagement, preparation, consideration, and reflection. Being reflective is my most powerful tool in questioning whether my practice comes from a space of manaaki, aroha, and whanaungatanga rather than self-service. As a researcher, I found myself constantly repositioning myself between the differing institutions, all requiring different needs and responsibilities to be met. I countered these pressures by being as reflective, transparent, and honest as possible, making sure my intentions were clear and assumptions were discussed. This was a juggling act at times, as time pressures meant I had to make rushed decisions or that I missed out on opportunities to engage. I learnt that my heartfelt intentions were not enough – I drew heavily on my support systems for guidance, including my whānau, supervisors, and advisors.

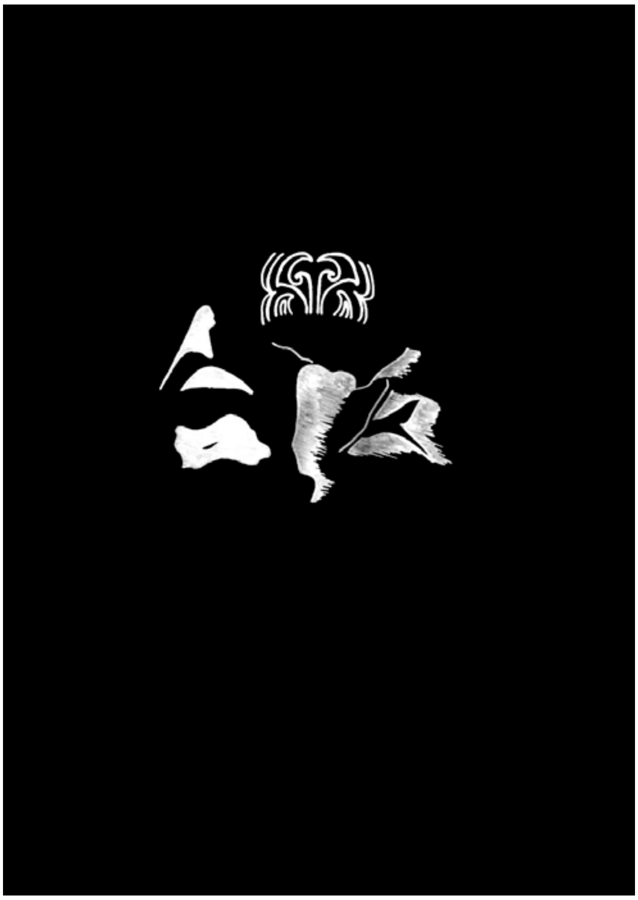
Whakapono

Whakapono is fundamental to Te Ao Māori and entails a belief and acceptance that something exists beyond physical realities. Acknowledgement of the spiritual realm is a feature in many Māori customs. Tikanga on marae acknowledge and bind to this realm, from the karanga (ceremonial chant of summons) to manuhiri on the marae, to whaikōrero, karakia, and the poroporoāki. Belief manifests itself in the recognition of those who have passed and by making links to atua and seeking and commanding spiritual protection (Te Kawa Rokihau, 2017). Belief in the research context involved belief and trust in me as a researcher; trust that I would practice in safe ways, respecting the validity and legitimacy of Māori language and culture and making sure I maintained the confidence and anonymity of participants. Although I was conducting research where I grew up and where my whānau belong, I tried not to assume I knew the practices, tikanga, reo, and whakapapa. I tried to honour diversity and took strong direction and guidance from the support people around me – kaumātua, community members, and whānau. This meant I followed their lead in regard to te reo me ōna tikanga o Ngāti Porou: how, where, and when we would meet and the process of how hui were conducted. I took direction from the parent project and research advisory group. I took direction from the whānau when entering their homes, workplaces, and spaces. At times I would take the lead, but only when invited to. I did not view my position as a doctoral student as one of a research authority, but rather as a co-enquirer, retaining the responsibility for the graft of the study, with the power to elevate the participant voice throughout the research.

Summary

My research approach as a kaupapa Māori evaluator is founded on my background and experiences as an Indigenous woman, mother, sister, and daughter. Throughout this chapter, I focus on my research approach. Centring on the principle of whanaungatanga, I introduce my whakapapa, connections to land and people, and my experiences. Kaupapa Māori theory/research frame the process, analysis, and praxis of this research, bounded in collaboration – the requirements for action, reciprocity, responsibility, and relationship. Then, I describe my values and how they inform my research ethics. In the next chapter, I outline in detail the design and methods of this research.

CHAPTER THREE: MY RESEARCH

[8]

Adding textured layers, I focus on how I feel. I ask what do you feel?

At this stage, I feel uneasy, uneasy with making mistakes, asking the wrong questions, not knowing where I am going and even questioning who I am. I turn to the words of Kathie Irwin for comfort and guidance.

> We don’t need anyone else developing the tools which will help us come to terms with who we are. We can and will do this work. Real power lies with those who design the tools – It always has. This power is ours. Through the process of developing such theories we will contribute to our empowerment as Māori women, moving forward in our struggles for our people, our lands, our world, ourselves.
> (Irwin, 1992 as cited in Smith, 1999a)

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[8] Teah Carlson, Painting my gaze – who I am, what I have learnt, and what I see, 2017
Liquid chalk on black card, 637 × 415 mm, Private collection, Auckland

Aims and Objectives

This chapter outlines the aims and objectives of the research, the relationships in the research, the design and the methods used to gather, analyse, and present the research contributions. Also covered is the research methods used when developing the Ngāti Porou health literacy framework.

The purpose of this study was to carry out a kaupapa Māori evaluation of the effectiveness of the *Cardiovascular Disease Medications Health Literacy Intervention* (parent project) by gaining insights into perceptions, practices, and experiences of the intervention through

1. semi-structured interviews and weekly phone contact with six patients and whānau, and
2. semi-structured interviews with three health practitioners

and to develop wider learnings in relation to health literacy interventions with Māori and Indigenous communities by

1. collaboratively designing and testing an evaluation framework with Ngāti Porou Hauora,
2. gaining insights into health literacy approaches through key informant interviews with six health literacy informants, and
3. synthesising the data and seeking input and feedback from Māori providers.

Parent Project

The parent project involved two health providers running delivery components, with a research component running alongside to determine whether health literacy in relation to CVD can be strengthened through a culturally appropriate intervention targeted at patient participants and their whānau. Overall, the project sought to establish whether such an approach was associated with increased confidence and ability to self-manage CVD and empowered interactions with health workers (Crengle, 2009). The project, which was designed as a kaupapa Māori research project, was run by a Māori research team and was to draw participants from among the patients and whānau in two Māori health provider services, one rural and one urban. The parent project negotiated with two Māori organisations to locate its pre-/post-intervention research design in their services (Crengle, 2009). The two organisations were Te Hononga o Tāmaki Me Hoturoa (Te Hononga), a kaupapa Māori Whānau Ora non-government organisation (NGO) in Auckland, and Ngāti Porou Hauora, a subsidiary of Te Runanganui o Ngāti Porou providing health services to the Ngāti Porou, East Coast region.

Intervention

Participants were selected for the intervention if they were Māori adults ≥20 years of age, enrolled with Ngāti Porou Hauora, who had been diagnosed with angina pectoris, myocardial infarction, transient ischemic attacks, or stroke, and were taking at least two of the following types of medicines: a statin, aspirin, a beta blocker, or an angiotensin-converting enzyme (ACE) inhibitor.

The intervention consisted of educational sessions conducted by a health practitioner and delivered in the participants' homes. The health practitioner received training in health literacy, including strategies to support knowledge acquisition and the development of health literacy skills based on adult education principles. Each patient was provided with a booklet designed by the parent project team members. The booklet contained information about CVD, medication use in general, and specific information about the four CVD medication classes (statins, aspirin, beta blockers, and ACE inhibitors). However, only the medication classes the participants were currently taking were covered during the session. For example, if they were taking a statin and aspirin, they would not cover beta blockers or ACE inhibitors.

During the session, an interactive tablet application was used. It was designed to ensure that the health practitioner covered the CVD medication information in a structured and consistent manner and provided interactive opportunities for the participant. A personalised pill card with images of the participant's medications was provided during the session as well as a list of three questions for the participant to ask their health practitioner.

Each participant completed three educational sessions at intervals determined by adult literacy principles to enhance learning opportunities. The second session was held one week after the first, but it could be completed within a two-week time frame. The third session was scheduled one month later but could be completed after the one-month time frame. Each session ranged from 30 to 75 minutes depending on the participant's requirements.

Doctoral Relationships

Originally, my doctoral research was embedded in the parent project. The Aotearoa component of the parent project was delivered through the host institution, Auckland University. My supervisor at the time was the principal investigator in the parent project, which involved the interventions and evaluation, including the PhD. The PhD was therefore embedded within and funded through the parent project and an Auckland

University doctoral scholarship. This changed in 2012 as my supervisor left the University of Auckland – the parent project host institution. My PhD became independent in terms of funding and supervision, as my supervisors were from Massey University, and I gained funding through the Health Research Council of New Zealand. Relationships, processes, and communication were then re-negotiated in relation to the PhD evaluation. This process involved submitting a new ethics proposal with Massey University, submitting a new research proposal and budget to the Māori health organisations, and developing a memorandum of understanding (MOU) with Auckland University and the organisations.

The development of the MOU included details about relationships and communication regarding the development of the evaluation framework, the advisory group, and the evaluation framework. Second, it included details around the evaluation process, including recruitment, data collection, analysis, and formulation of findings. Third, it included details around written and other outputs in which evaluation findings were discussed with the parent project and provider group. Lastly, it stated that Massey University supervisors would provide guidance for the broader PhD development and reflections. During the development of the kaupapa Māori evaluation framework, the research advisory group met with me at the Ngāti Porou Hauora offices in Te Puia to plan, outline, develop, and refine the kaupapa Māori evaluation framework.

The research proposal was revised and submitted on 7 December 2013 after feedback and revision from the principal investigator and the Ngāti Porou Hauora research coordinator. The letter of acceptance was received on 14 January 2013, subject to ethics approval and the project details being approved by the Chief Executive. The MOU and budget were sent on 9 May 2013 and approved on 15 June 2013.

Design and Methods

I travelled over 3,200 km during my data collection; between Tāmaki Makaurau and two small towns (approximately 500 people) on the East Coast of Aotearoa – Tikitiki and Te Araroa.

Figure 2. Data collection: backblocks of Rangatukia

Research Diary – 24 June 2013

> I cross the awa; I notice it is a bit low for this time of year
> New road works, old road works
> I cross the cattle stop, open the gate
> Check the mail to bring in
> I bring bread, milk, butter, and biscuits
> The basics matter
> Never turn up empty handed, Dad taught me
> The dogs bark

Nan opens the sliding door, gumboots all sizes line up next to the full scrap bucket
She welcomes me with the touch of a hand, a smile
Our noses press
Nan turns and yells to Koro in the garden, “The girl’s here! Come inside, have a break!”
She turns to me “The old bugga, he would be out there all day if I let him”
I hand the mail over with a smile
My heart is beating
My head is racing
I want to just relax, but I have all this academic stuff in my brain
A hand on my shoulder, kia ora, our noses press, Koro is puffing
Nan “What would you like, my girl, tea, coffee?”
Me “Tea, please”
We all sit with our drinks and open the biscuits
I say, “I just wanted to introduce myself; my nan is a Waiariki–Heremia from the Cape and my pāpā is a Carlson–Maxwell from Mata Road in Toko”
Koro “Yes we know, we knew your grandparents, good people, hard workers,
I asked Dury down the road where’s this girl from – when the nurse asked if you could come, we know all your whānau; I used to play rugby with your uncle. And who is Dick to you?”
Me “He’s my uncle, one of Dad’s older brothers”
Koro “Oh, we brought a trailer off him the other day”
Me “I hope it’s a good trailer? Or I might be in trouble”
We all laugh
Oh hika, the paperwork, I better get it out of the way
I hand the information sheet over
Nan “We trust you my dear, it’s for your tohu”
Me “Can I summarise the information for you, just in case.”
All the T’s crossed and I’s dotted
but I notice on the information page a spelling mistake grrrrrrrr
They don’t even notice; they don’t even look at the form,
Nan begins “Well I have this pain in my knee its really sore, but I try and walk every day cause if I don’t it will get worse.”
I think noooo, don’t start talking yet; I haven’t started the recorder and I haven’t even asked to turn it on yet?

Maybe I’ll sneakily start it then ask later . . . better not.
Koro says “Hey aha that’s enough ‘bout your knee, let her ask her questions!”
I so badly want to honour my people, my participants, make them feel at ease . . .
but it turns out it was them; they made me feel at ease
Mauri Ora

Evaluation Structure

The evaluation was conducted in two phases: Phase one consisted of semi-structured interviews and phone contact with patients and whānau and of interviews with health practitioners involved in the intervention. Phase two involved the development of a kaupapa Māori health literacy evaluation framework shaped by semi-structured interviews with key informants (selected Māori health literacy professionals) and Ngāti Porou Hauora staff and governance members (research advisory group).

The kaupapa Māori evaluation approach focused on aspirations of co-ownership, mutually beneficial outcomes, and shared power by prioritising the patients’ voices to shape the evaluation criteria for defining the intervention as “effective.” Invitations to participate were part of the collaborative process. Ngāti Porou Hauora were involved in methodological decisions, interpretation of data, and the analysis and discussion stages of the evaluation.

Table 4 provides an overview of the data collected; more detailed breakdowns of the data collected are provided after the table.

Table 4
Data collection

Participants	**Number of participants**	**Type of data collection**	**Rounds of contact**	**Total interviews**
Patients	6	60- to 120-min semi-structured, face-to-face interview	3	18
Patients	6 (same participants as above)	15- to 30-min phone contact	3	
NPH health practitioners	3	60- to 120-min semi-structured, face-to-face interview	2	6
Indigenous health literacy key informants	6	60- to 120-min semi-structured, face-to-face interview, or Skype for international	1[a]	6
Ngāti Porou advisory group	7–12	60- to 120-min hui (meeting)	5	[b]
Totals	**28**		**13**	**30[b]**

[a]One key informant was interviewed twice as the first interview was cut short.
[b]Total interviews/numbers do not include the data from the Ngāti Porou Advisory group because of the different kind of data method utilised
NPH = Ngāti Porou Hauora.

Phase One: Participant Data Collection

Phase one of the research aimed to benefit Ngāti Porou Hauora and the community it served by exploring the effectiveness of the intervention (as defined by the Ngāti Porou Hauora patient participants and selected health practitioners working with the organisation). The qualitative evaluation was undertaken with a sub-group of patient/whānau participants and health practitioners directly involved in the intervention at Ngāti Porou Hauora. The kaupapa Māori evaluation included impact and outcome components to identify strengths of the intervention and suggest improvements. The evaluation specifically aimed to identify patient and whānau (a) experiences of the intervention; (b) reports of changes in medication practices; (c) changes in understandings of CVD medications; (d) satisfaction with the intervention, including interactions with research nurse, use of CVD medication booklet, electronic tablet application, and pill card; and (e) suggestions for potential improvements.

Patient and Whānau Interviews

Table 5
Demographic information of patients

Contributor	**Age (years)**	**Ethnicity**	**Gender**	**Attending whānau Interview 1**	**Attending whānau Interview 2**	**Attending whānau Interview 3**
George	90+	Māori	Male	2	1	1
Nellie	80+	Māori	Female	6	2	6
Kiriama	80+	Māori	Male	6	2	6
Joan	64	Māori	Female	1	0	1
Ma	70+	Māori	Female	1	1	5
Hemi	57	Māori	Male	2	2	0

Iwi: Ngāi Tai, Ngāti Porou, Tainui, Te Aitanga-a-Hauiti, and Te Whānau-ā-Apanui

Semi-structured interviews were conducted with six of the 56 patients participating in the intervention. I conducted three 60- to 120-minute semi-structured, face-to-face interviews with each patient/participant and their attending whānau. The first interviews were conducted before the intervention. The second interviews were carried out after all the participants had completed the intervention, and final interviews were conducted six or seven months after the intervention was completed. Weekly telephone calls, ranging from 10 to 30 minutes, were also conducted with the participants during the first month.

Participants were drawn from a list provided by the parent project. Although (as a supplementary sample) they were not formally part of the parent project data, they were, for the purposes of my evaluation, to receive exactly the same one-month, three-part intervention as those in the main sample of that study. Participants were contacted by a health service staff member who was not directly involved in the intervention and asked whether they would like to know more about the intervention. Participants who accepted the invitation were then contacted by the research nurse who provided information about the intervention and undertook formal consent procedures (this process had been approved by the parent project ethics application to the Massey University Human Ethics Committee [MUHEC]) (see Appendix A for the nurse's script). Patients were able to invite whānau to sit in on the sessions, but no data were collected from whānau members. When the research nurse met with the potential participant and invited whānau, the nurse informed them about the intervention and the evaluation and provided an information sheet (Appendix B) and consent form (Appendix C).

I then contacted the willing patients to confirm a time to meet in person to receive more detailed information about my project, sign the consent form, and arrange interview times. Interviews were conducted at the discretion of the participant, at the clinic, whānau home, or other mutually agreed community setting.

I conducted the majority of the interviews in the participants' own homes with whānau around; at times whānau would sit with us and contribute to the conversation. This was always the case when their partners were around. They did not even need to be in the same room; at times I would hear contributions to the kōrero from the next room. All the patients had tamariki and mokopuna who were present at all the interviews in their homes. The research nurse gave all patients the information sheet prior to my arrival. When I arrived at the first interview, I had with me another copy of the information sheet and consent form, and I discussed the research and gained consent before interviewing began. I used an interview guide (Appendix D) that had been reviewed by the research advisory group. The interview guide was used as a guiding reference to cover key topic areas of interest (Patton, 1990). Patients were able to explore, ignore, or modify questions accordingly. I utilised topic areas rather than specific questions to allow me to tailor my questions to the kōrero and build on the conversation. Topic areas ranged from specific structural intervention questions such as recruitment, baseline data collected, timing, and frequency through to questions around the effectiveness of the resources used in the intervention, research nurse interactions, CVD medications booklet, CVD medications application, and CVD medications pill card.

All the patients used te reo Māori in their kōrero and had a good understanding of it; they would switch between Māori and English with ease. During and after interviews, I recorded field notes detailing contextual information, reflections, reminders, and observations. This information was later used in the analysis process to synthesise, contextualise, and clarify information (Phillippi & Lauderdale, 2017). All patients consented to their interviews being audio-recorded. Participants were given the option to review their transcripts; if they wished to do so, transcripts were posted for editing with two weeks in which to review and return them.

Phone Contact

It was envisioned that the patients would participate in journaling practices during the data-collection phase to record details in between interviews. At the end of the first interview, I asked the participants whether they would like to keep a journal during the intervention period. Posible record-keeping methods included pen and paper, electronics, photo elicitation, voice recording and phone calls, Skype contact, email and texts to the researcher. All participants chose to be contacted via landline telephone. I contacted each participant a few days after each health literacy intervention session to offer support and record their impressions of the intervention and their progress. I recorded the phone conversations and transcribed them verbatim. These transcripts supplemented the interview data and shaped the questions I would ask in the interviews.

Journaling as a data-collection method enabled participants to actively contribute to reflecting on their own practices (Milligan, Bingley, & Gatrell, 2005). The journaling method can augment individual interview methods, fit well with a participatory research approach to everyday life (Johnson & Bytheway, 2001; Milligan et al., 2005), and reveal understandings about issues taken for granted in health and illness (Elliot, 1997; Verbrugge, 1980). Journals also provide “a record of an ever-changing present” (Elliot, 1997, p. 2) that is useful in researching sensitive issues (Meth, 2003) over a short period of time (Ross, Rideout, & Carson, 1994).

Health Practitioner Interviews

Table 6
Demographic information of health practitioners

Contributor	**Ethnicity**	**Gender**	**Role**
Jen	Māori	Female	Nurse
Matt	Māori	Male	GP
Mereana	Māori	Female	Kaiāwhina

Iwi: Ngāti Kahungunu, Ngāti Porou, Tainui, Te Aitanga-a-Hauiti, and Ngā Puhi
GP = general practitioner.

The health practitioners had collective work experience of 45 years in community and rural health practice, in both clinical and non-clinical support.

For the health practitioners, I conducted two 60- to 120-minute semi-structured, face-to-face interviews: one immediately after the intervention was completed and the second six months after completion of the intervention.

Health practitioners were purposively selected to be a part of the evaluation in relation to their involvement in the intervention. The research administrator of Ngāti Porou Hauora contacted the selected health practitioners and asked whether they would like to participate in the evaluation. They then chose to be sent the information sheet (Appendix E) and the consent form and/or to meet with the evaluator to discuss their potential participation further. Health practitioner interviews were held within the service location boundaries and took place during work time. Permission was granted by Ngāti Porou Hauora.

Health practitioners were given the option of conducting their interviews at their home, workplace, and/or local café; all chose their workplace at the medical centre'. The research administrator gave all the health practitioners the information sheet prior to my arrival. When I arrived at the first interview, I took copies of the information sheet and consent form; I discussed the research and gained consent before interviewing began. I used an interview guide (Appendix F) that had been reviewed by the research advisory group. The health practitioners were able to explore, ignore, or modify questions accordingly. Key topic areas included gaining an understanding of the health practitioner's role, including their involvement with the intervention and the participants, and the perceived outcomes. I also aimed to discuss their expectations of the intervention and the strengths, weaknesses, and areas for improvement of the intervention and/or its sessions.

During and after interviews, I recorded field notes detailing contextual information, reflections, reminders, and observations. All the health practitioners consented to their interviews being audio-recorded. They were given the option to review their transcripts and were emailed transcripts for editing. They were given two weeks to review and return them – all the health practitioners edited their transcripts and returned them via email.

Multiple Interviews

I interviewed patients and health practitioners more than once. The process of multiple interviews enabled me to build rapport and connection with participants and encouraged participants to reflect on their previous interview experiences. Mishler (1999) noted multiple interviews separated by relatively short intervals of time turn out to be a particularly rich source of data, especially in chronic illness studies. Multiple interviews enabled me to create follow-up questions from previous interviews, expanding my understanding, and enabling contradictions and topics to be explored in more detail over time. For example, one patient discussed never changing her medication practices and only following doctors' orders. She then moved onto examples of missing and sharing medications. In the second interview, I was able to explore these topics in more detail.

Phase Two: Evaluation Framework

The second phase of the research involved the development of the *Kaupapa Māori Health Literacy Evaluation Framework*, specifically designed to assess the effectiveness of health literacy interventions. First, it involved a collaborative Māori practice approach with the Ngāti Porou Hauora research advisory group (described below), in which insights from phase one data, practitioner knowledge, theory, and research literature were pooled in working toward the evaluation tools. Second, it involved a formal data-collection process with six key informants, in which insights from phase one data informed semi-structured interview questions. Participants were selected on the basis of their experience and expertise in the field of health literacy approaches that work with and encompass Māori. I conducted one 60- to 120-minute semi-structured, face-to-face interview with each participant.

Advisory Group

In 2010, I was selected to carry out qualitative aspects of the parent project and work alongside a quantitative evaluation. At this time, the research coordinator invited me to present my proposed kaupapa Māori evaluation to the advisory group and formally requested that I work alongside them collaboratively during the development of the evaluation. The parent project advisory group and the kaupapa Māori evaluation advisory group consisted of the same iwi, community, and Māori organisation representatives.

Research advisory group members included a pakeke (Māori), a Ngāti Porou Hauora board member (Māori), the Ngāti Porou Hauora research coordinator and "local investigator" on the parent project team (Pākehā), a manager (Māori), a chronic care nurse (Māori), a general practitioner (Pākehā), and a kaiāwhina (Māori). The research advisory group provided feedback and monitoring of the *Cardiovascular Disease Medicines Health Literacy Intervention* from its inception through to the dissemination of the research. The introduction of the evaluation research component of the intervention was discussed, starting from the project's inception.

Due to the timing of the introduction of the kaupapa Māori evaluation, the parent project already had an established relationship with the advisory group. At the time of my introduction to the advisory group, I had no knowledge of the agreements, conduct, and running of the advisory group with the parent project. I therefore followed the direction of the broader project for tikanga and kawa.

During the development of the evaluation framework, I met with the research advisory group to plan, outline, develop, and refine the evaluation framework[9] (Cornwall & Jewkes, 1995). This involved five advisory group meetings (Appendix G).

Key Informant Interviews

The six key informants were Indigenous health professionals who had knowledge of and experience working in the health literacy field but were not directly involved in the intervention (minus one informant). Their areas of experience involved developing and

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[9] In terms of timing, aspects of the evaluation framework (i.e. programme logic) were developed prior to commencement of the evaluation processes (i.e. recruitment, data collection, analysis, and formulation), but otherwise the development of the evaluation framework and the conduct of the evaluation processes was run in parallel, allowing the data collected from the evaluation to inform the refinement of the evaluation framework.

implementing health literacy approaches in private and government sectors as well as the adult education field. Three of the key informants had clinical backgrounds in medicine, and the others had management and community engagement experience. Key informants were from nations of: Te Rarawa, Métis, Cree, Saulteaux, Ojibway, and Celtic.

Key informants were recruited through known contacts to whom they were connected professionally, and then from their recommendations. This recruitment method, known as snowballing, enables participants to be approached through known contacts whom they trust (Penrod, Preston, Cain, & Starks, 2003). Potential participants were selected on the basis of their experience and expertise in the field of health literacy interventions that work with and encompass Māori.

Interviews with key informants took place at their desired setting (home, workplace, and/or local café). I conducted all overseas interviews via Skype. All key informants were given the information sheet (Appendix H) prior to the interview. When I arrived at the interview or connected on Skype, I took/sent another copy of the information sheet and consent form (all consent forms for the international participants were received before the formal interview began), and then I discussed the research and gained consent before interviewing began. I used an interview guide (Appendix I). The interview guide was used as a reference to cover key topic areas of interest. Key informants were able to explore, ignore, or modify questions accordingly. The aim of the interviews was to develop wider learnings in relation to health literacy interventions with Māori and Indigenous communities by exploring their perceptions, practice, and experiences of health literacy. During the interview, I provided a draft copy of my kaupapa Māori health literacy evaluation framework and asked for feedback. During and after interviews, I recorded field notes detailing contextual information, reflections, reminders, and observations. All key informants consented to their interviews being audio-recorded and were given the option to review their transcripts. Transcripts were emailed to key informants for editing, with two weeks in which to review and return them. Most of the key informants edited their transcripts and returned them via email.

Ethics

The research was approved by the MUHECN on 8 March 2013; approval was given for three years from the date of the letter (MUHECN 12/095) (Appendix J). Data collection was completed within the stipulated time frame. Patient and health practitioner interview guides were developed with feedback and approval from the Ngāti Porou Hauora research coordinator and parent project team members.

All participants gave written consent but were given the option of providing verbal consent if it was deemed more appropriate as pakeke/kaumātua. All participants were asked whether they wished to use pseudonyms, and all accepted. All participants were made aware that, although quotes and information would not be attributed by real name, it was possible that they could in some cases be recognised by some people because of the nature of their role and the small community to which they belonged. For instance, the provider and organisation staff were likely to be known. If the data were of a sensitive nature and could be linked to specific participants, its use was cleared with the participant.

The provider organisations are identifiable and were aware that they were the focus of the research. This process is outlined in the research proposals sent to Ngāti Porou Hauora, for which I received research approval (Appendix K). The information sheet for participants outlined the research, introduced me as the researcher, explained their contribution, advised what would happen with the information, outlined participant privacy and rights, and provided contact information.

Analysis

The data analysis provided a set of interpretive materials and practices that made the participants' contexts visible. These practices described representations of ideas, meanings, and understandings, including field notes, interviews, hui, and drawings. One of the complexities of qualitative data lies in its interpretive nature (Ziebland & McPherson, 2006). Developing a convincing account is not a straightforward process. It involves a patterned, systematic, reflective, cyclical process that aims to honour the mauri of the data.

My approach to the analysis is based on the notion of researchers as bricoleurs (Kincheloe, 2005) who operate in inter-disciplinary ways to bring together analytical strategies necessary for the needs of the specific research. Here, research is seen as a process involving problem solving and flexibility that is adjusted in response to emerging insights (Kincheloe, 2005). This exploratory process was used to explore the attitudes of providers, key informants, health practitioners, and patients with regard to the concept of health literacy. When considered alongside my research aims and objectives, engaging in an inductive analysis as described by Braun and Clarke (2006) is a process of weaving together content and discourse analytical methods and was an important part of locating Māori values, attitudes, and practices as foundational to the research. More specifically, I employed techniques commonly associated with thematic analysis. Thematic analysis is the process of identifying, analysing, and highlighting patterns (themes) within the data (Boyatzis, 1998; Braun & Clarke, 2006). Braun and Clarke (2006, p. 3) wrote that it "minimally organises and describes your data set in rich detail." The researcher plays an integral role in this process as ultimately they make decisions based on their experience and knowledge of the topic (Braun & Clarke, 2006). This approach allows the researcher to make sense and meaning of the participants' experiences and, in turn, the ways in which the broader social context impinges on those meanings. Using thematic analysis as a framework allowed me to draw on content, rhetorical, discursive, and narrative analytical techniques as required (Braun & Clarke, 2006; Yanchar, Gantt, & Clay, 2005).

All interviews were audio-recorded, and I transcribed them. This allowed me to further familiarise myself with the content and to clarify unclear recordings, muffled words, and non-verbal communication (Bailey, 2008). I read over transcripts numerous times to become familiar with the patients' accounts. While reading the data sets, I noted, on one margin, information I deemed to be significant in what the patients said (Braun & Clarke, 2006). Some of the comments were attempts at summarising a response, using one word. I then extracted the comments to a separate document and developed connections between them. Particular subjects, ideas, or practices were placed under an umbrella term (theme), which could also include extracted passages (extracts) that best represented the theme (clustering extracts into groups of similarity), ensuring I did not lose the meaning of what the patients spoke about. These processes involved a cyclical progression of reading literature, re-reading transcripts and listening to the recordings, and discussing the topics with supervisors while also re-examining the themes or subthemes in context with other sections (Braun & Clarke, 2006; Bryman, 2004). Eventually, the lists of themes (topics) were narrowed down to main findings. Most of the findings were drawn from the core research questions, which had been developed from the research aims and previous literature research (Braun & Clarke, 2006).

I sought feedback with Ngāti Porou Hauora (research advisory group) on the draft theme development and findings from analysis of the interviews with the patients and health practitioners. This method of analysis is described as crystallisation and provides a "deepened, complex, thoroughly partial understanding of the data" (Richardson, 2000, p. 934). During the first stage of data collection, I provided a summary of identified themes and asked the group to review the theme construction and descriptions. This process also enabled me to reflect on the quality and validity of the research questions and identified themes. I also recorded and wrote field notes before, during, and after interviews and research advisory group meetings to document my thoughts, feelings, and impressions. Themes from these notes were also made available to the research advisory group.

Developing a convincing account through the data is not a straightforward process. It involved a patterned, systematic, reflective, cyclical process that aimed to honour the mauri of the data. Therefore, it was imperative that participants were invited to feedback, change, and interpret the thematic findings and the direction and dissemination of the research because the power of the narrative was in its use and usability for the Māori organisation and community. I do acknowledge there were limitations to this process, but this did not discount the validation of the findings; rather, the awareness contextualised the conclusions that were made in order to build understanding and highlight areas for further inquiry (Meyrick, 2006).

Dissemination

The audience for this research is primarily located in three domains: patients and their whānau; the Māori health workforce, Māori health organisations, and Māori communities; and academic institutions. To reach these domains, a range of dissemination techniques were (and will be) employed. Patients and whānau indicated on their consent forms whether they wanted a summary of the research findings. Preliminary research findings were emailed and also presented twice to health practitioners, community members (including research advisory group members), and to the Māori organisation, Ngāti Porou Hauora. A dissemination hui took place on 24 November 2017, to present the *Emerging Ngāti Porou Hauora Health Literacy Evaluation Framework* and gain feedback and consent for the finalisation of the framework. Additionally, participants that requested a findings summary of the kaupapa Māori evaluation of the *Cardiovascular Disease Medicines Health Literacy Intervention* will be sent a copy. The dissemination process will be guided by the organisations' established protocols, relationships, and networks so as to disseminate the research findings in a timely and useful manner. Academic dissemination, including the four peer-reviewed publications and conference presentations was negotiated with Ngāti Porou Hauora and the parent project. Ngāti Porou Hauora and the parent project were given draft versions of all publications and provided feedback.

Research Process: Health Literacy Framework Development

Collaboration between myself and the research advisory group meant involvement with Ngāti Porou Hauora at all stages of the framework design: from the communication processes, data-collection methods, and recruitment of participants to the development of the evaluation criteria with research stakeholders. Structurally, the framework design was shaped by the relationship between the parent project and Ngāti Porou Hauora. I followed Ngāti Porou Hauora board policy by using te reo me ōna tikanga o Ngāti Porou (Ngāti Porou philosophy, knowledge, practice, and identity) practices.

Initial Hui

A key first step was my introduction to the research advisory group members. I was formally introduced to Ngāti Porou Hauora kanohi kitea at a meeting located at their office. I gave a short presentation about the proposed kaupapa Māori evaluation and answered questions in a discussion session. The discussion was important for gaining consent to work with the research advisory group. I invited them to participate collaboratively in my doctoral project, secured permission to run four hui, and obtained agreement that they would provide advice and feedback on the development of the kaupapa Māori evaluation and the *Ngāti Porou Hauora Health Literacy Evaluation Framework*.

Second Hui

Prior to the second hui, a background paper was supplied to the research advisory group detailing an overview of my doctoral research, relationship to the parent project, and proposed methodology. At the second hui, I presented an overview of the doctoral research and proposed the kaupapa Māori methodological approach, which was premised on values of partnership (active collaboration) and participation (deliberative engagement).

I first asked the participants to split into two groups. Each group was given Post-it notes, coloured pens, and large pieces of paper.

I asked each group:

> Please describe the long-term visions of the community (e.g. healthy people, increasing Māori life expectancy). What do you want to see happen in the future? Visions can be as big and as small as you like. No right or wrong answers.

Each participant wrote their responses on the Post-it notes. Then, each group was asked to group their visions together and give them a title. I asked the group:

> Do you think there are any areas missing?

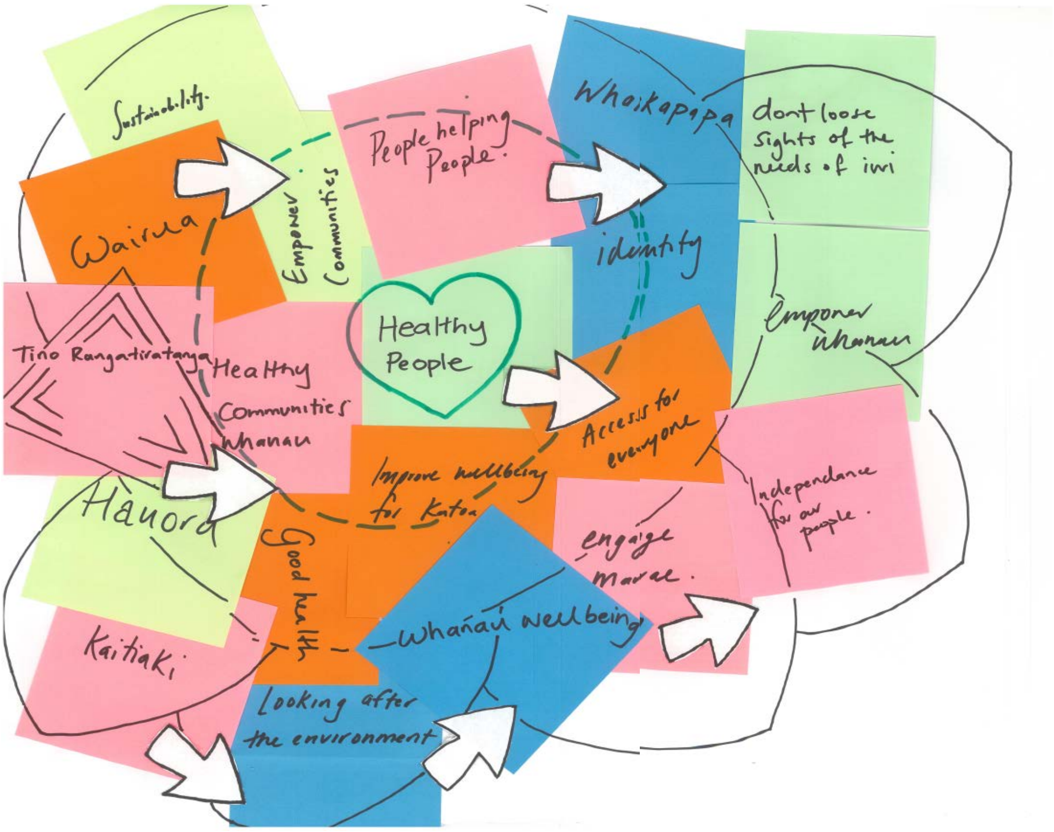

Figure 2. Evaluation framework visions

In Figure 2, the Post-it notes have been moved from their original paper to merge the two groups' responses. The lines and arrows in Figure 2 were added after the hui. The lines drawn were part of grouping the framework visions together and placing under titles/themes.

I then looked at each title and asked whether any additional information needed to be added. For example, for the vision "healthy people", I asked, "What things need to be put in place to reach that vision?"

Developing the Evaluation Criteria

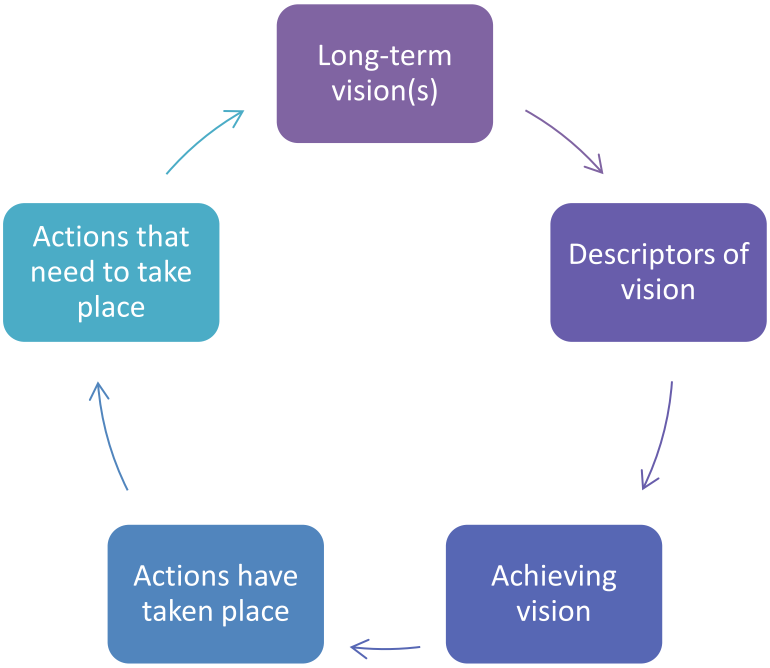

Figure 3. Steps towards developing evaluative criteria for evaluation framework

We began with the long-term vision(s), then moved on to the descriptors of the vision(s): What things make up the vision(s)? We then explored what would we do to achieve the vision(s). Next, we detailed what actions have taken place and moved on to what actions need to take place; these became the basis of the criteria. Lastly, we explored where the intervention project fits in with the descriptions. For example, I asked groups to describe their overall vision for the "intervention (parent project)" (e.g. increase patient health literacy levels, increase medication use) and asked whether the visions linked with the long-term visions and/or criteria.

Figure 4. Evaluation framework criteria

In Figure 4, the Post-it notes have been moved from their original paper to bring together the two groups' responses. The text and images outside the Post-it notes were added after the hui and reflect the dialogue within the gathering as well as my research field notes as part of the analysis process.

When discussing the parent project and kaupapa Māori evaluation, the concept of health literacy was explored. At this stage, I did not introduce the colonial ideas of health literacy; I wanted to explore their understandings. The research advisory group explanations of health literacy and the parent project varied (as discussed in *Chapter Four: Kaupapa Māori Evaluation: A Collaborative Journey*). Their understandings are explored in Figure 5.

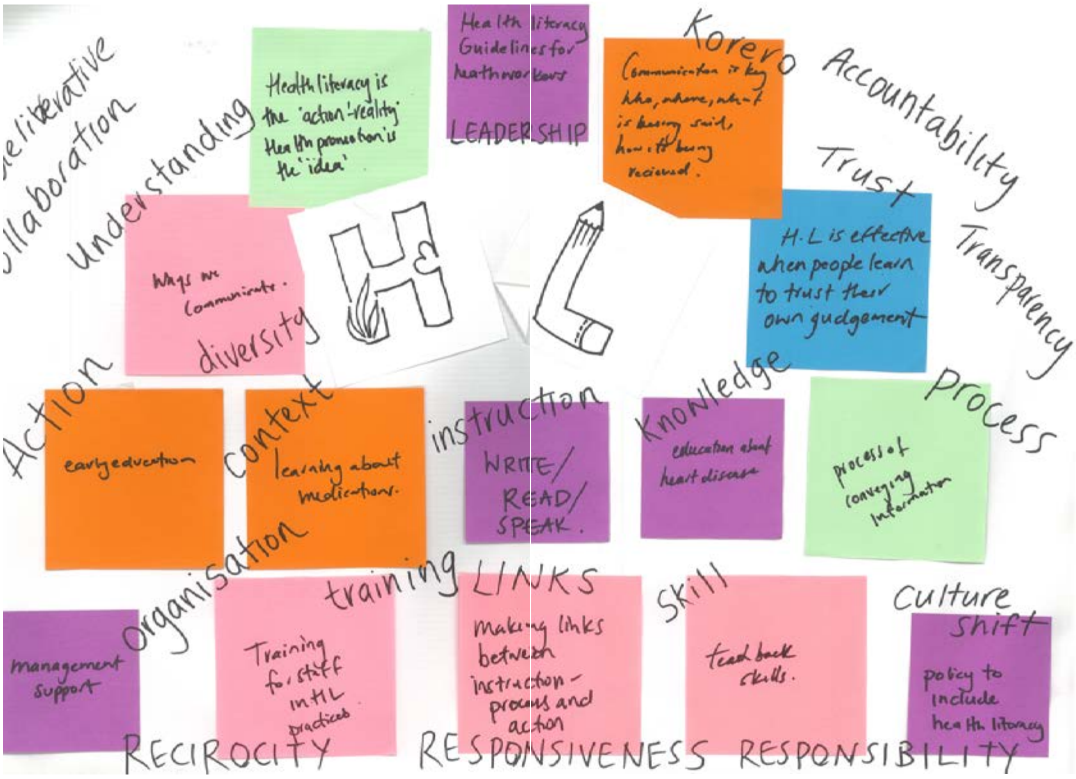

Figure 5. Exploring the concept of health literacy

In Figure 5, Post-it notes have been moved from their original paper to bring together the two groups' responses. Again, I added the text and images outside the Post-it notes after the hui to reflect the dialogue and my research field notes as part of the analysis process.

Table 7
Themed participant written responses

Principles	**Visions**	**Goals**	**Engagement criteria**	**Health literacy intervention criteria**
- Tino rangatiratanga - Hauora - Mauri Ora - Wairua - Kaitiakitanga	- Whanaungatanga - Whakapapa - Pakari - Manaakitanga - Mātauranga	- Healthy whānau - Holistic health - Provide services for all - Improve health status - Sustainable practices	- Te reo me ōna tikanga o Ngāti Porou - Partnerships - Shared power - Strength-based approaches - Accountability and transparency - Long-term investment - Systemic change - Honour our context/diversity	- Build on whānau knowledge, skill - Promote health literacy - Health literacy training - Resources that are clear, simple, and understandable

Third Hui

The third hui was held via email (telehui was offered, but email was the preferred contact method) because of resource and time constraints (related to the parent project and out of my control) to discuss matters in more detail and gain feedback on the development of the kaupapa Māori evaluation framework. I provided an initial draft of the framework that I prepared from the second hui. This draft outlined the proposed data-collection methods and the interview topic areas that I provided to the Ngāti Porou Hauora research coordinator as the proposed project details; she provided these to the Acting Chief Executive and managers for approval. At the time, more specific interview guide scripts were being developed pending approval to proceed.

Proposed Draft Ngāti Porou Hauora Kaupapa Māori Health Literacy Evaluation Framework

The themed/tabled participant responses (Table 7) provided the content for the proposed framework. The framework was initially presented in five domains: principles, visions, goals, engagement criteria, and intervention criteria. The framework begins with *Tino rangatiratanga* as an underpinning principle of *Hauora*.

This expanded to broad visions (*mauri ora* – healing and wellbeing; *wairua* – connecting to spiritual elements; and *kaitiakitanga* – protection and guardianship of the environment) that sum up the aspirations of the people in regard to hauora. On the next level, the visions were *whanaungatanga* – responsive and reciprocal relationships; *whakapapa* – ancestral inheritance and interconnectedness; *pakari* – collaboration and partnership; *manaakitanga* – equality and equity; and *mātauranga* – quality practices and services. These visions informed the following goals:

- Healthy whānau
- Holistic health
- Provide services for all
- Improve health status
- Sustainable practices.

The goals are achieved through engagement criteria, such as

- te reo me ōna tikanga o Ngāti Porou,
- partnerships/collaboration,
- shared power,
- mutual accountability,
- strength-based approaches,
- accountability and transparency,
- long-term investment/funding,
- systemic change, and
- honour our context/diversity.

The next domain represented a set of criteria that related to the principles to provide a practical context in which the principles play out in relation to the intervention:

- Build on whānau knowledge and skill.
- Promote health literacy in the organisation and the community.
- Provide health literacy training for all staff.
- Provide resources/materials that are clear, simple, and understandable – that can be shared and personalised.

These criteria provided an initial landscape of measurable indicators of the effectiveness of the intervention and more broadly what effective health literacy practice looks like.

Feedback

As discussed in *Chapter Five: Kaupapa Māori Evaluation: A Collaborative Journey*, after the third hui, I received two email responses. The first highlighted a spelling mistake in the framework and the second congratulated me on my doctoral enrolment and encouraged me to “come home with the tohu [qualification].” At the time, I was disappointed with the low response rate. On reflection, the email communication was not ideal and emphasised the importance of kanohi kitea – meeting face-to-face.

Fourth Hui

The fourth hui involved a presentation to the research advisory group on the preliminary findings of the participants and my interpretation of incorporating the core themes into the framework, as well as including literature on Māori health and evaluative models and frameworks.

Refined Draft Ngāti Porou Hauora Framework in Light of Patient and Health Practitioner Findings

Two additional domains were added to the Ngāti Porou Hauora health literacy framework: “Themes” – patient and health practitioner findings, and “Future development” – improvement areas. Core participant themes that either recurred or were seen as important by my participants emerged from the data I gathered from interviews with patients, whānau, and health practitioners:

- Self-management
- Analysis skills
- Increased patient knowledge
- Patients self-monitoring medication scripts
- Whānau communication – sharing information
- Research nurse – reciprocal relationship, reciprocal learning
- Resource booklet provided a sense of security and wellbeing
- Connection and communication, health practitioner listened and spent time
- Timing and frequency were effective
- Patients refining medication-taking practices.

These themes represented key reflections offering participant perceptions, experiences, and understandings of the *Cardiovascular Disease Medicine Health Literacy Intervention* and – along with the criteria in particular – could be used to develop measurable indicators of the effectiveness of the intervention. The final domain represented the areas for improvement:

- Future development: health literacy training for staff
- Change target group: prevention medications
- Guidelines and training around health literacy practices

Feedback

The presentation was planned for the end of the hui, and the timing would include at least an hour after my presentation to kōrero about the findings and how they might integrate into the framework and receive any comments/feedback on the framework components. However, as the day progressed, and people went over their allocated time slots, less and less time was left for discussion. Many people had to leave straight after I presented as they had prior commitments. However, they all committed to contacting me via email with feedback. Again, feedback was not forthcoming. I reflected on the contextual nature of the organisation, possibly competing responsibilities, interests, and skills that may have led to the lower than anticipated level of communication.

Final Hui

As part of my agreement with Ngāti Porou Hauora, I presented the framework developments regarding incorporating key informant data and feedback as well as the

Indigenous framework development (Hawai'i)[10] at a final dissemination hui to Ngāti Porou Hauora. Feedback from this hui was overwhelmingly positive, with all participants endorsing the relevance and usability of the framework within the Ngāti Porou Hauora strategic visioning, policy development, and development of their new model of care plan for 2018.

Summary

This chapter has outlined my research approach, setting a foundation on which the following chapters are built. I provided an overview of the research and its relationships to the parent project, design and methods, and dissemination as well as the health literacy methodology used with the research advisory group.

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[10] The *Ngāti Porou Hauora Health Literacy Evaluation Framework* was expanded to incorporate the perspectives of Indigenous health practitioners and community representatives on goals and aspirations for the health and wellbeing for the communities they serve at the 2014 World Indigenous Peoples' Conference on Education. Kapiʻolani Community College: O'ahu in the Hawai'i Archipelago.

FINDINGS: SECTION ONE

The following section presents findings that amplify the “voice” of health consumers/patients and whānau perceptions, practices, and experiences as well as health practitioners working and delivering services in communities. This is followed by a second section of findings, presented in four chapters that focus on specific aspects of the evaluation.

CHAPTER FOUR: AMPLIFYING VOICE

[11]

When I paint, it is my escape, my chance to channel the stillness, be in wairua. Other times, painting is a chance to reflect.

As I journey further through the research, I reflect on the spoken words, the connections made and maintained and the roads that I have travelled.

I also paint with words.
Here, I share one of my poems written after my conversations with kaumātua.

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[11] Teah Carlson, Painting my gaze – who I am, what I have learnt, and what I see, 2017
Liquid chalk on black card, 637 × 415 mm, Private collection, Auckland

Reflections on the Road

His skin is rough
blistered and calloused
from years of manual labour
living in a world of inequality
he has never asked for help

He wears a coat of armour –
made of pride and resilience
It is thick
dark and primed
but on the inside
he is vulnerable
made of vessels, cells, blood and bones

His body has seen better days
but his heart still beats
beats for his mokopuna
his tamariki
his whānau
his whenua

But he is dying
dying in silence

The symptoms are present
tucked away underneath the armour
the signs are there but no one sees
or is no one willing to look?

In a world of inequality
in a system of injustice
his armour is cracking

My people
my people are dying
dying from a disease
a disease that is preventable
that is manageable
that is liveable
damaging bodies
hearts
whānau
our future

22 June 2013

Introduction

This chapter sets out the patient, health practitioner, and key informant findings. The themes represent participants' kōrero and are organised in a patterned way that reflects the rich data set, guided by the broad research aims. First, I detail patient findings pre- and post-intervention, then health practitioner, and lastly key informant findings.

Participant findings are presented in core themes:

(1) Themes before the intervention in relation to patient beliefs, experiences, and practice with health practitioners, services, and the health system.
(2) Themes related to the effectiveness of the intervention.
(3) Health practitioner findings are outlined in relation to the effectiveness of the intervention for their patients as well as their own professional practice and development.
(4) Key informant findings are explored to develop wider learnings in relation to health literacy interventions with Māori and Indigenous communities by exploring their perceptions, practice, and experiences of health literacy.

I begin with patient themes before they participated in the intervention.

Patient Experiences and Expectations Pre-intervention

Patient themes from a round of interviews conducted before the intervention provide insights into their wheako whaiaro (experiences), whakapono (beliefs), and whakaharatau (practices), particularly in relation to long-term conditions and health encounters (both environmental and with people). Although detailed separately (Table 8), the themes overlap. For example, patient experiences influenced their beliefs, which in turn affected behaviour and practice. Table 8 explores patient themes pre-intervention, covering areas of the intervention.

Table 8
Overview of patient themes pre-intervention

	Wheako whaiaro Experience	**Whakapono** Belief	**Whakaharatau** Practices
Whakaaro Health system history	- Have a range of chronic conditions - Patients and whānau have considerable experience in the health system	- Feel dependent on medications - Do not want to depend on/fear depending on medications - Believe medications can be bad for you long term	- At the time medications are prescribed and when picking up medications, given very little or no information about why, what they are, how to take, or side effects - Have to get GP or nurse to explain medications, but some do not do a good job
Mōhio Knowledge	- Patients and whānau did not recognise signs of stroke or heart attack before, during, and after their event	- It is hard to learn about health situation/condition/medications when seeing different health practitioner - Given conflicting information - We need to be supported to learn, understand, and process	- Whānau medication practices influence use - Do not understand what medications are for, just following GP's orders
Taumautanga Experience with health practitioners	- Patients and whānau have bad or lack of communication with health practitioner - GPs do not understand/listen	- Patients and whānau believe health practitioners do not care, understand, or listen - Believe self-medicating is necessary practice due to limited access to health practitioner	- Patients and whānau try to follow GP's advice to the best of their ability - Patients and whānau seek connection and a reciprocal relationship with health practitioners
Whakahua Access	- Patients experience lack of specialist care, long waiting times, delayed care, being moved from service to service - Rural location makes it hard to access medical care - Do not want to be a "nuisance" for ambulance service so do not call	- Important for everyone to have access to quality healthcare - Essential to have access to services on the East Coast	- Missed medications, running out of pills, and have lack of access

Whakamahi Medication use	- Not on preventive medications before event (stroke/heart attack) - Whānau experienced medication overdose	- Mistrust, or trust has been broken, with health practitioners - Have relationship with current GP	- Diligent about taking medications - Exercise agency to self-medicate, medicate others, share medications, change dosage, and miss medications - Relational practice with medications as whānau would remind, administer, access, share, and support medication use

GP = general practitioner.

Whakaaro – Health System History

All patients had a range of chronic conditions, including diagnosed angina pectoris, myocardial infarction, transient ischaemic attacks, or stroke. All patients were taking at least two CVD medications, which included statins, aspirin, beta blockers, or ACE inhibitors. Five of the six patients had been taking CVD medications for at least five years and were expected to take them long term. Patients spoke of feeling dependent on their medications and expressed resistance to taking medications long term. Five patients felt that taking medications was not a health-sustaining option, and one felt they were detrimental long term. Patients spoke about being prescribed medications after their event. They talked about receiving a list (script) of several medications to take and very little or no information about why they were being prescribed them, what they were, how they worked, how long they needed to take them, and little or no mention of side effects.

Mōhio – Knowledge

All patients spoke about not recognising the symptoms of their cardiac event and not immediately seeking medical attention. All patients spoke about not understanding much about their heart condition or even being aware that they had a heart condition prior to their cardiac event. Generally, they were not prepared for their heart event or the effect it was going to have on their lives. They described it as being a time of crisis and not being in control or aware of what occurred until days later. Their knowledge of the health setting came mainly from experiences in the hospital and with GPs. They spoke of finding it difficult to learn about their health situation/condition/medications when they saw different health practitioners in the hospital and at the clinic; they reported receiving conflicting information and being expected to recall medical details. They all felt they needed to be supported to learn, understand, and process information and to be given clear, practical, and consistent content and resources. Patients said their medication knowledge was influenced by whānau (more so if they had experienced similar circumstances), and they valued whānau advice and support. When it came to utilising knowledge, they would often find themselves not asking questions and just following the doctor’s directions as best they could.

Taumautanga – Experience with Health Practitioners

All patients spoke of having negative experiences with health practitioners before their diagnosis, during the surgery experience, while staying at the hospital, and during after care (GP services). The most prominent theme was patients reporting poor communication skills from health practitioners. They spoke of not understanding the words they used, not being given enough time to comprehend information and to ask questions, receiving information from different health practitioners that did not match, having to answer questions they felt unprepared for, being given too much information at once, or not being given any information. For patients, communication with health practitioners was vital to understanding their health situations. When patients spoke about encounters with the health practitioners, it was clear that having a connection or relationship was important in the communication process; this was described as health practitioners spending time with the patients, explaining, informing, and checking that the information was understood.

Whakahua – Access

Patients experienced difficulty in accessing speciality services due to location as well as availability; they reported being on waiting lists for long periods, even years. They spoke of not having access to health practitioners for periods of time, such as a rural health nurse or a long-term GP. They also faced being shifted from hospital services to other services due to demand, availability of beds, and access to specialist care or resources. All the patients were located in a rural area, making access to medical care difficult. Patients believed it was vital to have permanent long-term staff available at the Ngāti Porou Hauora clinic and incentives and allowances to support health practitioners to stay. The system of accessing medications meant that scripts were sent to the city and the medications then couriered to the clinic. However, miscommunication and delay meant that medications could sometimes be missed. Participants also expressed feelings of uncertainty around their "demands" on services; for example, some had not called the ambulance service as they did not want to bother them.

Whakamahi – Medication Use

Themes of resistance to bio-medical approaches and practices were evident in all the narratives, particularly resistance to long-term medications. Patients described pathways and engagement practices in the health system, specifically between health practitioners and patients, where knowledge was perceived as data/fact gathering, which is then contextualised to circumstance – environment – and then practiced. Prior to the intervention, patients understood the use of their medications within the context of everyday life (describing their routines and practices) and how they understood them to work and be taken. Patients identified medications as compartmentalised approaches at odds with their holistic health perspective, which was understood as tinana (physical), hinengaro (mental), wairua (spiritual), and whānau (relationship) based (Durie, 1994a). Medications were taken long term; patients spoke about discovering what this meant for them – in terms of their experiences, health context, and social environment. A common theme discussed was not being on any preventive medications before their event. They spoke of having no awareness or warning signs that they were unwell and said they were not being screened or regularly monitored by their GP before their event. Patients and whānau spoke of their mistrust, or trust being broken, as they were not fully informed about effective medication use, monitoring, side effects, and risks involved. One pakeke spoke about how he lost his wife to a medication overdose a few years earlier. On the other hand, all spoke of having a relationship with their current GP and that they were diligent when taking medications. Although patients were diligent, they exercised their agency and self-medicated, medicated others, shared medications, changed dosages, and missed medications. Medication use was also expressed as a relational practice, where whānau members would remind each other, administer, access, share, and support medication practices. Two patients spoke of their partners attending their appointments with them and communicating with the GP about their symptoms and possible treatment options.

Summary

Patients' kōrero were structured around their experiences, beliefs, and practices. They discussed their health system history, knowledge in relation to biomedical health and understanding medications, as well as experiences with health practitioners. Patients had a range of chronic conditions and considerable experience in the health system. They spoke about the many challenges they faced in their health contexts and detailed practices to counter such challenges.

Patient Experiences and Expectations Post-intervention

Evaluating the effectiveness of the *Cardiovascular Disease Medications Health Literacy Intervention* was first approached by gaining insights into perceptions, practices, and experiences of the intervention, with a focus on change and change processes. The following sections draw on interviews in three rounds of data collection; one before the intervention, one near completion of the intervention, and the last six to seven months later.

Five core themes emerged, some of which are in common with the patient pre-intervention data. These were whanaungatanga – reciprocal and responsive relationships; takohanga – responsibility for understanding (health practitioner theme only); tūrangatira – engagement through presence (patient theme only); whakahua – purpose meets need; and whakawhanake – reflect to improve. Last, I present my contribution towards understanding the fluidity and contextualised nature of health literacy in light of the patients' findings – designed as three stages of "health literacy in action": Mōhio – shift in knowledge; whakaaro – shift in mind; and whakamahi – shift in practice.

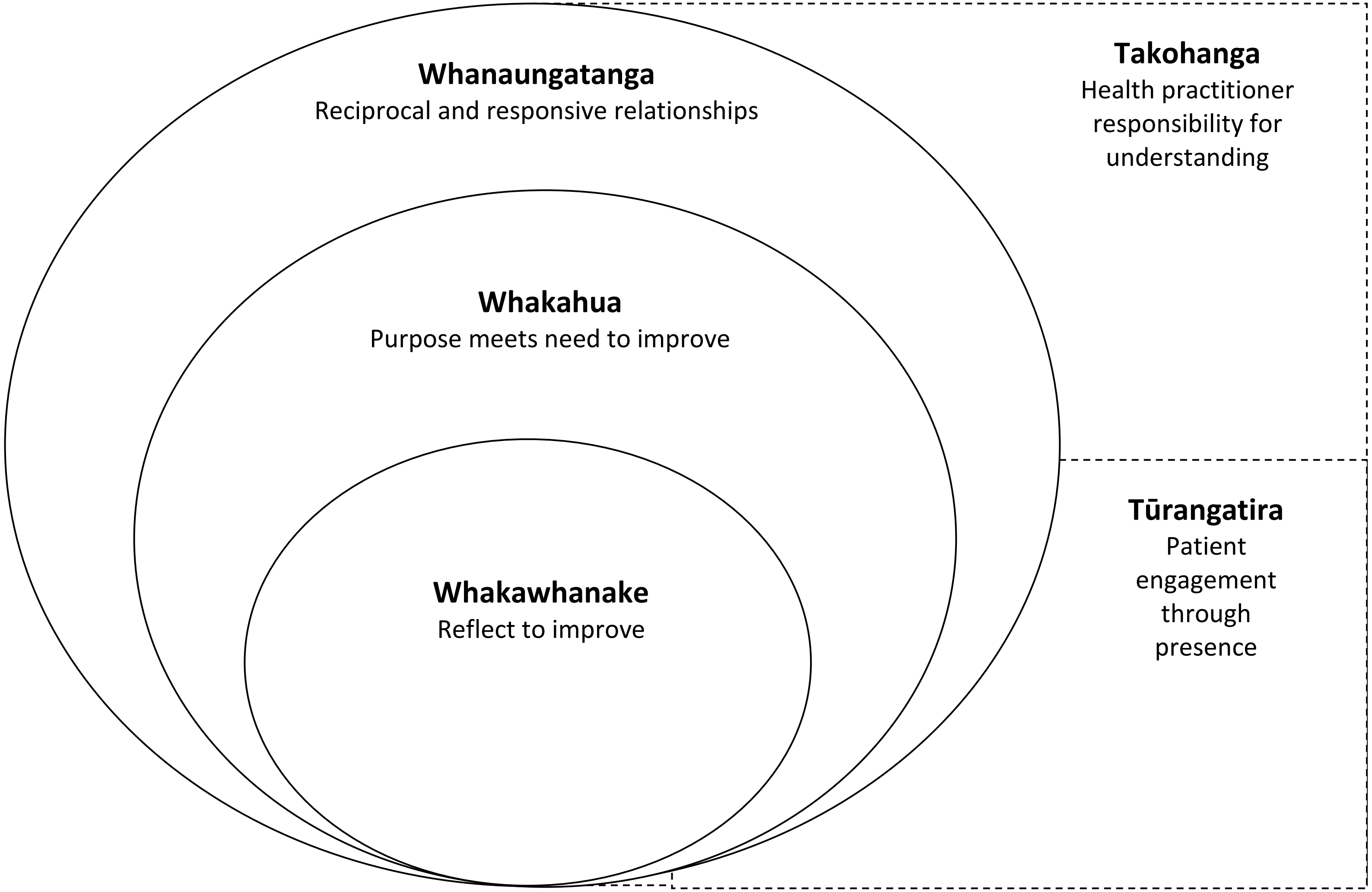

Figure 6. Overall patient and health practitioner themes

Table 9 explores themes in detail, covering each area of the intervention from structure and resources to perceived outcomes and short-term outcomes. In many cases, more than one theme is presented, reflecting the interconnection between the themes, as well as indicating the level of "health literacy in action" in effect in each area.

Table 9
Intervention patient findings

Area	Sub-theme	Theme
Structure		
Recruitment	- At first, some were reluctant to participate but felt they could trust the admin staff	Whakahua – purpose meets need
Baseline data	- Felt comfortable to share the baseline data	Whakahua – purpose meets need
Timing and frequency	- Timing, length, and frequency of the session were practical, reasonable, and attainable	Whakahua – purpose meets need Whakaaro – shift in mind
Resources		
Booklet	- Provided new information - Design of booklet was user friendly and easy to understand (wording and structure) - Felt a sense of security having booklet - Used booklet outside of sessions - Personalised booklet	Whakahua – purpose meets need Whakamahi – shift in practice
Application	- Majority watched app once - Found videos interesting to watch - Found app would be a good tool for the younger generation	Mōhio – shift in knowledge
Pill card	- 50% did not remember receiving pill card - Four did not use pill card – relied on their blister pack - One used pill card as a visual reminder	Mōhio – shift in knowledge

Perceived intervention outcomes		
Knowledge	- Gained new CVD medication information - Gained new information on CVD medication side effects - Did not feel they learnt any new knowledge around CVD (mainly focused on CVD medications) - Gained a sense of security (wellbeing) - Understanding made medication-taking practices more meaningful - Noticed medication misprint – used booklet to check - Shared intervention/medication information with others	Whakamahi – shift in practice
Medication use	- Medication-taking practice has/has not changed - Refined medication-taking practices - Started to keep track of blood pressure	Whakamahi – shift in practice
Experience with research nurse	- Increased understanding of medications and health - Felt and experienced connection, responsiveness, reciprocity, mutual respect	Whakamahi – shift in practice Tūrangatira – engagement through presence Whanaungatanga – reciprocal and responsive relationships
Experience with health practitioners	- Began to ask more questions with research nurse and health practitioners - Interactions with the GP have been positive	Tūrangatira – engagement through presence
Short-term perceived intervention outcomes (6–7 months)		
Structure	- Timing, length, and frequency of the sessions were practical, reasonable, and attainable - Availability to others in need (other age groups and high-risk patients) - Prevention approach to healthcare - Would like the intervention to be available to younger generations	Whakahua – purpose meets need Whakawhanake – reflect to improve
Resources	- Did not remember receiving the pill card - Did use the pill card, but it was out of date - Watched the app video once - Have not used booklet recently - Improve or take out app	Whakawhanake – reflect to improve
Knowledge	- Gained medication knowledge	Whakaaro – shift in mind

	- Medication-taking practices unchanged - Medication-taking practices have refined - Medications have changed - Sharing medication knowledge - Unsure of medication prescription - Have not retained the medication knowledge	Whakawhanake – reflect to improve
Medication use	- Whānau share responsibility for medication use - Do not like taking medication - Like taking supplements more than medication	Whakaaro – shift in mind
Experience with research nurse	- Increased understanding of medications and health - Felt and experienced connection, responsiveness, reciprocity, mutual respect	Whanaungatanga – reciprocal and responsive relationships Tūrangatira – engagement through presence
Experience with health practitioners	- Interactions with GP have not changed due to GP changing/access - Access to medical care is difficult as the GP has left and no district nurse	Tūrangatira – engagement through presence

CVD = cardiovascular disease; GP = general practitioner.

Whanaungatanga

All themes are founded on the practice of whanaungatanga, the guiding principle for effective health literacy. Whanaungatanga is about whānau, whakapapa, manaaki, reciprocity, friendship, and quality time. It is about building relationships between patients and health practitioners and having structures and environments that nurture and support relationship building.

> **George:** It was good, was good experience really with [the nurse] well now I know more about my medicines than I did before and how to treat them. (Second interview)

In their accounts, the patients highlighted that the design of the intervention to support relationship building was one of its most effective features. The intervention focused on valuing patients as autonomous beings holding their own important and expert knowledge about their lives. Whanaungatanga was developed through shared interests and through consistency of care; that is, building a relationship by seeing the same health practitioner. The research nurse provided tūhononga, aroha, manaaki, and ahua within the intervention. From this foundation, relationships formed based on trust, reciprocity, and admiration. Short-term patients were asked whether their interactions with health practitioners had changed over the past few months post intervention. They highlighted that the GP leaving the clinic made it very difficult for them to have interactions with health practitioners, let alone assess whether they were good ones, as they only have locum doctors and other staff numbers were low. This theme is written about in more detail in chapters six and seven, specifically under *Whanaungatanga – Relationship Building*.

Tūrangatira

This theme is about patients engaging with health practitioners through presence. The behaviours referred to within this theme are a practiced skill that correlate with the whanaungatanga – relationship-building theme. Tūrangatira is about participation practices between patients and health practitioners, which were an important focus of the intervention. Patients were encouraged to become more assertive and ask questions during their engagement with health practitioners.

> **George:** . . . now that I'm doing this (laughs) [intervention], I want to learn more about myself. You know. I'm starting to ask questions yeah, before oh well I just

> accepted [the information] aye. The doctors says it, well the doctor says it about that [chuckles]. (First interview)

This theme highlights a limitation in this approach, as without compassion and contextual and cultural understanding, health practitioners can undermine this skill. Practicing presence when engaging with health practitioners meant that patients became more confident in knowing their rights and felt empowered to ask questions, resulting in medication scripts being reviewed. This theme is explored further in chapter seven under the heading *Tūrangatira – Presence*.

Whakahua

This theme is about purpose meeting need. Specifically, it is about how the intervention structure, components, and resources met the needs of the patients and their whānau. Patients were asked about recruitment, baseline data, timing and frequency, implementation of sessions with the research nurse, as well as the resources: the CVD booklet, application (electronic application on a tablet), and pill card. Patients stated that, when they were recruited for the intervention and the kaupapa Māori evaluation, it helped that they knew administrative staff and/or the research nurse personally. All patients found the timing, length, and frequency of the intervention sessions with the research nurse practical, reasonable, and attainable. The booklet was identified as one of the strengths of the intervention in terms of design, usefulness, and comprehension. Patients shared their experiences.

> **Interviewer:** How did you find the booklet?
> **Nellie:** Nah yeah, it’s good I understand it, I enjoyed reading it.
> **Kiriama:** Yeah, it’s a good book, we should have had this before, it’s good for old people

> **Interviewer:** So, it is written well, and you like the look of it?
> **Nellie**: It's simple language everyone can get included, it's good for everybody cause like me they don't know, like me, I didn't know why I was swallowing my pills, oh yeah this is what it is, whatever cholesterol is, just take it [laughing]. (Second interview)

The application was less effective with the patients, as they found the videos on the application interesting but only wanted to watch them once although they were offered at each intervention session. The pill card had varied results – half the patients did not remember receiving the card, and only one patient utilised it for the first two weeks.

Whakawhanake

The whakawhanake theme covers patient responses towards improving the intervention. Participants reflected on their experiences of the intervention and their expectations and future aspirations for the intervention for themselves, their whānau, and their community. Patients spoke about increasing the availability of the intervention to others in need, which included widening the criteria to include those who had not had a cardiac event but were taking preventive CVD medications. Nellie shared her view:

> **Interviewer:** Would you like to see any areas on the intervention improved?
> **Nellie:** I think you need to go visit others who haven't had an event, the age group below us, I think they're the ones that really need to hear this information rather than us because we've already been through it and we can tell you what to do about it, in fact we can tell you how to do it because we've actually done it. (Third interview)

Patients spoke about extending the intervention sessions to include refresher sessions. They wanted to see the intervention include information on other medications and the booklets made available to all patients and whānau.

Health Literacy in Action

Figure 7. Health literacy in action scale

The health literacy in action scale (Figure 7) is part of a continuum of understanding and practicing health literacy: from *mōhio* – shift in knowledge (red), to *whakaaro* – shift in mind (orange), then to *whakamahi* – shift in practice (green). These themes are representative of the level of change that occurred in each area (structure, resources, outcomes, and short-term outcomes) for the participants and are individually recognised in the intervention patient and health practitioner findings and themes outlined in Tables 8 and 9. On the scale (directional arrow), participants' understandings and practices are understood as being variable, and only through structural support can participants sustain whakamahi – shift in practice. The goal for patients and health practitioners is to shift right towards practices of health literacy.

Mōhio

This theme is about patients receiving information and then that becoming attained knowledge. It involves the accumulation of facts, beliefs, myths and trivia. It is also about the ability to recall and retain the information. Patients stated they gained new knowledge about their CVD medications and their side effects. Some patients found that they did not learn any new knowledge around CVD, as the intervention was focused on CVD medications. The resources such as the booklet, application, and pill card were important in relaying and interacting with the information about CVD medications at this stage. George stated that he had not changed his behaviour around medication but had attained knowledge.

> **Interviewer:** . . . have you changed the way you take your medications?
> **George:** Well now at least I know what I should know, what each pill does, or is meant for, you know. Whereas before nothing was said, here just, "I'll send you, I'll send you some pills, right that's right come down and pick them up, take them." (First interview)

For George, gaining knowledge gave him a greater sense of agency around medication rather than being told what to do minus knowledge. Instruction without information treats the patient as a passive recipient who is told what to do, not why.

Whakaaro

Whakaaro is about applying knowledge (mōhio) to context and action, which involves the recognition that attained knowledge creates meaning for patients. As described above, patients moved from being passive recipients of instructions to informed parties in terms of their CVD medication use. This gave them a greater sense of agency and increased their confidence in their interactions with health practitioners. In regard to the intervention resources, agency was demonstrated by patients personalising their booklets and pill cards, highlighting information, and writing notes and referring to them in their daily lives.

> **Ma:** I grab my book then I write notes.
> **Interviewer:** And so what sort of notes would you write about?
> **Ma:** Testing myself. Oh well I did that the other day and test myself Saturday and Sunday I forgot. Oh well I'm getting dementia; I do forget a lot of things at times

> but that’s good ‘cause I can always look back at the book. So, it’s really handy that book for me. (Second interview)

The patients’ fluidity of understanding recognises the fluidity of knowing, understood and practiced for moments in time; it was only as effective as reciprocal and responsive relationships (whanaungatanga) connected to the patients. Six to seven months after the patients completed the intervention, they were interviewed for the third and final time. All the patients had changed their medication use in some way, including changes to brand, dosage, introducing new medications, and/or stopping others. Therefore, the resources and medication use practices became outdated, and – because their most effective way of clarifying information was with the research nurse – knowledge and understanding was reduced.

> **Nellie**: I get confused: do you know all these pills? What’s (?) on it?
> **Interviewer**: One tablet a day. . .
> **Nellie**: Is that correct? Because I think she [clinic nurse] got them confused, see? That one and that one. Is it really for that? So, I've got to take this pink one out and this one here replaces it . . . because she doesn't tell what they are.
> **Interviewer**: Has [name] explained it to you?
> **Nellie**: Yes, she did, but when they sent the medications, it was just like this and I couldn't decide which was which, so I stopped taking this one here. She's taken the little pink one out, because my feet started swelling. I had stopped taking it because I wasn't sure what it was for. (Third interview)

This theme is explored further in chapter seven under the theme *Whakaaro – Fluidity of Understanding*.

Whakamahi

Whakamahi is understood as a shift in practice. It is about patients taking their *whakaaro* – shift in mind and making changes to behaviours around CVD medications, interactions with health practitioners, self-care monitoring, increasing communication with whānau and sharing responsibility for medication use and uptake – both in the home and community wide. All patients spoke about refining their medication use in some way. Many patients had been taking their medications long term and welcomed the refreshed approach to their regimen. Although some changes were minor, they were significant in terms of making changes to already established practices. For example, they now take their medications at the same time each day, take them with food, avoid eating certain foods, and have become more aware of what is being prescribed. In one instance, increased awareness of what they were being prescribed led to a participant identifying a prescription misprint.

> **Joan**: No, it's the first time it's happened [prescription misprint] and I was telling her about it [research nurse] and she said well there's been someone else who's had an incident where on his pills he's been told to take two but actually he was only supposed to take one and he noticed that he'd been unwell, it only happened, he picked it up only on the second day and now he's more diligent about looking at his medication. (Third interview)

The CVD medications booklet provided an important reference at this stage; as time between sessions with the research nurse increased, patients would check their practices against the booklet. Patients valued their booklet and gained a sense of security knowing they could refer to the information at any time.

When patients were interviewed six to seven months after the completion of the intervention, their perceptions of the intervention structure and resources remained positive. They enjoyed their sessions with the research nurse and valued having the CVD medications booklet as a resource.

Knowledge sharing was an important part of shifting practice, whereby patients not only applied their attained knowledge to their lived everyday experiences, but shared their knowledge with partners, children, extended whānau, friends, and associates. Ma shared her experience.

> **Interviewer:** Have things changed for you in terms of the whānau support you receive?
> **Ma:** Yes, now we talk with dad and daughter. So, they know everything, why we taking our meds and how often.

Summary

Patients’ kōrero were structured around their perceptions, practices, and experiences in the intervention. Themes centred on whanaungatanga as the guiding principle for effective health literacy – connecting and building relationships between patients and health practitioners. Research nurse practitioner practice, coupled with the intervention’s structure, tailored resources, and materials, particularly the medication booklet, enhanced patients’ knowledge and skill in their CVD medication use, refinement, and uptake – whakamahi (shift in practice). For patients, positive improvements were made during the intervention in terms of knowledge, skill attainment, and practice. The most effective areas were the home-based, one-on-one, structured nature of the intervention, founded on practices and engagement – whanaungatanga and tūrangatira.

Health Practitioner Findings

All health practitioners directly involved with the parent project intervention trial were interviewed. Because of their differing responsibilities, roles, and associations in the intervention, no health practitioner themes were drawn up before the intervention. Their findings directly centred on their experience in and with the intervention. It is important to note that (a) the research nurse and the kaiāwhina received the parent project's health literacy training but the GP did not and (b) patients referred to in the kōrero by the health practitioners are all 56 patients involved in the intervention, including the six patients whose findings are reported on above.

The research nurse had the most insight into the specific details of the intervention and patient experience, as she completed the three intervention sessions individually with all 56 patients. The kaiāwhina was involved in a supportive capacity and worked with some patients and whānau of the 56 patients. The GP was the doctor for all patients involved in the intervention, with the exception of one patient interviewed for the evaluation.

Health Practitioner Perceptions and Expectations of Intervention

The following health practitioner intervention findings are presented as four core themes: whanaungatanga – reciprocal and responsive relationships; takohanga – responsibility for understanding (health practitioner theme only); whakahua – purpose meets need; and whakawhanake – reflect to improve. These themes form the basis of understanding the effectiveness of the cardiovascular disease medications health literacy intervention. Last, I present "health literacy in action," from the health practitioner perspective of the patients' perceptions, practices, and experiences of health literacy during the intervention.

Table 10 explores the themes in more detail, following a similar structure as for the patient findings and covering each area of the intervention from structure and resources to perceived outcomes and short-term outcomes.

Table 10
Health practitioner themes

Area	**Sub-theme**	**Theme**
Intervention structure		
Recruitment	- Obtaining patient numbers was difficult - CVD patients did not meet the specific criteria - Health system record keeping made it difficult to identify patients - It was helpful for recruitment that admin and nurse knew patients personally	Whakahua – purpose meets need
Attendance	- At times, responsibilities and activities would pull patients away from their appointments - Geographic location made access challenging at times	Whakahua – purpose meets need
Baseline data	- Patients felt comfortable to share the baseline data	Whakahua – purpose meets need
Whānau participation	- Some husband and wife, whānau participation	Whakahua – purpose meets need
Participant expectations	- Expectations were based on the initial phone call and consent process - Felt patients' expectations were met	Whakahua – purpose meets need
Home visit approach	- Home visits were about meeting the patients' needs	Whakahua – purpose meets need
Timing and Frequency	- Timing and frequency of the session worked well, but in some cases patients were distracted by the third session	Whakahua – purpose meets need

Resources		
Booklet	- Strength of the intervention. - Highlighting the text was a good tool when going through the booklet - Both positive and negative reactions from health practitioner in regard to patients taking the booklet to their healthcare appointments - One person out of 56 had negative reaction to the information in the booklet - Not many patients used the back notes in the booklet - Use of some Māori text was difficult to understand as some words were unfamiliar dialect or transliterations	Whakamahi – shift in practice
Application	- Effective teaching prompt for research nurse - The majority of patients watched the application once	Whakahua – purpose meets need Mōhio – shift in knowledge
Pill card	- Good visual tool - Usability was 50/50 - Blister pack and pill card in some cases had conflicting information	Whakahua – purpose meets need Mōhio – shift in knowledge
Perceived intervention outcomes		
Patients	- Medication-taking practices have improved, which has improved patients' health - Knowledge of their CVD medications has increased - Becoming more assertive when communicating with health practitioner - Becoming more proactive in monitoring medication scripts (may be an indication that they are taking their pills) - Noticed medication misprint and prescription - New knowledge of their CVD medications' side effects enabled them to approach GP to review medications - Personalised the booklet - Sought more medication information online - Communicate that they are participating in the intervention to their GP	Whakamahi – shift in practice Tūrangatira – engagement through presence Whanaungatanga – reciprocal and responsive relationships
Patient experience with research nurse	- Strength of the intervention - Excellent feedback about the effect the research nurse is having on the patients - Whānau communication - Different communication approach	Whakamahi – shift in practice Tūrangatira – engagement through presence Whanaungatanga – reciprocal and responsive relationships

Patient experiences with health practitioners	- Mistakes were identified by the patients when prescribing - Perception of health literacy has changed for some health practitioners - Practice with patients has improved - Patients do not understand (GP)	Whakamahi – shift in practice Tūrangatira – engagement through presence
Short-term perceived intervention outcomes (6–7 months)		
Structure	- Implement the intervention to all patients - Change the high-priority group from patients who have had an event to patients on preventive medication(s)	Whakawhanake – reflect to improve
Resources	- Would like to see the booklet replicated for other diseases - Patients would like to have a weekly meal plan in the booklet - Would like to see the inter-related reliability tool reviewed	Whakawhanake – reflect to improve
Patients	- Have become more proactive - Retained some of the information on CVD medications - Improved knowledge around medications - Excellent feedback on the research nurse - Excellent feedback on the booklet - Did not mention the pill card or application - Noticed medication misprint and prescription	Whakamahi – shift in practice Whanaungatanga – reciprocal and responsive relationships
Patient experience with research nurse	- Strength of the intervention - Excellent feedback about the effectiveness of the research nurse with the patients - Whānau communication - Different communication approach	Whakamahi – shift in practice Tūrangatira – engagement through presence Whanaungatanga – reciprocal and responsive relationships
Patient experience with health practitioners	- Individual understanding of health literacy - Intervention highlighted the need to improve health practitioners communication - Would like to see all health practitioners in the organisation receive health literacy training	Whakaaro – shift in mind Whakawhanake – reflect to improve

CVD = cardiovascular disease; GP = general practitioner.

Whanaungatanga

Whanaungatanga concerns relationship building between patients and health practitioners and the way structures and environments nurture and support relationship building. Health practitioners stressed that the design of the intervention to support relationship building was one of its effective features.

> **Matt:** . . . [the research nurse] is quite personable and quite caring, and that made the difference for the patients as they remembered her, and if they didn't know her or remember her they said, "I spoke to that lady about that booklet and it was good." She delivered it really well in an effective way and at that level for that person. So, if they were older and a bit different she would break it down. So, interacting with her was very important, and getting that population that appreciate the one-to-one interaction, people to come out and see them. (Second interview)

The research nurse's engagement skills coupled with time spent with patients in their homes were important features of the intervention. According to health practitioners, she spent time getting to know patients and their whānau as well as sharing information about herself and her interests. This theme is written about in more detail in chapters six and seven, specifically under the theme heading, *Whanaungatanga – Relationship Building*.

Takohanga

Takohanga covers health practitioners taking responsibility for patient understandings. This theme correlates with whakawhanake, as it was through reflection processes that health practitioners came to understand that the most important shift for them, in terms of understanding and professional practice with health literacy, was taking responsibility for patient and whānau understanding.

> **Jen:** When we had our nurses, they would say they've heard wonderful things about the project and the value the people are getting from it. Their level of understanding has improved, but I don't think that they realised that it has to start from themselves, like us. I still think that they don't understand that concept. I think we need to be looking at that a lot more. Because when you hear them talking about it, they're saying their understanding has improved, it's a lot better, but they don't talk about themselves. That's what I think: we need to fight as an organisation. (Second interview)

Jen articulated the vital shift from placing responsibility on patients for not understanding information or making behavioural changes to health practitioners reflecting on their own practice and taking responsibility for being clear with whānau. An identified strength was health practitioners utilising the three-step "ABC" model, delivered as part of the health literacy training: ASK what patient and whānau know, BUILD on their understandings and clarify misunderstood information, and then CHECK with patients and whānau what they have heard (Health Quality & Safety Commission New Zealand, 2013). Health practitioners considered the realisation that responsibility for health literacy lies with everybody was necessary for substantial systemic change.

Whakahua

This theme focuses on intervention purpose meeting patient need. Specifically, it covers health practitioners' perceptions, practices, and experiences of recruitment, baseline data, whānau participation, participant expectations, effectiveness of home visits, timing and frequency and implementation of sessions with the research nurse, as well as the resources: booklet application and pill card. Initially, health practitioners found that getting sufficient patient numbers was difficult as many CVD patients did not meet the specific criteria. As a result, the intervention project broadened its catchment areas to include two other areas on the East Coast. Health practitioners also stated that identifying patients was difficult due to the health system record keeping. Knowing patients personally made recruitment easier for the administration staff and the research nurse. Whānau participation varied with each patient and between sessions, as whānau might happen to be present but not participate in the intervention itself. The home visit approach was identified as a strength of the intervention.

> **Mereana:** I was just sort of trying to meet their needs rather than them meet mine because that just happens so often and that's where we fall down is because we expect to come to us and they can't always do that, so I think that's the most important approach to the intervention is to be able to get out there and meet them. (Second interview)

The booklet was identified as another strength of the intervention in terms of design, usefulness, and comprehension for both patients and health practitioners. Health practitioners shared their patients' experiences.

> **Jen:** We had a local doctor that visited, and a participant took in one of the booklets and he . . . flicked through it [and said] this [is] one of the best resources that he's ever seen, and he wanted a copy. (Second interview)

For the research nurse, the application was seen as an additional visual tool for the patients, but she highlighted that they were only interested in using it in the first session. The application was identified as an important resource for the research nurse, providing a structured teaching prompt. The pill card was also viewed as a useful visual tool by the research nurse, but results varied, with only half the patients reporting using it.

Whakawhanake

The whakawhanake theme is about health practitioner responses towards improving the intervention. It is about health practitioners reflecting on their experiences of the intervention, and expectations and future aspirations for the intervention for themselves, their patients, and their community. As suggested by patients, health practitioners wanted everyone in the community to be able to access the intervention and its resources, as well as extending its focus to incorporate other diseases.

> **Jen:** I would like to see a booklet based on diabetes medications, on the three main medications and insulin being one of them, the initiation of insulin at an early stage rather than the last option 'cause it can just do so much. (Second interview)

Health practitioners identified that, to support the effectiveness and success of interventions, the organisation needs to implement a comprehensive workforce development programme that includes health literacy practices.

Health Literacy in Action

Figure 8. Health literacy in action scale

Again, I present the action scale – this time from the health practitioner perspective of patients and their own perceptions, practices, and experiences of health literacy during the intervention.

Mōhio

This theme is about information becoming attained knowledge for patients. Health practitioners stated that patients gained new knowledge about their CVD medications and their side effects.

> **Matt:** Again, they retained it really well, so it just shows you that what was taught was taught well, even the ones that didn't even remember that well were still sort of "well, we spoke to [research nurse] yeah." (Second interview)

Health practitioners stated that the booklet was a strength of the intervention in terms of relaying and interacting with information about CVD medications at this stage. The application was an important teaching prompt, enabling information to be relayed in a structured and systematic method.

Whakaaro

Whakaaro is about applying a shift in mind, it is the recognition that attained knowledge created meaning for patients in terms of their CVD medication use.

> **Jen:** An ex teacher in [town] he said he sat with some so, so and so and they all talked about their pills, and he said once upon a time he could never talk about his pills. (First interview)

Health practitioners reported that patients valued their CVD medication booklet and gained a sense of security knowing they could refer to the information at any time. Health practitioners stated their health literacy practices need systematic support in order for all patients to benefit. The research nurse and kaiāwhina benefitted professionally from attending health literacy training and felt that all health practitioners need to be trained and coached to use health literacy approaches and services.

Whakamahi

Whakamahi is understood as shift in practice. It is about patients taking their *whakaaro* – contextual knowledge – and making changes to their behaviour around CVD medications. Health practitioners reinforced these findings and went further to say that patients' medication-taking practices improved their health and wellbeing.

> **Interviewer:** If the intervention had not taken place, what may have been some effects for the patients?
> **Mereana:** I don't know, for the amount of people that were out there that were not taking their medication like they should have been just randomly taking them, I'll take them if I remember or if I run out I run out, no big deal just get some next week, I think that we'll probably see a lot more people dying. (Second interview)

Attaining more knowledge around medication side effects led patients to review medications and discuss alternative options with the GP. At this stage, the booklet was a useful reference, as patients could check their practices were correct; this led to them identifying medication misprints and prescription mistakes. Some stated that patients became better communicators, more proactive about their health and were more confident in their interactions with health practitioners. Health practitioners noted that patients became more assertive when communicating with them, more proactive in monitoring their medications and blood pressure, and – in some cases – sought more medication information online.

For health practitioners, their understanding, awareness, and practice of health literacy all increased; however, the degree of change varied with the level of training and involvement in the intervention. The research nurse had the most exposure to training and involvement in the intervention and she spoke about how her engagement practices had improved significantly in terms of taking responsibility for patient understanding.

Summary

The health practitioner substantive findings were interwoven with those of patients and whānau, aligning with and giving similar accounts of patients' medication use, knowledge acquisition, and health literacy skill and engagement practices with the research nurse and their GP. The three health practitioner accounts were difficult to converge as they all had different roles and responsibilities that varied in terms of insight, knowledge, and exposure to the intervention; only the nurse and kaiāwhina received the intervention's health literacy training.

Health practitioners indicated that the intervention provided a foundation for patient understandings of CVD medications and tailored medication information and tools to facilitate communication with health practitioners. The most important strength identified was the health literacy training conducted by the intervention. The intervention delivered health literacy training to the health practitioners involved, which incorporated the three-step "ABC" model (ask, build and check) (Health Quality & Safety Commission New Zealand, 2013) into practice. These health literacy practices were vital to the effectiveness of the intervention sessions with patients. Health practitioners made a conscious shift in their practice and took responsibility for not being clear if whānau did not understand, instead of focusing on patients as not understanding.

Aligning with patient accounts, health practitioners wanted people on preventive medications to complete the intervention and wanted all health practitioners to provide support for and access to ongoing health literacy training. They also highlighted the most effective areas of the intervention as its home-based, one-on-one, structured nature, which was founded on practices and engagement – whanaungatanga and tūrangatira.

Key Informant Findings

The six key informants were Indigenous health practitioners who had knowledge and experience working in the health literacy field. Only one key informant was directly involved in the development of the intervention.

Key informant themes centred on five identified collective values and principles: maia – transformation through action and usefulness; mātauranga – reclaiming and defining health literacy practice and evaluation; atawhai – capacity and capability building and contextual understanding; ngakau tapatahi – ethical and moral conduct; and whakahautanga – relational practice.

Table 11 explores key informant themes in detail. Themes are structured around collective values and principles, moving to visions and aspirations and how they relate to health literacy practice, health services, and health system.

Table 11
Key informant themes

Collective values and principles	Visions and aspirations	Health literacy practice	Health services	Health system
Maia Courage	- Transformation through action and usefulness	- Every health practitioner is responsible for health literacy and promoting and engaging in good health literacy practice	- Indigenous leadership and management	- Health literacy leadership to develop and flourish
Mātauranga Wisdom	- Reclaiming and defining health literacy practice and evaluation	- Provide supportive environments that acknowledge whānau knowledge and power	- Prevention and wellness pathways/approaches	- Strategic guidance to the health sector on health literacy activities and holistic healthcare
Atawhai Compassion	- Capacity and capability building and contextual understanding	- Health practitioners work in ways to build and improve patient and whānau health literacy	- Health literacy planning - Tailor resources, initiatives and programmes that reflect quality ethnicity data	- Building quality research and evaluative approaches, initiatives and resources aimed at reducing health literacy system demands
Ngakau Tapatahi Integrity	- Ethical and moral practice	- Willingness to connect - Cultural safety and competency practices	- Collaborative service approaches	- Redesign systems to support relationship building at all levels health practitioner/patient and between services
Whakahautanga Self-mastery	- Relational practice	- Health practitioners skilled in facilitation and knowledge sharing	- Supporting and encouraging health literacy training and practice	- Incorporate health literacy concepts into recommendations and system design

Maia

Maia – courage – relates to boldness, purpose, resistance, leadership, ambition, and grit. The vision for this theme is around action and usefulness; it is about honouring the collective priorities of Indigenous communities that we serve in order to support and advance Indigenous aspirations. In this context, it encompasses the key informants' discussions around promoting and coordinating action to raise awareness of and build skills in health literacy practice.

> **Sarah:** I think whānau have a role [in health literacy] no doubt about it, I think the health system has a role and healthcare providers have a role, so whether you're a DHB, PHO or a primary care practice or Māori health organisation you have a role, and I think health professionals have a role. So, there is this old saying in literacy that literacy is everyone's business, so I think health literacy is everyone's business. Because if you take out whānau that means you have taken out the pull, I want to know, so basically you end up with a push strategy but if this system started to say look what makes it hard for you to explain to whānau and says to our whānau what parts don't you understand, it's a big shift. (First interview)

Key informants discussed ways in which health services focus on implementing and maintaining Indigenous leadership and management in the health workforce and organisations. Discussions centred on the health system providing policy guidelines for organisations to develop health literacy leadership pathways. How this is operationalised is an issue.

> **Caroline:** The ministry, they do see it as a system issue – they use levers and policies and they say "yes, it is about how we design things," a reasonably easy thing for them to see but they design the system. But they don't actually have that much of an influence on day-to- day care, GP practice, that's professional practice, private business; they are more likely to have an influence over DHB design but not

> doctor practice, so they are always courting this kind of tension. They are trying integrated services and putting incentives in place to encourage providers to work together and all that sort of thing, but you could still have people doing it entirely their own way and that’s still legit that’s in the clinical realm, that’s outside of us, that’s at the college of GPs so I mean for DHBs it works better ‘cause they are more publicly funded but it’s like turning a ship, turning a university. (First interview)

Mātauranga

Mātauranga – wisdom – means to enlighten or illuminate. It is concerned with the ability to apply experience, knowledge, and judgement to enlighten and assist a situation. The aspiration for this theme is about reclaiming health literacy as an Indigenous practice and being able to define what effective and successful health literacy practice and evaluation looks like in our communities. From key informants’ perspectives, important considerations for health literacy practice are providing supportive environments, cultural protocols, native language, and intergenerational connections to build relationships and promote care. Health literacy was described as health practitioners appreciating and valuing patient and whānau (family, extended family) structures.

> **Caroline:** For [whānau member] it was, “I don’t want to be on too many pills,” and his GP says, “well that’s fine and we will keep assessing until we get you onto the minimum level that keeps everything going well.” So, he asks that kind of question – “what would being healthy mean to you?” And I sit in there with him when he is having these discussions and the doctor talks to him, even though he’s really deaf, he talks to him and I’m sitting there, and he doesn’t talk to me instead, which is great because he knows why I’m there because I just need to know what is happening. So, he asks him those questions, he takes lots of time and he tried to meet his health goals for what it means to be healthy.

Key informants referred to effective health literacy practice as prioritising and investing in prevention and wellbeing pathways/approaches – meaning tensions between the clinical agenda and the patient-centred agenda need to be identified and reduced.

> **Nina:** There is this enormous tension between the clinical agenda, I have to do these things and get them ticked off, and actually we want to become a patient-centred system that requires an entirely different set of skills and an ability for the nurse to make the call and say, "actually I'm going with the patient-centred agenda today." It's this simple, just have a little quadrant, "today I'd like to talk about how you have been going for the last three months, how that has been going for you? Then I would like to talk about your tests, so what would you like to talk about?" So, it's like you get to choose. (First interview)

Health literacy skills were not just discussed as tools of practice encompassing contextual awareness but also as balancing between bio-medical and patient-centred systems when needed. Key informants suggested that the role of the health system is to provide strategic guidance to the health sector to support literacy activities, prevention, and wellbeing approaches.

Atawhai

Atawhai – compassion – evokes different emotions depending on the situation, environment, and context. It relates to empathy, forgiveness, thoughtfulness, support, sincerity, kindness, love, positivity, and sympathy. The aspiration for this theme is about making a positive difference in our communities while building capacity, capability and contextual understanding.

One key informant, Sarah, a Māori health literacy expert, provided insight into the difficulties of implementing change within organisational structures. She emphasised that individuals understood what needed to take place in terms of becoming more effective in health literacy practices. However, depending on the realities of resources and staffing levels, funding and competing priorities, and the political climate, organisations may not be so responsive.

Another Māori health literacy expert had a similar view, but from a wider systemic perspective.

> **Caroline:** I think it's a flaw in many systems, within the health system that the idea that as long as you have some consumer representatives on the health board you will get services that meet community needs and it's unfair to expect the least informed to make decisions that are meant to sway the informed majority of clinicians or whoever are on these groups, so it doesn't really work either when you have minority trying to influence majority. (First interview)

Caroline highlighted the importance of making sure community voice is heard within a process that values community input and where collective understanding is sought. Considering that issues may arise during the research process, the context in which concerns are voiced and presented is worth analysing since communities may be unaware of the specific systemic, organisational, and clinical tensions in play. Community perspectives can be invaluable, as they are not bogged down with trying to think about issues within the health system but can be a hindrance if their advice is too far removed from such an understanding. Caroline's observation was followed by criticism of health practitioners because of their inability to understand the complexity of community understandings of health issues.

> **Caroline:** The other thing health professionals say is that we need to test people to see what their health literacy is . . . [the] Ministry knows that that's just a deficit

> approach, it's not where things need to be, they very much have supported a system service approach rather than diagnose an individual deficit and treat them differently from that point on cause that's just dumb and then you blame the patient and all sorts of things. (First interview)

Caroline argued that health literacy approaches need to be implemented at a service level, where organisations are supported by the system to implement effective health literacy policies. They can provide adequate training for management and staff, which can in turn impact on the type of service patients are receiving. This is an important observation, as communication between patients and health practitioners is vital to the success and maintenance of effective health pathways for patients. This approach was implemented as part of the parent project, which provided health literacy training for management and staff at both Māori organisations after the intervention was completed.

The issues of communication breakdown are eloquently summarised in the following excerpt from Sarah's interview.

> **Sarah:** I think too, believing that whānau have stuff already for me is the biggest issue of the three-step model, they know stuff, it may not be perfect, and it may have myths, but they know stuff and unless you find out what they know and if its imperfect address it and if it's perfect build on it, whatever you have you gotta build on it [otherwise] you're wasting your breath because if you're telling something that where there is a strong dissonance with what they believe, it's gone, it's like "I don't believe ya, sorry doc but that's not what my Nan told me." (First interview)

The three-step model Sarah is referring to is assessing ABC (Health Quality & Safety Commission New Zealand, 2013). This is a clear example of how to positively communicate and build on people's strengths.

At the health practitioner level, key informants talked about health literacy practice as working in ways to build and improve patient and whānau health literacy – using plain language and proven health literacy practices.

> **Caroline:** we worked with a couple of DHBs to review their services from a health literacy perspective and I think for each of them it's been a real surprise that even though we have interviewed consumers it hasn't been a customer service review, what we have done is transcribe the conversations we have observed, in reception, over the phone, with a clinician and follow-up, so helping staff see that has probably been more helpful for them to recognise that it's not just their customers, or clients that don't understand them, they actually do make this really hard because of the way information is delivered. We provided a kind of independent view of what was happening so it's easier for them to see health literacy issues when it's a third party pointing out just what happened so they can sort of see it themselves, you know this is what was said – so you can understand why that confuses the heck out of people and they are like "oh yeah," whereas if a client says "I found it a bit confusing," that's easily dismissed as an individual's issue. (Second interview)

Key informants suggested that effective health literacy practice at the health organisation level means encouraging and creating collaborative approaches between health literacy practising organisations, the health workforce – and sharing resources when possible. More broadly, at the health system level, participants discussed redesigning systems to support relationship building at all levels: between patients and health practitioners, between practitioners, and between organisations.

> **Nina:** I think health literacy should underlie a system and every health target should have to be patient centred or health literacy, patients should have the knowledge and skills they need to manage this process, the system should be integrated, streamlined to make it easier to access and the health professionals should have the cultural competence to communicate perfectly and have the health literacy tools to build patient knowledge. (First interview)

Ngakau Tapatahi

Ngakau tapatahi – integrity – builds on concepts of tika and pono by adding an overarching expectation of ethical and moral conduct. For health literacy, ethical and moral practice means that health practitioners must have a genuine willingness to connect with patients and have a good understanding of their own power, culture, and identity. Key informants spoke of successful health literacy practice as being reflective – working on improving health literacy practice and communication.

> **Jane:** So, in health literacy it's really common for health professionals, when you ask them what would improve this process, for them to say, "oh we don't give them enough information about X – what we need is a resource, a written thing, so when they go home we can give that to them, it can tell them what to do." That's never the answer, but you can easily start producing all of that stuff, it's part of an answer but you can never write specific enough cases but what you actually need is someone talking to you about what you need to do and what you need to look for in your case and in the book here there are pictures of what you might want to look out for . . . what you need to do is train the health professionals to work differently around communication and if it is using the resource it's about them using the resource and arguably it's about working with the practice to ensure that there's time for these people to have those conversations. (First interview)

Key informants suggested that the health service role requires a commitment to organisational health literacy planning that involves review of signs, directions, use of plain language with forms, resources, educational material both in print and online, as well as tailoring resources, initiatives and programmes to reflect quality ethnicity data. Key informants spoke about a systemic responsibility for health literacy by building quality research and evaluative approaches, initiatives, and resources aimed at reducing health literacy system demands.

> **Carol:** [Organisations] can encourage people to use what they know and having to work differently and think about changing themselves [health practitioners]; it's a lot easier than trying to change the patients. And they have got to start thinking about themselves. They need to start thinking about their people yes, their service design, their policies and their integration with other services. The changes are going to be difficult, but professional development is relatively straightforward in the workforce, and if they are still stuck in 10-min consults, they need to address that. (First interview)

Whakahautanga

Whakahautanga – self-mastery – covers the interdependency of wisdom and self-mastery and is the ability to modify behaviour and actions for a desirable effect. The vision for this theme is about the promotion of relational practice, which involves being industrious, having perspective, being willing to collaborate, and showing humility, engagement, preparation, consideration, and reflection.

It appears that, in connecting with Indigenous communities worldwide, there are important similarities. Nina, an international Indigenous educational expert from Canada, spoke about the importance of relationships when collaborating with communities. I asked about how she effectively engages with communities in her work.

> **Nina:** Individualised relationship building is key to working with native communities, one of my elders told me one time that to do true community development you need to drink 10,000 cups of tea, and I've taken that to heart. I got to get to know people; I've got to go to where they are . . . This is not just some faceless email address requesting something from them, that the most important things we can do working with communities, that has to be the priority, get out there introduce yourself, say I'll do the best I can to get you what you need, I'm that facilitator I can get you what you need, I can be culturally sensitive to that as well cause I'm not working within my own nation, I'm working with Cree people, Algonquin people, Mohawk people. So I have to be aware of some of those

> protocols and make sure I don’t offend people, and I think when non-native people go into communities thinking they know best they offend and just shut down, that’s one of the most important things for me to do . . . I don’t have to speak with the chief in council in terms of traditional protocol, so I don’t have to be too formal in terms of engagement in that sort of official way, but if I ask for something specific I’m going to bring tobacco, I’m going to bring a small gift, I’m going to show that I’m serious about what I’m doing, and I’m not just there on behalf of my organisation, I’m there because I do really wanna do this work.

Nina highlighted the importance of relationship building, sensitivity, and context when working with Indigenous communities. She explained the tikanga she follows, which closely resembles the kaupapa Māori evaluation principles highlighted in this research. This includes the importance of kanohi kitea, manaaki, whakapapa, whanaungatanga, tūrangawaewae, and koha while striving to meet their needs and being culturally sensitive. Collaboration takes hours of relationship building, trust, and commitment. Nina emphasised the importance of this as she has built her community relationships over 25 years, through guided traditional practices of reciprocity, mutually beneficial relationships, and relational understanding.

Key informants suggested that health literacy practice means health practitioners being skilled in facilitation and knowledge sharing. They spoke about practitioners continuing to reflect, examine, and evaluate their practice. Sarah suggested that health practitioners always offer patients options to build their health literacy knowledge and skill.

> **Sarah:** I think we need to give people information about things so that at least they are informed decisions; they are not decisions that are being made on limited information. So, if you had a patient who decided to not take their medications at least you would know they were fully informed about their decision, that’s their

> choice, and they have a right to that, no matter what you say, but at least you are not thinking you could have done something differently. And I think we should never give up too, someone was talking to me about whānau not wanting to be involved in screening like cervical or breast screening and I say that's absolutely their choice, but I say "Whaea, I understand today, this year you don't want to be screened but in a years' time I will come and talk to you again and you can tell me then you still don't want to, but I'm coming back in case you may have changed your mind." Because I think you need to go back, you don't want them sitting there thinking maybe I do need to. (First interview)

Within health services, key informants recognised that health literacy practice requires organisations to support and encourage health literacy training and practice, implement incentives, extend consultation times, and provide supplementary and complementary resources and environments. At the health system level, key informants spoke of health literacy practice as incorporating health literacy concepts into recommendations and system design to equip individuals and whānau to live well and stay well, manage any conditions, navigate the health system, communicate effectively, and make informed decisions.

> **Caroline:** I think that family developing solutions that work for them is what you want for a health literate population but you need to ensure that there's the expertise being offered to that group to be able to do that, you know that there are a lot of expectations on people to develop solutions and know what would work best without really providing them with the input to make those decisions, so I suppose health literacy takes that one step back to who's providing that and how, who is resourced to do it? (Second interview)

Summary

The key informant findings differed from those of the patients and health practitioners as they were not directly involved in the intervention. Instead, they were asked questions around what, in their experience, effective health literacy practices, interventions, and approaches involved. Fundamentally, their accounts centred around the vision and aspirations of the communities and peoples they collaborated with, connected to, and served. Their accounts provide the foundation and basis of what effective Indigenous health literacy practice may look like and significantly informed the development of the emerging *Ngāti Porou Hauora Health Literacy Evaluation Framework* (chapter eight).

Key informants' broad insights converged with patient and health practitioner accounts in a way that gave their accounts structural and systemic perspective. The focus of the intervention was highlighted as centring on basic functional literacy, numeracy skills, and communicative–interactive (applying information to changing circumstance) skills related to medication use. For example, the responsibility for building health literacy skills with patients and whānau was seen as lying with front-line health practitioners, specifically some nurses and kaiāwhina. However, as the key informants pointed out, this focus is a limited approach to improving health literacy with health practitioners and Māori patients and their whānau. The key informant findings inform a broader systematic and multilevel practice and understanding of health literacy and the complexities involved, particularly within the overarching domain of health systems/services.

Conclusion

The main aim of the kaupapa Māori health literacy evaluation was to evaluate the effectiveness of the *Cardiovascular Disease Medications Health Literacy Intervention*. The overall findings of the evaluation provide a contextual understanding around patient and health practitioner experiences, beliefs, and practices, reviewed in light of broad key informant insights into effective health literacy practice.

The effectiveness of the intervention approach for patients and health practitioners, based on building on patient knowledge of CVD medications, centred on five core themes: whanaungatanga – reciprocal and responsive relationships; takohanga – responsibility for understanding; tūrangatira – engagement through presence; whakahua – purpose meets need; and whakawhanake – reflecting to improve.

The evaluation underlined that health literacy – obtaining, processing, and understanding health information and services – entails a complex, varied, fluid, and – often – conflicting state for patients. According to patients, health practitioners, and key informants, the woven strands of effective health literacy practice are grounded in whanaungatanga – relational, reciprocal, and responsive relationships, based on criteria of active collaboration, shared power approaches, partnership, collaboration, and deliberative engagement. The health practitioner role in effective health literacy practice is orientated around taking responsibility for whānau understanding and taking ownership of their communication practices, rather than focusing on patients as not understanding. The key informant findings highlight a valuative approach to the effective practices of health literacy, focusing on systemic impacts at all levels of the health system.

These findings highlight the complex and contextual nature in which health literacy exists and the challenges of achieving healthier lives for Ngāti Porou peoples. Considerations for change need to move beyond intervention efficacy to concerted efforts to understand participants' lived experiences and ways of knowing and being in the world. Without this appreciation, research interventions can fail to translate into meaningful patient care outcomes (Damschroder et al., 2009).

FINDINGS: SECTION TWO

This section consists of four chapters in the form of published papers. Chapter five: *Kaupapa Māori Evaluation: A Collaborative Journey* begins by providing the background context to the development of the published paper. I then explain my doctoral journey in more detail relating to the positioning of my research in regard to the responsibilities and relationships involved. The paper – co-authored with my supervisors Helen Moewaka Barnes and Tim McCreanor – is written in first person narrative to acknowledge and underscore that the content is centred on my reflections as a kaupapa Māori researcher/evaluator. I begin with a discussion of my value-based collaborative journey through the kaupapa Māori health literacy evaluation project. I explore the complexities involved in navigating kaupapa Māori approaches within a colonial system that perpetuates Western thinking and practice.

Chapter six: *Whanaungatanga – A Space to be Ourselves* starts with background information on how the paper was formed. I then introduce health literacy in relation to its evolution and practice. The paper is co-authored with my supervisors and my colleague, Māori health literacy expert, Susan Reid. In the chapter, I draw attention to patient–practitioner relationships, healthcare relations, and health literacy in Aotearoa, arguing that the interpersonal dynamics of health literacy are key in understanding how it might be more effective in the context of Māori communities.

Chapter seven: *Health Literacy in Action,* co-authored with my supervisors, begins by describing various interactions that arose from sharing the ideas at Indigenous conferences. I introduce the chapter by presenting the theme of medication use, which explores patient experiences, practices, and understandings. The chapter builds on the practice of health literacy explored in the previous chapter by examining the intervention. I argue that the responsibility for improving health literacy lies with multiple stakeholders, including those involved in making substantial systemic change. To illustrate the multiple areas of responsibility, I present a kaupapa Māori health literacy evaluation framework.

Chapter eight: *The Power to Define* addresses the development of an indigenous health literacy framework and begins with background information and then details the method of developing the framework with the research advisory group. The particulars of the framework development process present a clear picture of how the principles, goals, and action areas were identified and defined. The chapter is centred on reclaiming health literacy as a practice that we as Māori have been enacting through our ways of knowing and understanding for thousands of years. I propose *re-writing* and *re-righting* the historical account and practices of health literacy as a practice shared by Māori. The process and development of the framework provided pathways to reclaim the action areas and goals of health literacy specifically in the historical and contemporary context of Ngāti Porou.

LINK ONE

The following chapter, *Kaupapa Māori Evaluation: A Collaborative Journey*, documents the beginning of my evaluation and doctoral journey. It was the hardest paper to write, had the most iterations, and took the longest to finalise. It was the most personal and reflective piece and was born out of the emotional turmoil and frustration that I faced nine months into my preliminary year at Auckland University, when staff changes meant I had to relinquish my candidacy and scholarship and enrol at Massey University.

Material from this chapter was presented at the Aotearoa New Zealand Evaluation Conference in 2012,[12] and the Evaluation Research Community Psychology Evaluation Class in 2012 and 2013.[13] The presentation *A Journey through Kaupapa Māori Evaluation* covered evaluation methodologies and kaupapa Māori theory and research. I discussed the methodological considerations and complexities involved in collaborative research and the considerations I grappled with when centring my research as kaupapa Māori.

After the presentation at the conference, many attendees provided words of support and invitations to collaborate on future projects. A lecturer invited me to present to her evaluation class later in the year and again the following year. After both presentations, the students asked methodological questions relating specifically to their own evaluation projects and how they might overcome collaborative challenges they faced

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[12] Carlson, T. (2012, July). *A journey through kaupapa Māori evaluation*. Paper presented at the Aotearoa New Zealand Evaluation Conference 2012, University of Waikato, Hamilton, New Zealand.

[13] Carlson, T. (2013, July). *Research methodologies and analysis*. Paper presented at the Evaluation Research Community Psychology Evaluation Class, University of Waikato, Hamilton, New Zealand.

in their community contexts. At this stage, my reflections/findings were in their infancy; these discussions were an important part of developing and refining my ideas and experiences in a supportive environment.

My final presentation in relation to the chapter was at the MAI Ki Pōneke Māori Doctoral Conference 2016, at Victoria University in Wellington.[14] The conference was a space for Māori/Indigenous doctoral students to share their research in a supportive environment, from the pre-doctoral stage through to candidacy, enrolling, and graduating. The presentation, “What does Kaupapa Māori Evaluation Look Like?”, was drawn from the finalised paper, later submitted to the journal, *Evaluation Matters – He Take to te Aromatawai*. I drew on four core themes: collaboration; titiro, whakarongo . . . kōrero – my ethical approach to the research; contextual understandings of the research methodology; and participant priorities and voice. In the presentation, I wanted to engage with the audience in a way that gave meaning beyond words and speech. Drawing on my artistic style, I painted a picture while presenting. I began with an abstract image that appeared visually dislocated, fluid, and non-complementary to the themes on which I was presenting; however, this process was purposeful. I wanted the audience to strive to make sense of the image – to try and “connect.” I wanted people to experience confusion and misperception, mirroring parts of my reflective, emotional, and practical responses to the kaupapa Māori journey. I then asked audience members to read out loud – one at a time – from pieces of paper that had core themes

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[14] Carlson, T. (2016, December). *What does kaupapa Māori evaluation look like?* Paper presented at the MAI Ki Pōneke Māori Doctoral Conference 2016, Victoria University, Wellington, New Zealand.

from the paper: collaboration, context, reflexivity, participant priorities, and power. I carried out this exercise to emphasise participant voice; it also helped me to structure my presentation while continuing to draw and complete the artwork presented in this thesis at the beginning of each chapter. I received comments of support and appreciation. Session leader, Associate Professor Leonie Pihama, stated it was "exciting to see the future development of kaupapa Māori evaluation, its contribution to kaupapa Māori and its transformative potential." After the presentation, I also handed out copies of the journal article for feedback and comment.

I collected data and conceptualised and drafted the paper; Tim McCreanor provided feedback and revisions; Helen Moewaka Barnes provided feedback and final revisions. This chapter was submitted to the journal *Evaluation Matters – He Take to te Aromatawai* in December 2016. Peer reviewers provided excellent comments and feedback. I received notification on 16 February 2017 that the paper was accepted for publication subject to revision. The revised version was submitted on 3 April 2017, and the paper was published on 19 June 2017.

The journal submission process afforded me the opportunity to publish a paper alongside my supervisors, leaders in the field of kaupapa Māori evaluation, and go through a peer-review process led by the editor, Dr. Fiona Cram, whom I extensively reference in all my doctoral work. This paper was written for evaluation practitioners, social scientists, social policy analysts, and people teaching and studying in the fields of evaluation and social policy analysis.

The paper is available online as an open access article:

http://www.nzcer.org.nz/system/files/journals/evaluation-maters/downloads/Evaluation%20Matters_07_Carlson%20Moewaka%20Barnes%20and%20McCreanor_prf1.pdf

The paper has been uploaded on Academia.edu – to date, it has had 80 reads and 20 downloads. The paper has also been uploaded on Research Gate.net – to date, it has had 60 reads and 12 downloads.

The chapter is a reflective personal narrative of my practices as a kaupapa Māori evaluator, exploring the complexities involved where kaupapa Māori evaluation was a guiding construct, and detailing the successes as well as the considerable challenges.

CHAPTER FIVE: A COLLABORTIVE JOURNEY

[15]

Adding fine lines to complement the space. It might look messy and abstract but meaning is starting to form. I write in my journal.

I feel an inherent responsibility to amplify the voices of my people. For so long, our stories have been told for us, about us, and to us. Our histories have been told from a colonial perspective for hundreds of years, and now it is time for us to take back the narrative. You can remove us from our lands, remove our languages, our traditions, the very root of who we are. You can expose our people to institutionalised racism and have policies that are meant to wipe out an entire population and then expect us to come out well and healthy? How we can go forward?
It is hard to imagine what decolonisation looks like, but I know how it will feel. It will feel like us, like we have arrived home.
Research Diary Entry, Aug 2014

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[15] Teah Carlson, Painting my gaze – who I am, what I have learnt, and what I see, 2017
Liquid chalk on black card, 637 × 415 mm, Private collection, Auckland

Abstract

The interpretation and practice of kaupapa Māori evaluation take many forms, each involving its own set of considerations, challenges, and outcomes. This paper explores the complexities involved in a collaborative journey through an evaluation project where kaupapa Māori evaluation was a guiding principle, highlighting its successes and challenges. The evaluation aimed to benefit Ngāti Porou Hauora, a Māori health provider, and the community it served, by evaluating the effectiveness (as defined by the community) of a health literacy intervention. Ultimately, kaupapa Māori evaluation in this project was about meeting the aspirations of co-ownership, mutually beneficial outcomes, and shared power by prioritising the participants' voices to shape and develop the criteria to determine the effectiveness of the intervention. Stakeholders' understanding of health literacy and the intervention varied, making the vision of collaboration more complex as individuals worked through personal, community, and organisational implications.

Introduction

Māori have had negative experiences as subjects of research, which has often served to advance colonial powers (Bishop, 1999; Cochran et al., 2008; Smith, 2012). In more recent years, there has been a shift to Māori re-purposing research, with kaupapa Māori an influential part of turning the tables on academic research methods and practices (Cram, 2016; Kerr et al., 2010; Masters-Awatere, 2015). This shift has allowed Māori issues, concerns, ways of understanding, and practice to be placed at the centre of research enterprise rather than on the fringes. Principles and practices developed by

Māori, such as those of kaupapa Māori evaluation, can be applied effectively from the beginning of a research journey.

Descriptions of kaupapa Māori research range from broad guiding principles to more prescriptive notions. Taking the commonly agreed broad principles as a framework, the evaluation concerned itself with being led by Māori, collectivity, and transformation (Kerr, 2011; Moewaka Barnes, 2006). In applying these principles, the evaluation set out to develop approaches based on connections, partnerships, and collaborations. However, discrepancies can emerge between expectations and practice as researchers and research “partners” grapple with real-life contexts. This paper explores the complexities involved in a collaborative journey through an evaluation project where kaupapa Māori evaluation was a guiding principle, highlighting its successes as well as some considerable challenges.

My (Teah Carlson’s) research involved the conduct of a kaupapa Māori evaluation established on mutually beneficial foundations, where the goal was for Māori stakeholder groups to become co-designers and researchers, from the inception of the research through to the end. The evaluation aimed to benefit Ngāti Porou Hauora, a Māori health provider, and the community it served by evaluating the effectiveness—based on perceptions, practices, and experiences (as defined by the community)—of a health literacy intervention in their catchment. Within the intervention, health literacy was defined as “the ability to access, understand and act on information for health” (Nutbeam, 2008, p. 2076). The intervention was part of a larger international collaborative research project on cardiovascular disease medication health literacy interventions, the Aotearoa component of which involved one rural and one urban Māori health provider organisation. Both providers were involved from the outset with co-designing the larger project, both as active partners and as part of the research team. In addition, Ngāti Porou Hauora (the rural organisation) was invited to be a part of a kaupapa Māori evaluation process that would evaluate the intervention with Ngāti Porou Hauora participants and provide a framework that Ngāti Porou Hauora could utilise for other health literacy interventions.

As a descendant of Ngāti Porou, I had direct connections to the project and wanted to contribute to the positive development of my iwi by utilising research in a way that had real-life, community-based meaning and outcomes. I wanted the research to be an evolutionary process, where learning and changes were made along the way by all parties, me included. I envisaged that the research would allow me to engage in a collaborative process and gain experience in this area. Finally, as part of my doctoral study, I needed the research to address my own doctoral research questions and enable me to complete a thesis. I was supported in this by my supervisors, the co-authors of this paper.

As an iwi member, I was both an insider and positioned outside the community (Smith, 1999a). I am an insider as I am of Ngāti Porou descent, and the majority of my whānau still reside in the rohe and are current users and/or employees of Ngāti Porou Hauora services. I am also positioned as an outsider because I attend university away from home and no longer live in the takiwā, and I have received a Western education. However, my connections and responsibilities will always remain with my iwi.

Kaupapa Māori

Kaupapa Māori originated out of concern for the unjust and harmful impacts endured by Māori at the hands of Tauiwi researchers (Eketone, 2008; Smith, 1997; Smith, 1999a; Walker, 1996). Kaupapa Māori theory (Smith, 1997) is the foundational lens for kaupapa Māori research and kaupapa Māori evaluation. Kaupapa Māori evaluation is an evaluative method that seeks to explain, measure, and assess the quality of an intervention on the basis of how it relates to Māori and obligations that need to be considered under Te Tiriti o Waitangi[16] (Moewaka Barnes, 2003). Kaupapa Māori theory, research, action, and evaluation are critically oriented, methodologically eclectic, and encourage rigour while celebrating diversity, community-centred approaches, and the expanding sense of understanding of the realms of Te Ao Māori (the Māori world). Kaupapa Māori research describes the everyday, taken-for-granted practices and knowledge of Te Ao Māori (Moewaka Barnes, 2000b). As an approach, it places emphasis on the collective voice on the basis that we are all subjective beings enmeshed in our perceptions of reality. Kaupapa Māori research has played an integral role in reorienting social science research practices by creating a space for Māori to honour our histories, world views, and knowledge. However, we still recognise the continued impact of the colonial discourse (Smith, 2012), including a rationalising impetus from science that sidelines these approaches and too often justifies a status quo of Māori marginalisation and disparities.

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[16] Te Tiriti o Waitangi: signed in 1840, the Treaty of Waitangi is an agreement between the British Crown and the Māori peoples of Aotearoa. The treaty essentially characterises a relationship between the Crown and iwi Māori, which, through a mutually beneficial partnership, intended to ensure the wellbeing of all people in Aotearoa.

In terms of practice, kaupapa Māori research can align closely with the principles of action research (Kerr et al., 2010). Both approaches emphasise community voice, collective understanding of issues, and developing participant definitions, processes, actions, and outcomes. As a result, they both draw attention to areas of strategic importance by revealing real and pressing issues for the communities and participants concerned. Action research also complements kaupapa Māori research because it includes a reflective cycle that ensures the research approach, processes, and outcomes are not a fixed or static modality but rather are flexible and adaptive (Kerr et al., 2010).

Notions of collaboration are used widely in descriptions of kaupapa Māori research, and by definition they are context specific. Collaborative approaches are grounded in the recognition of an interconnectedness and commonality of experiences as Māori, whānau, hapū, and iwi members, health consumers, and health workers. Collaboration is about the collective process of theorising participation and co-designing opportunities for the involvement of iwi representatives, community members, and managerial, clinical, and community staff in all stages of the research (design, data gathering, analysis and interpretation, dissemination). Examples of collaborative approaches that facilitate and underpin a collective process include “whitiwhiti kōrero” (reflexive/spiral dialogue) (Holmes 1992, cited in Bishop, 1996, p. 104), “co-exploration” (Diller 1993, cited in Noddings, 1995, p. 93), “collaborative storying” (Connelly & Clandinin, 1990, p. 336), and “spiral discourse” (Bishop & Glynn, 1999, p. 119).

Collaboration goes beyond notions of being *responsive to Māori* and conducting research in a *culturally appropriate* way towards a more reciprocal, mutually invested and beneficial approach (Cram, 2015). Durie 2005 (cited in Ahuriri-Driscoll et al., 2007) describes collaboration approaches as providing a platform for different knowledge systems to be validated, explicitly considering the short- and long-term benefits for stakeholders, conducting research respectfully within research teams and with research participants, and placing emphasis on exploration, innovation, and transformation. Collaboration recognises that learning and expertise are held by all stakeholders (Cram & Lenihan, 2000). Collaboration can also involve researchers going beyond their immediate responsibilities to the research. Researchers can contribute unforeseen benefits to the research collaboration, for example, skills transfers and capability building (Ahuriri-Driscoll et al., 2007). Descriptions of collaboration in kaupapa Māori research also include a commitment to continuously critique power effects through reflection and collaboration processes (Gifford & Boulton, 2007).

According to Cram and Lenihan (2000), Kerr (2012b), and Moewaka Barnes (2009), in utilising kaupapa Māori theory and research, kaupapa Māori evaluation can be described as seeking, exposing, and highlighting the practised and lived realities of Māori using Māori forms of enquiry and accountability measures and criteria. Kaupapa Māori evaluation can provide the evidence needed to assist an organisation, programme, project, or initiative to find areas for improvement or to generate an assessment of overall merit or worth (Davidson, 2005; Scriven, 2003). It is an evaluative practice that privileges processes rather than outcomes and determines merit and worth through a collective and collaborative process (Cram & Lenihan 2000; Jackson, 2000; Wells et al., 2008).

Kaupapa Māori evaluation practitioners describe processes of exploration, innovation, and explanation (Cram & Lenihan, 2000; Kawakami et al., 2007) in pursuing information and knowledge formed through the lens of Te Ao Māori (Kerr, 2012a). As a reflective and analytical process, kaupapa Māori evaluation is about determining the merit, worth, and value of something against a collective Māori good, for instance, how a programme may align with the goal of tino rangatiratanga (Kerr, 2012a). Reflection has the potential to highlight strengths and the potential for change and to assist in the development of pathways forward. More specifically, this can be done by making assessments and judgements within a Māori evaluative framework (Masters-Awatere, 2015).

Kaupapa Māori evaluation shares its approach with empowerment evaluation because it recognises social problems and strives towards social justice through capacity and capability building, mutual respect and accountability, community ownership, and community knowledge. However, kaupapa Māori evaluation is specifically focused on the emancipation of Māori, striving towards tino rangatiratanga, transformation, and a space that is uniquely and unapologetically Māori. A kaupapa Māori evaluation approach does not have an entry and an exit point along the research journey; it is an ongoing relationship that can evolve and grow depending on the level of collaboration and partnership between the stakeholders and the evaluator (Cram & Lenihan, 2000).

The interpretation and practice of kaupapa Māori vary across disciplines and contexts, and its methodologies are fundamentally complex, collectivist, and evolving (Bevan-Brown, 1998; Levy, 2007; Smith, 2012; Te Awekotuku, 1991; Walker, 1996). Moreover, stakeholders and participants, as well as researchers, are all explicitly located within whānau, hapū, and iwi realities (Walker, 1996). Kaupapa Māori evaluation is a local performative endeavour rather than one where practitioners are looking for universalities. Kaupapa Māori evaluation is context specific, always has historical significance, and is grounded in the politics, circumstances, and economies of local people, focusing on movement within localised settings to confront and break through local systems of domination (Bishop, 2005).

Within the collaborative process and relationship envisioned with kaupapa Māori evaluation, it is important to consider each stakeholder group's ecological, social, political, and historical context. Māori and iwi organisations have their own unique and important contextual issues that need to be acknowledged during the collaborative journey. Cram (2005) noted that there are multiple dimensions to attend to.

1. Māori and iwi organisations may evolve a community-led response to an issue that needs urgent attention. Therefore, they may not begin with a grand plan for service provision, and this may have an impact on the structure and operations of the organisation as it evolves.
2. The services they provide are intrinsically connected and grounded in who they are as Māori.
3. They have dual accountabilities to both their funders and to the communities they are serving.
4. They are striving towards building their capacity, capability and tino rangatiratanga.
5. Political, historical, social, legal, and economic factors impact on their organisation (Cram, 2005).

In spite of the strength and focus of the kaupapa Māori paradigm, the reality is that most kaupapa Māori evaluation is funded by Crown or NGOs that primarily exist in relations of domination over communities. Often Māori evaluators end up compromising on the practice of kaupapa Māori evaluation, as funders determine parameters that do not necessarily align with an iwi's or hapū group's localised focus for kaupapa Māori evaluation (Stewart & Swindells, 2003; Te Puni Kōkiri, 2000). There is thus a distinct disconnect between theory and practice for kaupapa Māori evaluation where it is consistently impinged upon by colonisation. As a result, practitioners argue that communities often lose out and evaluators are placed in conflicted positions (Kerr, 2012a; Masters-Awatere, 2015).

Currently, there is limited literature on practical approaches to relationships, power, and collaboration within kaupapa Māori contexts, and more specifically practices between Māori researchers and Māori and iwi organisations. Current guidelines and frameworks that focus on research with or involving Māori provide an overarching guide to a principled and ethical approach. The guidelines are framed for research involving Māori (Aotearoa New Zealand Evaluation Association [ANZEA] & Social Policy Evaluation and Research Committee, 2008; Health Research Council of New Zealand, 2010) as opposed to providing guidance for Māori researchers (Cram, 2009; Moewaka Barnes, 2009). Although there is a considerable body of literature reporting on kaupapa Māori evaluation (Cram, 2005; Cram & Lenihan, 2000; Masters-Awatere, 2015; Moewaka Barnes, 2009; Pihama et al., 2002a; Pipi et al., 2003; Smith & Reid, 2000), peer-reviewed publications about the experiences of Māori researchers collaborating with Māori and iwi organisations are scarce.

Guidelines and frameworks provide principles for practice and ethical guides. However, the interpretation and practical application of these principles can produce varying outcomes. Therefore, it is important to provide contextual examples of the utilisation of kaupapa Māori evaluation and detail what mutually beneficial relationships, power sharing, and collaboration actually mean; the goals and written application of such agendas; and how these play out in the real world of kaupapa Māori evaluation. The current Health Research Council guidelines for researchers on health research involving

Māori are an example of how guidelines can misinform process and approach for Māori (Health Research Council of New Zealand, 2010). They outline a consultative process rather than a process of collaboration and partnership, focusing on a “culturally appropriate way” that is “responsive to Māori,” rather than research that is grounded in mutually beneficial partnerships. Thus, research is driven by those participating in or affected by the research – in terms of controlling the research agenda, methodology, development of findings, and dissemination and control of the knowledge (Cavino, 2013). In kaupapa Māori evaluation, the research power, focus, and lens are shared with Māori, rather than Māori being consulted as a step along the research pathway, or as an afterthought.

In this paper, we (the authors) seek to tell the story of what happened to the idealised scenario with which I (first author) approached the study. We will cover the twists and turns of a collaborative journey through an evaluation project, the conceptual and practical difficulties in applying kaupapa Māori evaluation to this exemplar, and the implications for kaupapa Māori evaluation research in the current policy climate.

The Project

In 2009, a tripartite partnership between the National Health Medical Research Council (Australia), the Canadian Institutes of Health Research, and the Health Research Council of New Zealand funded an international collaboration named *Strengthening Health Literacy among Indigenous People Living with Cardiovascular Disease, Their Families, and Healthcare Providers*, involving researchers in Aotearoa, Australia, and Canada. The broad aim of the Aotearoa parent project, known as the *Cardiovascular Disease Medicines Health Literacy Intervention*, was to determine whether health literacy in relation to CVD medications could be strengthened through culturally appropriate interventions, targeting Māori patients and their whānau. Furthermore, it sought to establish whether such an intervention was associated with increased confidence and ability among Māori patients to self-manage their CVD, while at the same time empowering patients in interactions with health workers (Crengle, 2009). The project was run by two Māori health providers and Māori health researchers, who were all involved in the development of the research question, research methodology, and funding application. The project team developed a pre/post-intervention design with the two Māori health providers, one rural and one urban, drawing eligible participants from patients and whānau in their services (Crengle, 2009). The two Māori organisations involved were Te Hononga o Tāmaki me Hoturoa (Te Hononga), a kaupapa Māori NGO located in South Auckland, and Ngāti Porou Hauora, a Māori primary health organisation that is now a charitable trust of Te Runanganui o Ngāti Porou. This iwi organisation provides health services to all in the Ngāti Porou rohe on the East Coast of the North Island.

In 2010, I was accepted to conduct a doctoral research project involving the qualitative aspects of the parent project. I was first introduced to the two Māori organisations at their research advisory group meetings. In meeting kanohi ki te kanohi (face-to-face), I sought consent from the parent research project to work with their research advisory groups (Ngāti Porou Hauora Charitable Trust, 2014). Once approved, I invited them to participate collaboratively in my project, including in methodological decisions, analysis, interpretation of data, and the concluding stages of the evaluation. I secured permission to attend their research advisory group meetings and obtained agreement that they would provide advice and feedback on aspects of my work.

The research advisory groups at Te Hononga and Ngāti Porou Hauora included organisation and community members. They met at various stages of the parent project, providing input to project plans, and feedback and monitoring for both the research and the evaluation projects. For Ngāti Porou Hauora, the research advisory group included a pakeke, a Ngāti Porou Hauora board member (Māori) from the community in which the project was sited, the Ngāti Porou Hauora research coordinator and "local investigator" on the project team (Pākehā), a manager (Māori), a chronic care nurse (Māori), a GP (Pākehā), and a kaiāwhina (Māori). All but one of these people who identified as Māori were from Ngāti Porou.

During the negotiation stage with Te Hononga, time frame clashes for data collection meant that I could not include this service in my evaluation project's schedule, so – after agreement with the research team – I focused on working with Ngāti Porou Hauora, with Te Hononga agreeing to key informant interviews. Organisational details such as a memorandum of understanding for the development of the kaupapa Māori evaluation were agreed to by me (Massey University), the project lead investigator (Auckland University), and the chief executive of Ngāti Porou Hauora. Ethical approval was gained through the Massey University Human Ethics Committee: Northern (MUHECN 12/095).

Ngāti Porou Hauora

Ngāti Porou Hauora was established as an incorporated society by iwi and community members in 1995 in response to the many issues faced by people in the region. These include poor health outcomes, limited access to health services, a determination to retain rural health services, a need to build a local Māori workforce, and a strong wish to develop innovative, locally relevant services that reflect Ngāti Poroutanga—health delivered in a holistic manner, consistent with the vision, values, and strategic pou (goals) of Ngāti Porou (Te Runanganui o Ngāti Porou, 2012). The organisation has built a strong health-delivery base over the past 21 years, with seven community healthcare clinics and a rural hospital. Ngāti Porou Hauora is a primary health organisation and provides a range of personal health, public health, and disability support services to all within the rohe. It has an enrolled population of approximately 8,854, who reside in rural communities along the coast and in Gisborne City (Tan, 2016). The organisation is now governed by the Ngāti Porou Hauora Charitable Trust Board (Ngāti Porou Hauora, 2014).

Ngāti Porou Hauora was involved from the expression of interest stage in developing the research proposal to the International Collaborative Indigenous Health Research Partnership for the research grant, and – at each stage in the funding application process – the research proposal was approved by the Ngāti Porou Hauora board under the terms of its Research and Evaluation Policy (Ngāti Porou Hauora Charitable Trust, 2014). This policy requires projects to be of benefit to Ngāti Porou and to meet specific criteria, which include contributing towards Ngāti Porou Hauora strategic priorities for sustainable health gains and service development; use of culturally appropriate practices that align with Ngāti Porou tikanga; openness and transparency; strengthening strategic partnerships and resources; involving and/or developing Ngāti Porou and other Māori researchers; engaging whānau and hapū in planning, management, and delivery where appropriate; and being approved by the relevant research ethics committee (Ngāti Porou Hauora Charitable Trust, 2014).

The Kaupapa Māori Evaluation

The study aims were refined in negotiation with Ngāti Porou Hauora and my supervisors. This included designing the evaluation in such a way that the needs of Ngāti Porou Hauora, the parent project, and the university institutional requirements for doctoral students could be met. Two broad aims were set:

- To carry out a kaupapa Māori evaluation of the effectiveness of the *Cardiovascular Disease Medicines Health Literacy Intervention*: This aim involved conducting semi-structured interviews with patients and whānau, health practitioners, and Māori health literacy informants to gain insight into their perceptions, practices, and experiences of the intervention.
- To develop wider learnings in relation to health literacy interventions with Māori and Indigenous communities.

Here, the plan was to work collaboratively with evaluation stakeholders in designing and testing a kaupapa Māori evaluation framework for health literacy interventions/services for Ngāti Porou Hauora. Additional perspectives would come from interviews with local and international key informants on the topic of indigenous health literacy. These understandings would be synthesised and grounded through input and feedback from the Ngāti Porou Hauora research advisory group. I aimed for a shared power base, where hierarchy was limited and the research advisory group, staff, and patients/whānau participants were invited to be a part of the decision-making process through hui, interviews, phone contact, and email.

Invitations to participate were an important part of the collaborative process. The desire was for the methodological decisions, interpretation of data, and final word to come from a collective voice, through a process where there would be a fair representation of the community, which honoured its diversity and open-ended communication, and where collaboration did not end at the end of a hui but was an ongoing process. The kanohi ki te kanohi engagement was of paramount importance to the process, as it is understood within Ngāti Poroutanga that to be heard you must be seen: he kanohi kitea. The value of being present – showing your face in the community, helping, touching, gifting time and presence, where people can engage with your mauri (energy) and wairua (spirit) – is far more powerful than words on paper, an email communication, or a phone call. In conventional evaluation, this might be viewed as a conflict of interest, but my links with iwi and hapū enhanced the collaborative experience and complemented the principles and values of kaupapa Māori evaluation (Smith, 1999a).

He Kanohi Kitea

Linda Tuhiwai Smith (1999) identified he kanohi kite – the face that is known and seen within a community. Cram (2010) adapted Smith's work to incorporate he kanohi kitea as one of seven cultural values that guide Māori researcher practice. To be known in this research context is about more than being seen; it is about becoming intrinsically linked through whakapapa and service. To be known creates a foundation of trust and standing. As Rubin and Rubin (2012, p. 79) stated, "trust increases as people see that you share a common background." I was born and raised in the community, I am invested and grounded in the community, and I perceive the world through my Ngāti Poroutanga, which is ordinary and everyday to me.

I grew up in Uawa and Tokomaru Bay and have used Ngāti Porou Hauora services since I was in primary school. My whānau have been farmers on the East Coast for generations and held mana whenua (territorial rights) before that. Many of my research participants knew my grandparents and worked, played rugby, and did business with them. My whakapapa, my people, and my knowledge and connections were critical to my decision to join a research team guiding and implementing a project about health literacy in my takiwā. As a direct acknowledgement of my history with the region, I felt that relationships, power, and collaboration were key terms of engagement because we were bound by whakapapa and everyday lived experiences through longstanding association.

All the evaluation participants were recruited by Ngāti Porou Hauora based on the parent project criteria, and, as it turned out, I had connections to six out of the nine participants. Since my involvement in the project in 2011, my whānau have made it a priority to attend marae and community events on my behalf because I live in Auckland. This was never a request made on my behalf but rather a right and responsibility taken on by my whānau. My aunt, uncle, and cousins joined the parent project hui when they were held at Hinerupe Marae; they worked in the kitchen and provided blankets and bedding to the international guests.

Collaboration Envisaged

Collaboration between me and the research advisory group meant involvement with Ngāti Porou Hauora at all stages of the evaluation: from the development of the kaupapa Māori evaluation framework, communication processes, data collection methods, and recruitment of participants to the development of the evaluation criteria with research stakeholders. Structurally, the kaupapa Māori evaluation design was shaped by the relationship between the parent project and Ngāti Porou Hauora. Due to university institutional and Ngāti Porou Hauora board requirements and parent project data collection time frames, I was obliged to conduct patient and staff interviews as the collaborative design of the kaupapa Māori evaluation framework was developing. I also followed the Ngāti Porou Hauora board policy by using te reo me ōna tikanga o Ngāti Porou (Ngāti Porou Hauora, 2014).

During the development of the kaupapa Māori evaluation framework, the research advisory group met with me at the Ngāti Porou Hauora offices in Te Puia Springs to plan, outline, develop, and refine the kaupapa Māori evaluation framework. Four hui, which were separate to the parent project hui, were held for planning, implementation, and analysis and in the concluding stages of the evaluation. Partnership (active collaboration) and participation (deliberative engagement) were imperative to ensure that the information generated from the evaluation was context focused. The first hui introduced the evaluation in terms of its placement with regard to the parent project and intervention as well as the proposed processes. The second hui involved identifying visions and goals for the community with regard to health and how the health literacy intervention trial aligned with these aspirations, as well as developing the evaluative criteria, and defining indicators for what would make an effective intervention. A third hui refined the evaluation framework and outlined data collection plans, backed by literature on current evaluation models and frameworks used in kaupapa Māori health contexts. The fourth hui provided feedback on the draft theme development and findings from analysis of the interviews with patients and health practitioners to further refine the evaluation criteria and framework. A final hui will disseminate all aspects of the kaupapa Māori evaluation, including framework, data analysis, and findings, and will seek research advisory group feedback on the project overall.

Data from the research advisory group hui were collected through audio-recordings of hui, transcribed verbatim, and supplemented with email correspondence. Additional information, including Post-it notes from working sessions, framework drafts, and researcher field notes, were included in the data set.

Titiro, Whakarongo . . . Kōrero

Another aspect of kaupapa Māori I utilised was the concept "Titiro, whakarongo . . . kōrero". Smith (1999a, p. 120) and Cram (2010, p. 9) describe this as an imperative to the researcher to "look and listen (and then maybe speak), and to develop understanding to find a place from which to speak." In essence, this was my reference for engagement during the research process. I only spoke with approval and by invitation and regarded my evaluative position as a facilitative role, a co-creator of understanding. I wanted the research advisory group to build enthusiasm, ownership, commitment, and a sense of purpose to enable the intervention to be evaluated on their terms, with their criteria, and against their indicators of effectiveness.

When it was time to facilitate the second research advisory group hui, I felt that I had stepped out on a star. This star aimed to take the research advisory group on a journey of exploration and connection to the values and principles that guided their practice. The hui was about building confidence within a process of kaupapa Māori evaluation, thereby allowing everyone to work confidently within the complexities of understanding. The intention of the hui was to understand and capture the participants' collective values and principles, then use them to guide the evaluation criteria.

When the hui commenced, I provided a draft framework to the research advisory group asking for input and feedback on my interpretation of the work that was conducted that day. This was done through email communication, as organisational and parent project time reduced contact time. I received two email responses. The first highlighted a spelling mistake in the framework and the second congratulated me on my doctoral enrolment and encouraged me to “come home with the tohu [qualification].” I was left with a feeling of uncertainty. I was unsure how to process the silence on the context, as there was no rejection of the information but also no written acceptance. I questioned my approach and reflected on the time frame restrictions and what the lack of content feedback might mean to the evaluation. I was between three entities to which I had accountabilities: the university, where my PhD was based; Ngāti Porou Hauora; and the parent project. All needed their accountabilities to be met and time frames to be adhered to. I questioned whether I had compromised the kaupapa Māori evaluation aims for external party agendas, but I felt I needed to carry on and continued to work to meet the evaluation needs.

Six months later, I completed data collection with patients and health practitioners. I refined the framework in light of the participant themes and presented the framework back to the research advisory group at our third hui. Due to time constraints, I was unable to receive feedback kanohi ki te kanohi from the research advisory group and was informed that members would email. Feedback was not forthcoming, even after prompting from the research coordinator. For me, the non-response was again difficult to process because I took it as a sign that the research and the process were not relevant or effective. I wanted to honour a kaupapa Māori process that went beyond notions of being “responsive” and conducting research in a “culturally appropriate” manner and move instead towards notions of shared input and benefit. I felt I had missed the mark. For me, input meant voice, and I was met with silence. I questioned whether I was honouring the participants’ ontological positions (lived realities and expressions) when it was only my interpretations that were being recorded.

This reflective process was important to me, as I wanted to be able to question the process while it was happening, and not assume and overstate my position as an iwi member or a Māori researcher. Cram et al. (2006) reflected on this dilemma, acknowledging that although Māori research capacity is growing, “the guidance offered to researchers does not fully explore the issues faced by Māori researchers who are conducting research with Māori” (p. 47). This was my reality as I negotiated, contemplated, and questioned myself, particularly considering the complex ways I was both insider to the research and an outsider, with responsibilities and consequences on both sides. The less-than-anticipated level of engagement with the process was, I reflected, possibly in part due to competing claims on the advisory group members and their interests and skills in areas other than health literacy. If so, I needed to shift my expectations and assumptions.

Contextual Understanding

Initially I had envisaged my work with the research advisory group would involve their participation from a position of understanding the content and context of the *Cardiovascular Disease Medicines Health Literacy Intervention*. I assumed members would have knowledge of the concept of health literacy and what it meant within the context of the project and the community, based on their involvement with the intervention project.

At the time the group was set up, however, health literacy was seen as a relatively new approach. The existing members of the advisory group were people with considerable local knowledge and understanding. I learnt that ideas about health literacy varied across the group and that they frequently differed significantly from the concept the research team was working with in terms of health literacy being defined as the degree to which individuals have the capacity to obtain, process, and understand the basic health information and services needed to make appropriate health decisions (Kickbusch et al., 2005). As identified in the parent project paper (Lambert et al., 2014), health literacy is an evolving concept, and interpretations and understanding can be diverse. However, limited understanding of health literacy has consequences in terms of addressing the health literacy barriers that patients face.

The following excerpt is from the first research advisory group hui with me (interviewer), held for the purpose of developing an evaluation framework for future use.

> **Interviewer:** What does health literacy mean to you and your mahi?
> **Participant A:** I'm not really sure. It's about the words, literacy. I think it's about promoting health messages, like our posters that we have. There's one over there [pointing to the wall]. It's literacy, messages, pamphlets.
> **Participant B:** It's about, how I can sit there and Doc can talk and I understand. When we talk at lunch time, I sort of know what he talks about now.
> **Participant C:** It's also about prevention, getting the target group of 35-about-50—we [are] trying to focus on that target group. And I'm always going "prevention, prevention." Let's prevent you from a heart attack, let's prevent you from having to go on pills.

Participant A expresses uncertainty about the meaning of health literacy, and while participant B expresses some of the main ideas, they appear to relate rather generally to her work rather than being seen as something that patients use to understand and control their personal circumstances. Participant C speaks about the health promotion agenda of prevention in terms of CVD and medications, the two key focus areas of the parent project. While health literacy may have a legitimate goal of prevention through patient use of knowledge to ensure the correct use of medications and proper application of other treatments, participant C constructs it as the main focus of health literacy.

This discussion was significant because it enabled the research advisory group to talk about their explanations of health literacy and understanding of the intervention. Realising the diversity of meanings ascribed to health literacy clarified and changed the possibilities for what could be achieved via the participatory process I was pursuing. It reinforced the need to gain – and not assume – an understanding of the research advisory group members' contexts, views, and understanding of health literacy interventions and, in this instance, their knowledge of the specifics of the project.

Participant Priorities

Masters-Awatere stated that,

> to be effective in evaluations we must take seriously an ethic of cultural safety that acknowledges the unique and collective needs of each community, engages in evaluation relationships with each of the stakeholder groups, and interrogates power and privilege. (Masters-Awatere, 2015, p. 246)

During the first two hui, it emerged that for some members of the group it was challenging to focus on health literacy concepts, when for them the more immediate needs were a priority within the community. In the following excerpt, participants were asked to write Ngāti Porou Hauora health goals and broader community health aspirations for hauora (health) on Post-it notes. The notes were then assembled on a whiteboard in a poster format and similar ideas grouped together to form themes. The following excerpt is from before we began writing on the Post-it notes:

> **Interviewer:** What other health goals do we have when it comes to thinking about hauora?
> **Participant A:** It's hard to think about good health for our people when we don't even have the basics. See up the coast water is a big factor, access to clean water in summer is hard, it's expensive, so trying to implement things like eating healthy kai, when they don't even have clean water, it's a hard one.
> **Interviewer:** So, would it be fair to add clean water to one of our goals?
> **Participant A:** Yeah, it's hard to move past. It's like kaitiakitanga [guardianship], all our responsibility.**Participant B:** Tino rangatiratanga – that's an important one. It needs to come back to that . . .
> **Participant C:** We need to improve on the way we do our contracts so that we can streamline our focuses.
> **Participant E:** Yeah, like getting more ongoing funding 'cause we can put all this effort in and then six months later we can't offer the same services [writing on Post-its and placing on board].
> **Participant C:** Would be better to build up more focus on prevention, have more of a positive move.

As the research advisory group hui progressed, I needed to consider how the parent project research focus might differ from the more immediate concerns of the group members and their perceptions of the needs of the community. By staying open to issues that might arise in the research advisory group rather than focusing on conventional understanding of health literacy, I gained fresh insight into the wider challenges facing those concerned with health in these communities. These "brainstorming" data demonstrate both their understanding of what could improve the health of their communities and describe the challenges faced by the parent project. As participant A reflected, “It’s hard to think about good health for our people when we don’t even have the basics.”

It may be that health literacy for over 50s is useful, but the health of the community is jointly constructed as being about fundamentals such as clean water, self-determination, and stable funding arrangements, among other things. Participant C’s reiteration of the call for preventive and positive approaches is an example of the complexity of needs that exist in the community. This example provides context for the diverse responses and challenges presented in the research advisory group data.

Reflections

Kaupapa Māori evaluation is about seeking a relational status with our communities in the search for understanding and knowledge (Smith, 1999a), as a basis for understanding the impact of an intervention in a community. All research stakeholders, including health consumers and community members, are seen as legitimate co-producers of knowledge in ways that are not traditionally approached by Western models of evaluation (Ritchie, 1992). As an iwi member, I feel obligated to my people and responsible for the kōrero they have shared with me, and it is my responsibility to prioritise their voice in this research because they will be directly affected by the outcomes.

Kaupapa Māori evaluation was the platform for an idealised scenario of collaboration, where I was the facilitator of the process, welcoming the adjustment of parameters by participants while making sure the invitation to share a pathway forward was available, accessible, and achievable. Ultimately, kaupapa Māori evaluation was about aspirations of co-ownership, mutually beneficial outcomes, and shared power, through prioritising the participants' voices to shape and develop the criteria to determine the effectiveness of the intervention. Stakeholders' understanding of health literacy and the intervention were varied, however, making the vision of collaboration more complex as individuals worked through personal, community, and organisational implications.

During this collaborative journey, I have learnt that being adaptive and responsive is an important part of kaupapa Māori evaluation by making sure that we, as researchers, are consistently checking that we are on the right track, that we have heard right, and, if this is the case, that our pathway forward is essential. The collaborative process has highlighted the importance of being heard and being able to listen, as it is written in an old whakataukī: "Whakarongo, whakarongo, whakarongo" (Listen with your upoko, manawa, and puku). It is understood that in Te Ao Māori it takes more than ears to listen: we listen with our heads to make logical sense of what we hear, against our experiences and understanding of the world. We hear with our hearts, the emotional connection to what resonates with us. Lastly, we hear with our stomach, listening to our intuition, our foresight. If we can provide environments and spaces where listening on all levels can take place, we can start building our knowledge capacities and our collaborative endeavours.

There is still an undercurrent of colonial power that we have to mindfully and actively resist in creating collaborative approaches. Communities are still fighting for fundamentals such as clean water, self-determination, and stable funding arrangements. Māori organisations are continuously balancing the tensions between community need and funding requirements, while kaupapa Māori evaluation approaches are trying to create spaces for understanding lived realities and practical processes that avoid added pressure on communities yet produce timely outcomes.

At times, the kaupapa Māori evaluation process was challenging, as the research design and implementation conformed to external time frames and resources due to administration pressures. This restricted the time and contact available to develop collaborative approaches, potentially undermining the principles and values on which kaupapa Māori evaluation is founded. On reflection, I gained many insights into the kaupapa Māori evaluation process, learning that kaupapa Māori evaluation assumes certain levels of power on the part of the researcher (Carlson et al., 2016; Moewaka Barnes, 2006). This reality sits in opposition to the notion of equality that dominates the literature. As a student working with more senior researchers, and as a younger person working with the research advisory group, my experience further affirmed this tension. Due to the nature of the research, I was on my own at times, and so collaborative approaches did not conform to the assumed power imbalance between the researcher and the researched, and also in relation to the roles that parties played. Having a senior Māori academic as my chief PhD supervisor provided me with support, guidance, and clarity and enabled me to reflect on my experiences and move forward.

As described in this paper, I actively sought opportunities for input, spent considerable time on this aspect of the evaluation, and continued to seek input despite experiencing concerns when little feedback was received. Relatively low levels of input from the advisory group led me to assume that the relationship was no longer collaborative. During discussions with my supervisor, however, she caused me to rethink this assumption. We questioned the nature of collaboration: in particular, whether it meant equal input, or whether collaboration was still occurring when input differed but power was shared and engagement opportunities were always offered and pursued. I came to think that it is not about power sharing but power acknowledgement and shift: I had certain powers and other stakeholders had power. In practice, I needed to do the bulk of the work, consequently, collaboration was not about requiring considerable input but about keeping communication open and offering opportunities for engagement that other parties (research advisory group) could then make choices about. While input may not have been equal, I hoped it was equitable.

Concluding Remarks

Through this kaupapa Māori evaluation experience, I have come to understand the complexity of grounding my approach in kaupapa Māori practices, as I was consistently reminded at every decision point and movement that we work within a colonial system that perpetuates Western thinking and practice, even in our small, vulnerable Māori spaces. While I chose to be a part of a larger project because I wanted to gain maximum impact for my community, I recognised that a PhD can be an individualistic pursuit of knowledge but wanted to be in a position to be a part of something that could change people's lives at the outset, that gave voice to those most affected, and that provided me with the opportunity to work with brilliant minds and learn from my elders. I chose to see this process as transformative, not in an earthshattering way but in a way that was valiant in its pursuit of making a contribution to the area of kaupapa Māori evaluation. Moving forward, a key learning has been the unexpected power inequalities within kaupapa Māori evaluation, and I would like to be able to consider and spend more time unpacking these dynamics.

LINK TWO

The following chapter, *Whanaungatanga: A Space to be Ourselves,* outlines the distal understanding of the relational dynamics of health literacy that is vital to understanding how it might be more useful in the context of Māori communities. It builds on the previous chapter by examining health literacy and its relevance to Māori patients, their whānau, and communities. This chapter seeks to highlight the invisible culture – the assumed practice of what effective health literacy looks like – in order to challenge these assumptions and give way to a space where Māori can be themselves. The chapter explores the experiences of Māori patients and their whānau as they engage with health practitioners; these engagements often fall short of the ideal, with detrimental effects for whānau.

Whanaungatanga – practices of connection, reciprocity, and responsibility – was the most influential and fundamental element of my thesis. Whanaungatanga was present in my aims, methodology, and theory and now it became the karanga in my findings. Whanaungatanga was a fundamental desire, longing, and right for all the participants and their whānau. Thus, this paper was already written in the participants' words, grounded in their narratives – I just needed to situate it in the context of health practitioners, healthcare relations, and health literacy.

Material for this paper was presented at the MAI Ki Tamaki Māori Doctoral Conference in 2013 at the University of Auckland, Auckland.[17] The presentation, *Kaupapa Māori Evaluation of a Health Literacy-Appropriate Cardiovascular Disease Intervention: Data Collection, Analysis and Preliminary Findings*, outlined my research aims and methodology; however, I spent most of the time discussing the core themes drawn from my patient and health practitioner interviews. The conference presentation was about relaying my findings in a way that was understandable and relatable and that honoured the kōrero of the participants.

The next presentation in relation to the chapter was at the MAI Ki Waikato Māori Doctoral Conference 2014, Waikato University, in Kawhia.[18] The presentation, *Whanaungatanga: A Space to be Ourselves*, became the basis for the paper that was submitted to the Journal of Indigenous Wellbeing Te Mauri - Pimatisiwin'.

For this presentation, the themes were refined and five were selected to present: Shared health system experience – participants' relationships with others were the most important part of patients' health system experience; Appreciating whānau – importance of health practitioners understanding that health and wellbeing are interwoven into the collective whānau; Ko wai ahua? Ko wai koe? Willingness to connect – the sharing of whakapapa, manaaki, reliability, advocacy, reciprocity, compassion, and

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[17] Carlson, T. (2013, October). *Kaupapa Māori evaluation of a health literacy-appropriate cardiovascular disease intervention; data collection, analysis and preliminary findings.* Paper presented at the MAI Ki Tamaki Māori Doctoral Conference 2013, University of Auckland, Auckland, New Zealand.

[18] Carlson, T. (2014, November). *Whanaungatanga: A Space to be Ourselves.* Paper presented at the MAI Ki Waikato Māori Doctoral Conference 2014, Waikato University, Kawhia, New Zealand.

continuity of care all contributed towards connection with health practitioners; Striving towards wellbeing – growing a sense of wellbeing is an important goal for patients and whānau and is facilitated by positive relationships; and *Importance of skilled facilitation and knowledge sharing* – essential components when interacting with patients and whānau.

The final presentation in relation to this chapter was in 2017 at the *International He Manawa Whenua Indigenous Research Conference* in Hamilton,[19] where I used the same title as the previous presentation. Here, I was able to gauge an international audience's perspectives on the findings to inform and shape the arguments of the chapter. Comments from the audience came from two members who both reflected on their personal experiences with loved ones in their respective health systems and spoke about the importance of being heard and the vulnerability of patients in clinical contexts.

Again, I chose to publish my paper alongside my supervisors as a manifestation of whanaungatanga: an endeavour of connection – acknowledgement of their mahi; reciprocity – mutually beneficial practice; and responsibility – accountability to the kaupapa. I chose to submit this paper to the *Journal of Indigenous Wellbeing Te Mauri – Pimatisiwin*, as they issued a call for papers focusing on original, informative, and scholarly articles on the broadly defined topic of Indigenous wellbeing. This kaupapa

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[19] Carlson, T. (2017, March). *Whanaungatanga: A Space to be Ourselves*. Paper presented at the He Manawa Whenua Indigenous Research Conference, Te Kotahi Research Institute, Hamilton, New Zealand.

aligned closely with the chapter, which explored Indigenous voice and control in the delivery of health services and in the design and implementation of health literacy. This paper was written for Indigenous health practitioners, leaders, researchers, and community members.

I conceptualised and drafted the paper and provided data; Tim McCreanor provided feedback and revisions; Helen Moewaka Barnes provided feedback and final revisions; and Susan Reid provided feedback on health literacy literature. The paper was submitted to the journal in September 2016. I would like to thank Professor Linda Waimarie Nikora, the editorial board chair, for her encouragement and acceptance of my paper, which was over the stipulated word limit. The journal conducted a double-blind peer review of the paper and provided excellent comments and feedback. I received notification on 16 November 2016 that the paper was accepted for publication subject to some revisions to strengthen the paper. The revised version was submitted on 30 November and the paper was published on 16 December 2016.

The paper is available online as an open access article:
https://journalindigenouswellbeing.com/media/2016/12/51.44.Whanaungatanga-A-space-to-be-ourselves.pdf

The paper has been uploaded on Academia.edu – to date, it has had over 100 reads and 40 downloads. The paper has also been uploaded on Research Gate.net – to date, it has had over 250 reads and 60 downloads.

The chapter explores the dynamics and manifestations of health literacy in Aotearoa, with a specific focus on what it means to Māori with chronic conditions.

CHAPTER SIX: WHANAUNGATANGA

[20]

I add lines above, reflections of mauri below. I have begun to frame, guided by whanaungatanga.

Ko whakawhanaungatanga	Establishing connections and relationships
Ko whanaungatanga	Relationships
Ko whanaunga	Relation, kin
Ko whānau	Family, extended family
Ko au	Me

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[20] Teah Carlson, Painting my gaze – who I am, what I have learnt, and what I see, 2017
Liquid chalk on black card, 637 × 415 mm, Private collection, Auckland

Abstract

Clinical engagement is often removed from everyday social processes familiar to Māori (Indigenous peoples of Aotearoa), as it can focus on health consumerism rather than communication and connection. The health encounter is not a routine social engagement, patients often feel unwell and experience a range of emotions: feeling unsure, vulnerable, nervous, and out of their comfort zone. Patients are faced with health literacy demands, such as new information, words, and concepts and may be faced with making quick decisions. Feeling guided, supported, and safe are important factors in interactions with health practitioners. Drawing on a literature review and some of the findings from a kaupapa Māori evaluation, which analysed some participants' perspectives of the effectiveness and impact of a *Cardiovascular Disease Medicines Health Literacy Intervention* trial, this paper provides a distal understanding of interpersonal dynamics of health literacy that is vital to understanding how it might be more useful in the context of Māori communities. The paper highlights a shared health system experience expressed by CVD patients as their yearning for *whanaungatanga* (relationship, kinship, connection) and reciprocal and responsive relationships; a space to be ourselves, to be Māori.

Introduction

Having the ability to make informed and appropriate health decisions is an important part of managing the ever-changing and increasingly complex health situation of individuals and is fundamental to health literacy at personal and population levels (Berkman, Davis, & McCormack, 2010). Health literacy is important to the clinical encounter, but such dynamics do not exist in a silo; systemic pressures are in play, and assessing the communicative, resource, and systemic demands on patients, also known as health literacy demands, is critical to successful outcomes between patients, health practitioners, and healthcare providers (McCreanor & Nairn, 2002a, 2002b; Ministry of Health, 2015b; Winefield, 1992).

Patients do not come to the patient–health practitioner encounter as empty vessels passively awaiting the wisdom of the health practitioner (Blaxter, 1979). People's understandings of illness, disease, and health are dynamic, contextual, and emotionally fluid, navigating turbulence between personal experiences, beliefs, and medical knowledge. Popay and Williams (1996) stated that lay people go through a "systematic process whereby experience is checked against life events, circumstances and history. They acquire an 'expert' body of knowledge, different from but equal to that of professionals in the public health field" (p. 760). Obtaining, processing, and understanding health information and services entails complex, varied, and often conflicted processes. Health literacy recognises the communicative, resource, and systemic demands placed on patients (Nielsen-Bohlman, Panzer, & Kindig, 2004) and focusses not only on increasing patient knowledge around their healthcare but also on enabling patients to navigate and interact with the health system (Ministry of Health, 2015b).

There is a variety of definitions of health literacy, which generally fall into two categories: health literacy as a set of individual capacities that allow a patient to successfully navigate a healthcare environment, and health literacy as an interaction between individual capacities of patients, *whānau*, and health practitioners and the healthcare environment in which they are operating (Nielsen-Bohlman et al., 2004;

Kickbusch et al., 2005; Nutbeam, 2008; Pleasant et al., 2016; Rudd, Epstein Anderson, Oppenheimer, & Nath, 2007). Most research on health literacy has focussed on the first category. It is only in the last few years that research relating to the second category has started to gather momentum. The practical application and assessment of health literacy requires a working definition incorporating settings, modalities, and media facets, along with the unique relationship of health literacy to empowerment, health behaviours, and practices (Pleasant et al., 2016).

In this paper, we explore the dynamics and manifestations of health literacy in Aotearoa with a particular emphasis on what it does and could mean for Māori with chronic conditions, particularly CVD. As researchers working within a critical Māori public health paradigm, we present analyses of qualitative data that challenge some epistemological underpinnings of health literacy and question its potential, in its conventional forms, to help reduce health disparities in Aotearoa.

Patient–Health Practitioner Relationship

The ultimate goal for health practitioners in their relationship with patients is improving their healthcare and patient satisfaction, and this is especially important in the management of chronic conditions (Goold & Lipkin, 1999; Ha & Longnecker, 2010; Kaplan, Greenfield, & Ware, 1989). Communication is viewed as a central component in an effective patient–health practitioners relationship (Beck, Daughtridge, & Sloane, 2002; Ha & Longnecker, 2010). Effective communication involves the health practitioner facilitating discussion, patient-centred questioning, exchanging information, attentive listening, reassurance, and empathy. Treatment options are then evaluated and tailored to the context of the patient's circumstances and needs (Parker, Clayton, & Hancock, 2007). Patients are involved in the decision-making process through consideration and exploration of their “expectations, outcome preferences, level of risk acceptance and any associated cost” (Ha & Longnecker, 2010, pp. 40–41).

Good communication has the potential to help stabilise patients’ emotions, facilitate comprehension of medical information, allow for identification of patient needs, and address both patient and health practitioners’ perceptions and expectations (Ong, de Haes, Hoos, & Lammes, 1995; Stewart et al., 1999; Stewart, 1995). When communication is effective, patients are more likely to share personal and important information for an accurate diagnosis, feel satisfied with the relationship, follow advice, and adhere to prescribed medications (DiMatteo, 1997; Little, Everitt, & Williamson, 2001; Mazur & Hickam, 1997; Stewart, 1995).

When it comes to the perception of effective communication, there is a clear discrepancy between the experiences of patients and those of health practitioners. Patients have consistently reported misperception, lack of connection, poor communication, and social conformity pressures with their health practitioners (Duffy, Gordon, Whelan, Cole-Kelly, & Frankel, 2004; Fischer & Ereaut, 2012; Frosch, May, Rendle, Tietbohl, & Elwyn, 2012). Doctors, however, report that they effectively communicate with patients and remain satisfied with their abilities (Bensing & Dronkers, 1992; Cooper et al., 2003; Fischer & Ereaut, 2012; Ha & Longnecker, 2010; Marvel, Epstein, Flowers, & Beckman, 1999).

International literature indicates the culture of healthcare practice, or at least the perception of it on the part of the patients, is an important factor in the interaction process between patients and health practitioners (Makoul & Curry, 2007; Mauksch, Dugdale, Dodson, & Epstein, 2008; Prideaux & Edmondson, 2001; Stewart, 1995). Lyons and Chamberlain (2006) highlighted that ethnic minorities living in a Western-dominated society often have different information requirements and prefer to communicate differently from those of the dominant culture; unrecognised, this can lead to problematic and dissatisfying interactions with health practitioners. Lyons and Chamberlain stated that it is vital for health practitioners to have a sense of cultural awareness and consideration and respect for the cultural context and to communicate with and advise people for whom they are providing care. The social and cultural context of patients should be central to any medical decisions made by health practitioners, including treatment options and medications (Makoul & Curry, 2007; Mauksch et al., 2008; Penney et al., 2011; Prideaux & Edmondson, 2001; Stewart, 1995). These competencies then become important factors to consider when building health literacy through better individual interactions and a systems perspective.

Illness-focussed systems tend to view individuals as *cases* and undervalue the sociocultural and humanistic aspects of patient care (Green, Carrillo, & Betancourt, 2002). Particularly in the currently widespread neoliberal political climate, the patient's role has become that of a consumer/client and the health practitioner has become more of a social health coordinator. This change has meant that health literacy has developed to recognise issues of equity, equality, and power faced by people when using the health system (de Leeuw, 2012). Traditional notions of health literacy suggest skills required to navigate the system are associated with patient advocacy and empowerment, but, more recently, the evolving health literacy literature (Nutbeam, 2008) identified that health system literacy “is something that should not, or possibly least, be attributed to or owned (in a real or rhetorical sense) by patients” (de Leeuw, 2012, p. 2).

One of the critical growth points for health literacy, identified by Chinn (2011), involves shifting the focus from an analysis of literacy as a set of skills and practices to the examination of literacy as “a set of practices embedded in broader social goals and cultural imperatives” (p. 61). Health literacy needs to be understood as situated social practices that are the sum of many everyday lived realities and decisions that occur outside the consultation room, where it becomes a shared resource frequently achieved collectively by people, whānau, and communities (Papen, 2009; Peerson & Saunders, 2009). In practice, health literacy, whatever the hegemonic commitments, is best realised when the expectations, preferences, and skills of the patients and whānau who are seeking health information and services align with the expectations, preferences, and skills of those providing the information and services (Nielsen-Bohlman et al., 2004).

Healthcare Relations in Aotearoa

Research has consistently highlighted that some doctors treat Māori patients differently than Tauiwi patients, and research comparing Māori and Tauiwi experiences of general practice services has consistently found Māori demonstrate differential usage of primary healthcare. Māori present with higher health needs than Tauiwi, present for treatment later, have shorter consultation times and lower referral rates, and are less likely to be offered choices at their general practice, to be seen in time, or to be seen within their preferred time frame (Crengle et al., 2005; Jansen et al., 2011; McAvoy et al., 1994). These studies indicate that Māori do not receive the same standard of care as that of Tauiwi. Additionally, the *New Zealand Health Survey* (Gerritsen et al., 2008) found that 4.5 percent of Māori surveyed reported unfair treatment, compared to 1.5 percent of non-Māori, Māori were almost 10 times more likely to experience multiple types of discrimination compared to non-Māori (Harris et al., 2006a).

Qualitative research projects on Māori patients' health interactions with Tauiwi general practice services and health organisations found that primary healthcare services and Māori users of those primary health services reported strongly opposing accounts of their interactions with each other (McCreanor & Nairn, 2002a, 2002b). Māori patients described the need for holistic, culturally appropriate, collaborative styles of consultation and recounted the effort required and the barriers faced by Māori to obtain quality primary healthcare (Cram, Smith, & Johnstone, 1998, 2003; Durie, 1994a). Data from GPs conveyed the perception that Māori patients had poor-quality health behaviours and choices, and Māori patients' behaviours were to blame for poor compliance levels (McCreanor & Nairn, 2002a, 2002b; Penney et al., 2011).

These stereotypes have the potential to influence health practitioner attitudes, interactions, and treatment. Cram et al. (1998) reported that interaction difficulties that occur between Māori patients and Tauiwi GPs are based on the differing health ideology perspectives around accessing health information and care. While GPs consider themselves at the centre of the patient's primary healthcare, Māori consider them to be merely one source of information and treatment. "Within a Māori health ideology GPs are seen as just another service provider and Māori patients use multiple forms of resistance in their refusal to buy into the GP power base – a power base that is established within the context of being, or seeing oneself, as the health professional" (Cram et al., 1998, p. 6).

An action-orientated research project that examined Māori pathways and barriers to care for patients with ischemic heart disease, in which patients were empowered to narrate their experiences, generated research-based solutions that highlighted the power- and control-related barriers to effective healthcare (Kerr et al., 2010). The study found major barriers to equitable provision of care could be traced to the ideologically driven (and ethnically biased) attitudes and behaviours of health practitioners. The action approach allowed systemic changes to be made within the service, highlighting the need to improve cultural competency among health practitioners. A significant outcome from the study was that, by sharing the patients' experiences of the service, the system was modified, primarily by health practitioners who held the most prominent position to "initiate effective systematic change, allowing Māori patients to work for change without having to take all the responsibility for creating it" (Kerr, 2010, p. 27). This emphasises the power health practitioners have to initiate immediate change in their interactions with patients; an example of health system health literacy. It is important that services and health practitioners are challenged by alternative discourses and offered ways of building more equitable relationships with patients, which in turn are likely to contribute to more equitable access and outcomes for Māori (Penney et al., 2011). As with other parts of the health system, such changes could incorporate health literacy practices to make immediate and effective improvements to patient knowledge and understanding about their health.

Health Literacy in Aotearoa

The health literacy field offers solutions to challenges that reduce the effectiveness of patient–health practitioner encounters that can be identified at systemic, organisational, and health practitioner levels; however, consideration of cultural barriers that patients face within the health literacy field are rarely discussed in the literature.

The *Kōrero Mārama: Health Literacy and Māori* report survey (Ministry of Health, 2010) focused on prose and document literacy, numeracy, and problem solving, which is largely consistent with Nutbeam's (2000) definition of basic/functional and communicative/interactive health literacy (Moewaka Barnes et al., 2013). Generally, New Zealanders were reported to have poor literacy skills, with Māori on average scoring below the minimum needed to counteract health literacy barriers faced in everyday life. Māori have much lower health literacy skill levels than Tauiwi, regardless of age, gender, education, work status, household income, and location. The survey highlighted the failure of connection, knowledge exchange, and skilled facilitation between Māori and health practitioners.

An international Indigenous health literacy research project (Crengle et al., 2014), of which my study was an evaluation component, aimed to strengthen health literacy among Indigenous peoples who were using CVD medicines in Aotearoa, Australia, and Canada. A paper from the first phase of the research project (Lambert et al., 2014) argued that many health practitioner have limited knowledge of health literacy and, in particular, of the barriers that Indigenous patients face within healthcare environments. They concluded that health practitioners' "lack of understanding, combined with the perceived barriers to improving health literacy, limit health practitioners' ability to improve their Indigenous health literacy skills and may limit patients' capacity to improve understanding of their illness and instructions to manage their health condition/s" (Lambert et al., 2014, p. 1). Further findings from the research project

(Crengle, 2016) provided insights into experiences of Māori using medications to control CVD, reporting that customised sessions about CVD medications delivered by Indigenous health practitioners trained in health literacy practices resulted in significant improvements in participants' knowledge of their medications.

As argued in the literature considered above, when patients and health practitioners meet, each party needs to understand each other's ways of being, including assumptions, beliefs, attitudes, and practices (Ramsden, 1994). There are deep influences inextricably linked to power, as Māori face cultural misunderstanding, unconscious bias, and institutional marginalisation (Cram et al., 2003; Kerr et al., 2010). Because the clinical and positional power lies with health practitioners, it is important for them to take the lead in facilitating the relationship and providing a space for connection, reciprocity, value, and practice that is shared, negotiated, and respected. Health practitioners have the ability and, in most instances, the will to be the change makers in our health system. They hold the power to diagnose, treat, and prevent human illness, injury, and other physical and mental conditions in accordance with the needs of the people they serve (Ramsden, 1994; Richardson & MacGibbon, 2010). Currently, Māori are not served well in the health system. They experience the health system differently to Tauiwi and, if Māori are less familiar/knowledgeable at all stages of the health system, it is likely that patient and whānau outcomes will be worse.

A promising aspect of the health practitioner field is the acknowledgement of these issues and the development of guidelines for practitioner cultural competencies. Written by the Māuri Ora Associates, *Best Health Outcomes for Māori: Practice Implications* provides a guide for doctors to work towards producing optimum outcomes for Māori patients. This booklet and its statement publication (Medical Council of New Zealand, 2006) provides practical approaches for Tauiwi practitioners to improve care for Māori patients and whānau. Ten years after its publication, however, health disparities persist (Minister of Science and Innovation and Minister of Health, 2016). The latest perioperative mortality report (Perioperative Mortality Review Committee, 2015) highlighted the inequities and inequalities that exist with the delivery of healthcare to Māori, with Māori experiencing higher rates of perioperative mortality than all other groups. Health inequalities have been exacerbated by an inequitable distribution of health resources, which the Medical Council of New Zealand determines as unjust and unfair (Perioperative Mortality Review Committee, 2015).

This paper draws from the findings of a qualitative kaupapa Māori evaluation that explored the understandings of health literacy of six participating Māori patients and their attending whānau. Data were also gathered from three Māori health practitioners about their experiences and perspectives of the effectiveness of the health literacy intervention around CVD and prescribed medicines in a Māori community. Thematic analyses present patterns in participants' narratives about their journeys through CVD and their yearning for *whanaungatanga*, reciprocal and responsive relationships with their clinicians. The work sheds light on the interpersonal dynamics surrounding health literacy, its potential to become a space to be ourselves, to be Māori, that is vital to understanding how health literacy might be more useful in the context of Māori communities.

Methods

An international Indigenous research collaboration spanning Australia, Canada, and Aotearoa developed a research project entitled *Strengthening Health Literacy among Indigenous People Living with Cardiovascular Disease, Their Families, and Health Care Providers.* The Aotearoa research project, known as the *Cardiovascular Medicines Health Literacy Intervention* was developed and implemented by a team of Māori health researchers and two Māori health providers. The objective was to test a customised, structured CVD medication programme delivered by health practitioners that focused on the development of health literacy with Māori patients and their whānau. Secondary outcomes focused on examining changes in patient CVD medication knowledge and health literacy practices (Crengle et al., 2014).

Patients were eligible to participate in the intervention if they were taking at least two CVD medications, which included a statin, aspirin, a beta blocker, or an ACE inhibitor (Crengle et al., 2014). All patients had been diagnosed with some combination of angina pectoris, myocardial infarction, transient ischaemic attacks, or stroke. All eligible patients were invited to participate in the intervention as well as the evaluation (Lambert et al., 2014). Our study sought to understand the effectiveness of this health literacy intervention within one Māori health provider location. Six of the 56 patients participating in the intervention at Ngāti Porou Hauora were invited to participate in our kaupapa Māori evaluation project (Carlson, 2013). Those six evaluation patients were enrolled in one of the three small rural health centres participating in the wider research project from amongst Ngāti Porou Hauora's six health centres.

Our kaupapa Māori evaluation approach focussed on aspirations of co-ownership, mutually beneficial outcomes, and shared power by prioritising the participants' voices to shape and develop the criteria to determine the effectiveness of the intervention. Invitations to participate were an important part of the collaborative process as Ngāti Porou Hauora were involved in the methodological decisions, interpretation of data, analysis, and concluding stages of the evaluation. Our research was approved by the Massey University Ethics Committee (MUHECN 12/095), and the patient and health practitioner interview schedules were developed with feedback/approval from the Ngāti Porou Hauora research coordinator and parent project team members.

A series of three semi-structured qualitative interviews were conducted with each patient to gain an understanding of their CVD experience, including medication use, understandings of health situation, and relationships with health practitioners and to discuss expectations and perceptions of the impact and effectiveness of the intervention. These evaluation interviews lasted between 60 and 120 minutes and took place in the patients' homes with varying attendance by whānau. Patients were re-interviewed within two weeks then again at six to seven months, providing 18 interviews overall. Weekly telephone calls, ranging from 10 to 30 minutes, were also conducted with the participants for the first month. At the time of the interviews, the patients accessed the services of their health centre's rostered clinical staff. The multiple interviews were an effective method, allowing the creation of follow-up questions, expanding understandings, and enabling contradictions to be explored and key themes to be reiterated. Multiple interview processes separated by short intervals is suggested in chronic illness research as it provides particularly rich data sets (Mishler, 1999).

Three health practitioners that were directly involved with the intervention, including the research nurse, *kaiāwhina*, and GP, were interviewed twice each in 60-minute semi-structured, face-to-face sessions. The first interview was carried out immediately after the intervention was completed to gain an understanding of perceived outcomes, impacts, and effectiveness of the intervention, while the second was conducted six to seven months later to probe medium-term outcomes.

A total of 24 interviews were audio-recorded and transcribed verbatim. A thematic analysis was completed to identify, analyse, and highlight patterns within the data (Boyatzis, 1998; Braun & Clarke, 2006). Here, we report on five key themes, drawing on participant data and presenting analyses of these to show how themes articulate with each other and account for different understandings of the health literacy intervention.

Findings

Shared Health System Experience

Understandings, traditions, and principles can significantly impact not only on perceptions of health and illness but also on expectations, perceptions, and choices of our medical journey. The six patients interviewed for the evaluation had a long history in the health system. They had all experienced a cardiac event and were taking some form of CVD medication. Five out of the six had been taking CVD medications for at least five years. Their ever-changing health situations ranged from ailments, short- and long-term conditions, disabilities, surgeries, and post-care experiences.

During the evaluation interviews with the patients, the most constant and vital theme in their accounts of their experiences were people: whānau, support people, and health practitioners. Whānau is the fundamental unit of Māori society (Durie, 1994b), and understanding whānau is key to understanding patients' interpretations, expectations, responsibilities, and practices of health and their wellbeing.

Participants' relationships with others, from short encounters with health practitioners to long-standing relationships with their GPs, were the most important part of patients' health system experiences. Successful and productive relationships were described as having a foundation of whanaungatanga, reciprocity, and mutual respect.

Whanaungatanga embraces *whakapapa* and focuses on connection, understanding, and relationships (Mead, 2003). Individuals expect support from their whānau, close or distant, and whānau expect individuals to support the collective need. Whanaungatanga also encompasses non-kin relationships that have become like kin through shared experience, friendship, *aroha*, and aspirations (Durie, 1994b, 2004; Mead, 2003). For patients, whanaungatanga played an important role in the interactions with health practitioners and was the distinction between a negative or positive experience. Whanaungatanga, in the form of whānau, whakapapa, manaaki, reciprocity, friendship, and quality time, was developed through shared interests and through consistency of care; that is, building a relationship by seeing the same health practitioner.

Appreciating Whānau

All the patients spoke about their responsibilities to their whānau and how their health and wellbeing was interwoven into the collective health of whānau.

> **Interviewer:** What is important to you when it comes to your health?
> **Joan:** I have trust in the doc or the nurse that they are educated enough to know . . . When they talk to me about things and I get angry then I won't do whatever it is and that's it. I got better things to think about like more important things like my whānau, their wellbeing, so what does that say about my health? It's not that [it's] not important, but they drive me to be well for them, so as long as I feel good, I don't got to worry about things. So, when I don't feel good, well, that's when I come to the doctors. (First interview)

For Joan, whānau wellbeing is important; it is a priority for her. This highlights the imperative to consider the role of whānau in order to understand perceptions of individual and collectivist health responsibilities about prevention methods, treatment, and care (LaVeist & Nuru-Jeter, 2002).

During the interviews, patients spoke about their relationship with the research nurse. They described her as *relatable* and embodying manaakitanga. Most importantly, the patients spoke about how they felt about the research nurse; they said she cared, described her approach and demeanour positively, and felt it was a reciprocal relationship. Moreover, the research nurse took time to learn about different members of their whānau and what role they played in their lives.

> **Interviewer:** How did you find the sessions with [the research nurse]?
> **Nellie:** Really good, she's been really good, she's got a good ahua, she's a nice person, you can relate with her, she's got a nice ahua . . . she's good at her job, she's a good girl.
> **Interviewer:** What makes her good at her job?
> **Nellie:** She listens; she's interested in our whānau, what's going on. . . She asks about my moko; she knows her pāpā. (First interview)

Nellie expresses her position as a pakeke by referring to the research nurse as a girl – "she's a good girl." This was said from the position of a pakeke to a younger whanaunga. It reflects the social status relationship they built and their kinship connection. In terms of health literacy practices, the research nurse *listens for understanding*; she does this by taking an interest in her whānau, acknowledging the social connections and the importance of this in Nellie's health journey. She asks how they are, remembers their names, their whakapapa connections and asks about her whānau wellbeing.

Ko Wai Ahau? Ko Wai Koe? Willingness to Connect

During the evaluation interviews, patients spoke about how connection on any level (place, space, people, experience) between the patients and their health practitioners was very important to them. Whanaungatanga was developed through the existence of experiences outside of the consultation room, just as much as inside such as whakapapa, manaaki, reciprocity, friendship, and shared interests. Quality time spent with patients was an important factor in developing a connection and a positive relationship.

> **Interviewer:** So, in your third session today, how was that for you? How did you find it?
> **Joan:** Oh, very good, very comfortable, very easy going. We spent more [time] talking about our mokos than anything else. I don't know. I know she [research nurse] asked me a few questions about how things [were] going blah, blah, blah, have you been to the doctors but it was sort of like in conversation, so I didn't really notice it so I actually thought she done very well in this session and even the second session 'cause it was all part of a conversation and she'll just write down as we went along . . . she would tell me about what was going to happen next so it seemed all straightforward no surprises. (Second interview)

Joan spoke of her connection to the research nurse through their shared sense of aroha for their moko (grandchild(ren)). Through a common connection and values, they developed and navigated through topics of health, medications, and wellbeing seamlessly. Joan highlighted that the research nurse anticipated the next steps for her as they went through the session, which is an important health literacy practice and part of building patients' health literacy knowledge and skills to meet their needs (Health Quality & Safety Commission New Zealand, 2013).

Interwoven into the patient–nurse relationship was manaaki. As well as making home visits to the pakeke, she would go above and beyond her role as a health practitioner by sharing and giving kai; this was seen as a clear expression of manaaki through actions of caring, protection, and respect.

> **Interviewer:** Would you like any changes made?
> **Kiriama:** No she's [research nurse] doing a good job, she's good at her job. She's awesome.
> **Interviewer:** Great, what makes her good at her job or the good things she does?
> **Kiriama:** She brought me crayfish when I wasn't at home, she's a good girl.
> (Second interview)

Connection is displayed through whakapapa, making references to connection through ancestry, linking each other to a wider context to place, wharenui, whenua, awa, and maunga. When patients were asked about their relationships with their health practitioners, they would often refer to their GP by their first name, initially talking about them by their whakapapa connections, then whānau, and then their practitioner relationship.

> **Nellie:** Yeah you know [GP] he's a young fulla, he's Tainui. (First interview)
> **Kiriama:** My nurse she's going away, nice girl man, she is Apanui, she has a lovely partner and children. (Second interview)
> **Hemi:** Yeah, the GP I've been seeing him for a little while now, think he's from

> Waikato ways, think I know one of his whanaunga, good whānau, his wife likes the horse in Te Araroa, she goes riding with Rita-mae, Kelly, and Tane. Think she really likes it. (Third interview)

When the patients spoke about the Māori GP or Māori nurses, it was a common, normalised process to identify their iwi. Whakapapa was paramount to their connections, relationships, to know about their whānau, what they were interested in, to know them as a person and to share.

Having trust in health practitioners was a prominent theme. Patients regularly spoke of experiences where they would seek out trusted whānau or health practitioners and take their advice over that of other health practitioners.

> **Joan:** When I was having the worst symptoms, my husband rang Doctor P, he's a close relation to my husband at Tairāwhiti at the time and he said "you better get her to the doctors and that." I said to Doctor P "we'll go see the local GP now [he] lives straight across the river."
> **Interviewer:** Why did you choose to call Doctor P in the city not the local health service?
> **Joan:** I trust him, plus we know we can call, it's not going to bother him, don't want to call 111 and then it's not even worth coming all the way up here. (First interview)

Trust with patients was built on relationships with a history of reliability, advocacy, reciprocity, compassion, and continuity of care (Arnold, Forrow, & Barker, 1995; Brody, 1992). Trust provides an opportunity for patients and providers to connect as people and provides a foundation for mutual decision making, thus allowing health practitioners to become "better advocates for their patients and allows patients some power by virtue of the personal relationship" they have with the health practitioners (Goold, 1996, p. 29).

Striving Towards Wellbeing

During the interviews, patients spoke of gaining a sense of wellbeing during the intervention. They spoke about growing wellbeing, security, and peace of mind. In this excerpt, Ma identified the actions and practices that led to her wellbeing.

> **Interviewer:** Would you like to see any improvements or changes in terms of your sessions with the [research] nurse?
> **Ma:** No not over my head no. It's all good what you both are doing. I am settled, I'm happy. [Getting teary] Good for me and for my spirit and my mind, I'm not confused because she explains it to me in ways that I get it. It is true, I find myself more relaxed and comfortable with myself and with my meds and with my family. There's a lot of things that's come out of it actually with my spiritual feeling. Well for me I feel as someone cares about me to come and talk to me and tell me what I'm doing and what do I need, apart from the last four years no one's been to ask "do you know what you're taking." What you and [research nurse] are doing [crying]. It's wonderful . . . I'm almost in tears but for me I'm all good about it and I'm sure there's a lot there who'd feel the same too. (Second interview)

Ma identified that wellbeing encompasses a spiritual feeling and includes experience, emotion, and affect. Both the research nurse and the lead author spent time with Ma in her home; we each visited on four separate occasions, as we did with each patient. This led Ma to feel cared for, understood, and connected. Ma was very emotional during this kōrero and began to cry; her deep sense of appreciation and connection was palpable. Ma felt that the information she received from the research nurse was relayed to her in a way that she understood, and she was able to tell others much of the information she had learnt about her CVD medications. Ma said that she was asked *do you know what* *you're taking?*, which is an important health literacy practice for health practitioners as they are able to acknowledge, clarify incorrect knowledge, and provide new information (Health Quality & Safety Commission New Zealand, 2013). Ma made it clear that gaining an understanding about her medications was not just about knowledge; it was about awareness and consciousness, about how she feels.

Wellbeing was also expressed as therapy, creating a consciousness of connection of your hinengaro to your tinana.

> **Interviewer:** What were the sessions like with the [research] nurse?
> **Nellie:** No, it's good I enjoy having her come and talk to us because it's good therapy for me. I find it good therapy because she keeps me alert and aware of what's going on in my body. No, it does, it makes me understand what's going on now in my body because I take time out, I think about what's going on in my body. (Second interview)

The research nurse's visits created a time and space dedicated towards the patient's wellbeing, a time to reflect on their health, medications, personal understandings, and management. The stimulus and reflections were seen as raising awareness in positive ways. George spoke about his state of wellbeing as feeling more relaxed and comfortable as the knowledge he gained gave him peace of mind.

> **Interviewer:** . . . my role is to come to you and see if there's anything we can change.
> **George:** Oh, I find it good, good . . . I found it's been really, really good and I'm more relaxed now than what I was before. [I] know what my meds are for as well, gives me great peace of mind for me. (Second interview)

Wellbeing was not fixed or defined. When it was discussed, it was understood as a feeling, an emotion or an experience that was negotiated, moulded, and fluid. It was a state of consciousness for the patient that was useful at these points along their health journey. The importance of wellbeing is the ability to continue and maintain such a state; this may be facilitated by positive relationships, willingness to connect, and appreciating whānau through the skilled facilitation and skilled knowledge sharing of the health practitioner.

Importance of Skilled Facilitation and Knowledge Sharing

Skilled facilitation is an essential component of the interactions with patients and their whānau. Patients found that the research nurse and the Māori GP used practices of facilitation as opposed to more traditional consultation approaches they experienced at hospital-based consultations and consultations in primary care. They provided a space for conversation to flow in contrast to patients' prior experiences of being spoken at in a one-way direction where they would listen and nod. Knowledge was shared with them where they would build on their understandings rather than their previous experiences of being told what was wrong and what treatment was going to be offered.

> **Joan:** . . . it wasn't until I was home, I was home for a few days anyway and I said to my husband "oh I got to go see the doctor" 'cause I had these different specialists and I had bottles and bottles of pills and I went to see the doctor and I came down here and at the time it was Doctor G and I said to him "I don't even know what happened" so he sort of explained what had happened.
> **Interviewer:** So, no-one explained to you at the hospital what happened to you? Did they use the word stroke?
> **Joan:** No, they never used that word they used other words that I didn't understand, so he sort of talked me through it and he said, "so what do you think?" and I said, "someone said infarction, something like that" and he said, "that's a stroke." I said to him "oh, so I had a stroke," and my husband is sitting there like this [shaking his head, with eyes wide open]. (First interview)

Relationships and experiences with health practitioners were the most important part of the patient's health system experience. Patients spoke about both negative and positive experiences, which were created on a foundation of whanaungatanga, connection, and communication. Participants' negative experiences related to dialogue: the way things were said, including tone, context, and speed; the amount of information; being talked at; not being listened to; not being given the opportunity to ask questions; and receiving conflicting information from health practitioners. How the participants felt during the health literacy intervention conversations was an indication of how successful it was for them.

> **Interviewer:** How did you find the sessions with the [research] nurse?
> **Kiriama:** Well, the difference is when you go to the doctors he just tells you what each one's for, that's it, and her [research nurse] . . .
> **Whānau member:** And we understand more now, you see.
> **Whānau:** You know why you're taking it aye, gives you meaning behind it.
> **Kiriama:** You know she's doing a good thing.
> **Whānau member:** Whereas before you swallow them, I don't know what they're for.
> **Kiriama:** Yeah, I just go to the doctor, get a pill and he'll say, "go home, here take this" tell us why we taking it aye? What for and all that, yeah . . . now I know why I'm taking these pills. (Second interview)

Due to the research nurse's ability to appreciate whānau, connect, facilitate, effectively communicate, and build health literacy through knowledge and information sharing, patients spoke about gaining a better understanding around the CVD medications they were taking. Most patients considered it the first time they had been fully informed about their CVD medications; names, categories, purpose, how they worked, and side effects. Patients spoke about gaining more meaning behind their medication use rather than just taking them as instructed.

Contextually, patients' experiences with health practitioners are enacted within the organisation and – more broadly – the health system. The Ngāti Porou Hauora Strategic Plan 2010–2015 (Ngāti Porou Hauora, 2014) included *improving health literacy* as one of their strategic aspirations. The established Ngāti Porou Hauora service system allowed the research nurse to develop close connections with patients through whakapapa, whanaungatanga, and long-standing relationships. Nurses and kaiāwhina engage in the community outside the clinic, visiting patients at home as required. In contrast, GP positions are faced with a mix of full-time and locum services, both of which turn over more frequently, making it more difficult to maintain rapport (Brewin & Coggan, 2004).

Conclusion

Health literacy is the interface between knowledge and skills of individuals and the demands of healthcare environments (Nielsen-Bohlman et al., 2004). The interface can be divided into two different perceptions; first, health literacy as a set of individual capacities that allow a patient to successfully navigate a healthcare environment; second, health literacy as an interaction between individual capacities of patients, whānau, and health practitioners and the healthcare environment in which they are operating.

Reducing health literacy demands for patients is an imperative part of increasing effective access to health information, care, and services. The evaluation findings demonstrated that whanaungatanga via reciprocal and responsive relationships and connections (particularly kin connections) underpins perceptions and acceptability of health literacy practices but is not exclusive to health literacy practices. As Moewaka Barnes (2006) noted, knowledge from diverse cultural epistemologies is much more likely to be useful and productive when power relations between different systems are equitable. In this respect, the ever-increasing health literacy demands and, along with the multiple barriers experienced by patients and their whānau in this study, call for whanaungatanga practices of connection, continuity, and collaboration to be implemented at a service level to guarantee the effective use of health literacy practices with Māori.

Low health literacy has been associated with a range of adverse health outcomes, including lack of access to preventive services; poorer knowledge of illness, treatment, and medicines; poorer management of chronic conditions; increased hospitalisations; and high use of emergency services. The vital elements of appreciating whānau, a willingness to connect, striving towards wellbeing, and the importance of skilled facilitation were the key findings representative of the experiences and perceptions of patients and their whānau. These findings highlight the lived expressions and realities of Māori who are trying to engage effectively with health practitioners and other environments within the health system. Without these fundamental components, health literacy practices cannot be supported and sustained in the clinical context; here, the face-to-face home visit nature of the intervention was a highly appreciated factor, as was the extended contact time available to each patient. If we are interested in the concept of health literacy for Māori patients, it has, like other features of the Māori world, to be understood as relational, collective, and centred in building the autonomy and self-determination of Māori communities.

This research explored the dynamics and manifestations of health literacy in Aotearoa with a particular emphasis on what it means for Māori with chronic conditions. However, the identified social practices can have broader implications for public healthcare practice. It is important to situate health literacy as a multidimensional approach that incorporates fundamental Māori cultural engagements and processes of whanaungatanga. The presented findings are by no means an extensive exploration, but are a place where we can begin to explore the lived expressions of Te Ao Māori, our ways of being, in health engagements. This research offers a powerful message – to bring about change, we need a deeper understanding of the nature of the relationship between clinicians and patients because they are at the heart of our health system.

This study supports and extends the conceptual development occurring in relation to the meaning and potentials of health literacy in such contexts (Ministry of Health, 2015b). In short, health literacy needs to broaden its scope towards an examination of literacy as a set of practices embedded in broader social narratives and cultural agency that recognises issues of equity, equality, and empowerment. Health literacy needs to be understood and enacted as a situated social and cultural construction that is negotiated and fluid and shaped by people, whānau, communities, and the complex array of other stakeholders (Papen, 2009; Peerson & Saunders, 2009).

LINK THREE

The following chapter, *Health Literacy in Action*, focuses on the experiences of patients and health practitioners involved in the intervention. This chapter was the most challenging in terms of word count, as I wanted to include as much of the participants' voice and perceptions as possible. However, I felt constrained, which is why I chose to present a more detailed account of findings from these informants in chapter four.

This chapter builds on the previous by highlighting the importance of whanaungatanga. I extend this by examining effective health literacy practice through the eyes of patients and health practitioners participating and involved in the CVD medications health literacy intervention. Effectiveness for patients and health practitioners was based on (a) extended time frames; (b) being home rather than clinic based; (c) tailored educational resources and materials; and, most importantly, (d) the connection and relationship with the research nurse. The chapter highlights the importance of health literacy training for health practitioner staff and the utilisation of the three-step model (Health Quality & Safety Commission New Zealand, 2013): first ASK to find out what the whānau know, then BUILD on that knowledge and CHECK you have been clear and prompt to build any knowledge that the health practitioner was not clear about. While health practitioners are responsible for being clear if whānau do not understand, the reflective practice enables patients to acquire and understand information and practice skills at their own pace – within their context. Thus, health literacy training and approaches need to be implemented at a service level, where organisations are supported by the system to implement effective health literacy policies and provide adequate training for management and staff that can then impact on the type of service patients receive.

The material in this chapter was first presented at the MAI ki Ōtautahi – Lincoln Māori Doctoral Conference in 2012 at Lincoln University, Christchurch.[21] The presentation, *Kaupapa Māori Evaluation of a Health Literacy-Appropriate Cardiovascular Disease Intervention*, was about relaying my methodological approach in a way that honoured Kaupapa Māori praxis and the practical implications of collaborative-partnership approaches to kaupapa Māori evaluation. The presentation was about gaining feedback and comments in a supportive Māori academic environment.

The next presentation in relation to the chapter was at Ngāti Porou Hauora ICIHRP Health Literacy and Cardiovascular Disease Medications Project intervention trial findings and evaluation hui in 2014 in Te Puia Springs, East Coast.[22] The presentation, *Kaupapa Māori Evaluation of a Health Literacy Cardiovascular Disease Intervention*, became the basis for the paper, which was submitted to *AlterNative: An International Journal of Indigenous Peoples*. The themes had been refined further, and four core themes were selected to present: *Fluidity of understanding* – importance of maintaining knowledge and nurturing relationships; *Medication use* – the impact the intervention had on changing and refining CVD medication practice for the participants; *Changing engagement* – changes patients made when engaging with health practitioners, as well

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[21] Carlson, T. (2012, December). *Kaupapa Māori evaluation of a health literacy-appropriate cardiovascular disease intervention*. Paper presented at the MAI ki Ōtautahi – Lincoln Māori Doctoral Conference 2012, Lincoln University, Christchurch, New Zealand.

[22] Carlson, T. (2014, April). *Kaupapa Māori evaluation of a health literacy cardiovascular disease intervention.* Paper presented at Ngāti Porou Hauora ICIHRP Health Literacy and Cardiovascular Disease Medications Project – intervention trial findings and evaluation hui, Ngāti Porou Hauora, Te Puia Springs, New Zealand.

as the limitations and outcomes of this approach; and *Building relationships* – covering the intervention structure and design and the role of the research nurse.

The development of the emerging Ngāti Porou Hauora health literacy evaluation framework was also presented at the hui. My reflections on this process were discussed in detail in chapter five: *Kaupapa Māori Evaluation: A Collaborative Journey*. This hui was an important part of the paper development, as the kaupapa Māori evaluation approach focused on aspirations of co-ownership, mutually beneficial outcomes, and shared power by prioritising the patients' voices to shape and develop the criteria to determine the effectiveness of the intervention. Invitations to participate were an important part of the collaborative process, as Ngāti Porou Hauora were involved in the methodological decisions, interpretation of data, analysis, and concluding stages of the evaluation. The final presentation in relation to this chapter was at the Māori Association of Social Sciences (MASS) in Palmerston North.[23] The presentation was titled *Health Literacy in Action: Kaupapa Māori Evaluation,* which became the title of the published paper. The conference presentation was intended to gauge a national audience's perspectives on the findings and help inform and shape the arguments of the paper.

Again, I chose to publish my paper alongside my supervisors, acknowledging the time and input they dedicated towards developing the paper. I conceptualised and drafted the paper and provided data materials; Tim McCreanor provided feedback and revisions;

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[23] Carlson, T. (2014, November). *Health literacy in action: Kaupapa Māori evaluation*. Paper presented at the Māori Association of Social Sciences (MASS), Massey University, Palmerston North, New Zealand.

and Helen Moewaka Barnes provided feedback and final revisions. This chapter was submitted to the journal in August 2017.

I chose to submit the paper to *AlterNative: An International Journal of Indigenous Peoples*, as they publish scholarly research on Indigenous world views and experiences of decolonisation from Indigenous perspectives from around the world. The journal is a leading international journal that is multidisciplinary and interdisciplinary, spanning themes of transforming places, peoples, communities, cultures, histories, and colonialism.

Ethnic inequity in healthcare is a complex subject that has been described in the literature for decades, with few helpful solutions. The main determinants of health have been conceptualised as multifaceted and multi-layered. The chapter focuses mainly on the locus of the intervention – interactions at the exo level of health systems and services. The chapter examines the experiences of patients and health practitioners involved in the intervention, centring on the importance of maintaining knowledge, nurturing relationships, changes in engagement practices between patients and health practitioners, and building relationships based on trust, reciprocity, and admiration.

CHAPTER SEVEN: HEALTH LITERACY IN ACTION


[24]

Filling in spaces to give depth. What is the focus is white, grey or black? Is it important to separate? Our whakataukī can provide an insight.

He mauri tō te tangata, he whakapapa tōna, he mana motuhake
Everyone has mana, everyone has a whakapapa, everyone has an identity that makes them no more or no less important than the next.

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[24] Teah Carlson, Painting my gaze – who I am, what I have learnt, and what I see, 2017
Liquid chalk on black card, 637 × 415 mm, Private collection, Auckland

Abstract

The healthcare system is complex and challenging to virtually everyone but more so to those who are marginalised, impoverished, and isolated; all factors that exacerbate health literacy barriers. This paper reports on an analysis of qualitative data collected for a kaupapa Māori evaluation of a CVD medications health literacy intervention. The evaluation study involved a kaupapa Māori evaluation of the effectiveness of the intervention and discussion of wider learnings in relation to health literacy interventions with Māori and other Indigenous communities. Findings are grouped around three key themes: Whakaaro, tūrangatira, and whanaungatanga. Whakaaro – fluidity of understanding – refers to the importance of maintaining patient medication knowledge and nurturing relationships between patients and health practitioners. Tūrangatira – presence – refers to changes in participation practices between patients and health practitioners as well as the limitations and outcomes of the intervention approach. The last theme, Whanaungatanga – building relationships – covers the intervention structure and design and the role of the research nurse. This study highlighted that the responsibility for improving health literacy lies with everybody in making substantial systemic change. In this intervention, the focus of responsibility for building health literacy skills with patients and whānau sat with front-line health practitioners.

Introduction

Persistent health inequities exist in Aotearoa, including significantly higher rates of "all-cause mortality" and shorter life expectancy for Māori compared with Tauiwi (Ministry of Health, 2015c, 2017). CVD is the leading cause of morbidity/mortality and a key factor in disparities between Māori and Tauiwi after adjusting for socio-economic status and timing of diagnosis (Bramley, Hebert, Jackson, & Chassin, 2004; Curtis, Harwood, & Riddell, 2007; Ministry of Health, 2011; Robson & Harris, 2007). Reducing Māori CVD rates and inequities between Māori and Tauiwi are urgent health priorities (Robson & Harris, 2007). An added layer of inequity also exists in remote and rural areas, which often have a higher proportion of Māori.

Health Literacy

Health literacy has been widely and variously defined. A recent systemic review found over 17 explicit definitions and 12 conceptual frameworks (Sørensen et al, 2012). In Aotearoa, health literacy has been defined as “the capacity to obtain, process and understand basic health information and services in order to make informed and appropriate decisions” (Ministry of Health, 2010, p. 1). While this definition focuses on individual capacity and skill, there has been a shift towards social and/or systemic factors that shape skills and ability (Pleasant et al., 2016). Engaging with health literacy may entail a focus on individual functionality, the testing of professional skills, and systemic demands and complexities (Pleasant et al., 2016). Social and cultural considerations are rarely discussed in the literature (Carlson et al., 2016).

The *Cardiovascular Disease Medications Health Literacy Intervention* research project (Crengle et al., 2014) aimed to strengthen patient health literacy knowledge, skills, and practices among Indigenous peoples in Aotearoa, Australia, and Canada. A published paper from the first phase of the research project (Lambert et al., 2014) argued that many health practitioners have a narrow patient-focused understanding of health literacy and limited understanding of the barriers that Indigenous patients face within healthcare environments. Crengle (2016) reported that customised sessions and associated resources about CVD medications, delivered by Indigenous health practitioners trained in health literacy practices, resulted in significant improvements in participants’ knowledge of their medications.

In 2015, the Ministry of Health published a critical systemic approach to health literacy, which focused on reducing barriers to patients, based on the Institute of Medicine guidelines (Brach et al., 2012) but tailored for the Aotearoa context (Ministry of Health, 2015a, 2015b). Walsh, Shuker, & Merry (2015) argued that health literacy is an inter-sectoral responsibility encompassing the entire healthcare system, allied sectors, and other entities, such as schools, workplaces, and social services.

Health literacy is embedded in social and cultural practices that are context bound, rather than skills held by individuals (Carlson et al., 2016). Rudd, McCray, & Nutbeam (2012) acknowledged the importance of context in health literacy and called for consideration of patient agency and participation. Papen (2009) stressed critical analysis of information, social determinants of health, and engagement in collective action. Ross, Culbert, Gasper, & Kimmey (2009) suggested that strategies to improve health literacy must include multi-level approaches that practice collaborative, communitarian partnerships among people.

The environment of healthcare organisations can affect the ability of patients to navigate, understand, and act on information within services (Ministry of Health, 2015b). The value organisations place on health literacy plays an important role in the quality of care experienced by patients. Health literacy practices include actively reducing health literacy barriers for patients, providing culturally safe environments, and focusing on quality patient–health practitioners engagement (Koh et al., 2012; Koh, Brach, M, Parchman, Harris, & Parchman, 2013; Walsh et al., 2015).

Causes of Inequity

Health inequities are systematic differences that have been analysed and evaluated as unjust and unfair (Whitehead, 1992). Many possible explanations for inequities in health outcomes are proposed in the literature. Māori are overrepresented in mortality/morbidity statistics, but explanations as to why are limited, and research specifically focusing on CVD is rare.

The social conditions within which people are born, grow up, work, and die play an important role in the health status and outcomes of individuals and groups (Marmot & Wilkinson, 2006). The World Health Organisation (WHO) Commission on Social Determinants of Health provided a conceptual framework depicting the situational and relational impacts of social determinants on the wellbeing of individuals, communities, and populations (WHO Commission on Social Determinants of Health, 2008). Moewaka Barnes and colleagues (2013) extended this framing to include an analysis of the effects of colonisation and racism on health outcomes.

Māori CVD outcomes can be broadly located within four domains: macro – governance, colonisation, cultural and societal norms, and policy; mezzo – community, place, and whānau; micro – material, psychosocial, behavioural, and biological; and systemic (exo) – health services located within life-course and intergenerational conditions (Moewaka Barnes et al., 2013). Inequities are exacerbated by the lack of control Māori have in shaping their futures, and the “mal-distribution of health-promoting and sustaining social commodities" (Brown et al., 2010, p. 265) crucial for the development and delivery of health systems/services. Although Māori are frequently identified as having the highest risk for and prevalence of CVD, few studies or interventions have involved Māori solutions, community engagement, and action.

This paper focuses on intervention within the exo domain of health systems/services. Substantial research-based evidence supports the argument that, in order to improve Māori health status and outcomes, health systems/services need to be based on Māori social structures, delivery systems, health contexts, and personnel (Cram, 2007; Masters-Awatere, 2015; Moewaka Barnes, 2012; Penney et al., 2011).

Role of Health Services

Health systems, which include policies, resources, and services, play an important role in determining differential outcomes of illness (Solar & Irwin, 2007). Within this system, service features that mitigate health inequities include preferential health benefits for socially marginalised groups; inter-sectoral action across providers; needs-based resourcing distribution; culturally responsive healthcare; and health equity policies (Benzeval, Judge, & Whitehead, 1995; Gilson, Doherty, Loewenson, & Francis, 2007).

Culture plays a vital role in the quality of care, and health services have a responsibility to provide appropriate care (Reid & Robson, 2007). In Aotearoa, the social and cultural acceptability of health services are strongly recognised as key factors in accessibility of services, reflecting government obligations under Te Tiriti o Waitangi (Came, 2012). The social and cultural acceptability factors are written into the *New Zealand Public Health and Disability Act 2000*, creating a greater emphasis on primary healthcare (Sheridan et al., 2011) and providing mechanisms to enable Māori decision making on, and participation in, the delivery of services. Factors related to patient and service interactions that contribute to poorer health outcomes for Māori CVD include inadequate prescribing of effective therapies (Riddell et al, 2007, 2008), inadequate follow-up of individuals at risk (Riddell et al., 2007), and poor communication by healthcare practitioners (Jansen et al., 2011; McCreanor, 2002a, 2002b).

Research into cardiac care interventions has concluded that, despite improvements between 2000 and 2012, inequities persist for Māori and Pacific populations (Sandiford, Bramley, El-Jack, & Scott, 2015). Barriers include systemic factors: substandard care, premature hospital discharge, and delayed presentation/advanced symptoms reducing treatment eligibility for procedures (Arlidge, 2004; Brown et al., 2010; Davis et al., 2006; McKinney, 2006; Ministry of Health, 2012; Wilson & Barton, 2012). Wilson and Neville (2008) highlighted how systems disregard patient social context, with implications for holistic care practices of nurses and others and reducing cultural safety[25] to a rhetorical construct.

Response to Treatment

Research into medication use in Aotearoa revealed people have a range of understandings and practices with regard to treatments: limited knowledge of medication in treatment regimens; non-completion of treatments; stockpiling

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[25] Cultural safety is concerned with the beliefs and practices of people who differ from the health practitioners. “Whether a health practitioners’ practice is culturally safe is determined by the recipient of care” (Wilson and Neville, 2008, p. 174).

medication; and sharing medications with others (Carlson, 2010; Dowell & Hudson, 1997; Hodgetts et al., 2011; New Zealand National Advisory Committee on Health and Disability, 2007). Adherence to prescribed medications is an ever-present and complex problem (Thornley, 2011). It is particularly prevalent for those with CVD, the management of which is often multi-faceted and requires high doses of multiple long-term treatments (Wilson, et al., 2002).

Although Indigenous peoples are commonly described as “less compliant” than non-Indigenous (Crengle, 2009), the literature is sparse. A qualitative study examining healthcare journeys of Māori patients with ischemic heart disease found that, in contrast to Māori patients’ accounts of being willing, attentive, and proactive in relation to their healthcare, clinician explanations focused on “non-compliance,” which they blamed on financial constraints, self-destructiveness, and ignorance (Penney et al., 2011). Similarly, McCreanor and Nairn (2002a) identified Tauiwi clinician bias against Māori that influenced their belief that “non-compliance” was related to Māori culture. These accounts have serious implications for Māori health outcomes because they place responsibility on individuals, allowing health practitioners to abdicate responsibility for their practices (Kerr et al., 2010; Penney et al., 2011).

This study evaluates the effectiveness of the *Cardiovascular Disease Medicines Health Literacy Intervention* for Māori who were involved and explores the contribution kaupapa Māori theorising may offer to the evaluation of health literacy activities. We report an analysis of qualitative data from a kaupapa Māori evaluation of a *Cardiovascular Disease Medicines Health Literacy Intervention*, focusing on the experiences of Māori patients and health practitioners. The evaluation was part of the first author’s doctoral evaluation of the effectiveness of the intervention and the implications for health literacy interventions with Māori communities.

Methods

The primary objective of the parent project was to develop and trial an intervention that focused on improving health literacy with Indigenous (in Aotearoa, Māori) patients and their whānau in relation to CVD medications (Lambert et al., 2014). Two Māori organisations were involved in Aotearoa – an urban provider, Te Hononga o Tāmaki Me Hoturoa (Te Hononga), and a rural provider, Ngāti Porou Hauora – and the study was run by Māori health researchers and the providers (Carlson, 2017).

This study was sited in the Ngāti Porou rohe that Ngāti Porou Hauora serves. The area has the highest overall mortality rate in Aotearoa, 66% above the national rate. The Māori mortality rate is 12% above the national Māori rate. Moreover, 91% of Ngāti Porou rohe live in deprived areas compared with both Tairāwhiti at 52% and 20% for all of Aotearoa (Tan, 2016).

Patients were eligible to participate in the intervention if they were Māori adults aged 20 years or older, enrolled with the providers, and had been diagnosed with angina pectoris, myocardial infarction, transient ischaemic attacks, or stroke. In addition, they had to be taking at least two of the following types of medicines: statins, aspirin, beta blockers, or ACE inhibitors (Crengle et al., 2014). Further, patients had to be registered with a Ngāti Porou Hauora health centre in the northern part of the extensive rohe that the organisation serves.

The intervention, the development of which was informed through focus groups with some of the participating organisations' patients and health practitioners, consisted of three educational sessions delivered by a Māori research nurse at a venue of the patient's choosing – in most cases, their home. The nurse had received training in health literacy and related adult education principles, including strategies to support knowledge acquisition and skills development based on adult education principles.

The first and second sessions were one week apart, followed by a final session a month later. Each session ran for 30–75 minutes. Each patient was provided with a CVD information booklet and information about medication use in general and the four types of CVD medication (statins, aspirin, beta blockers, and ACE inhibitors) in particular. The information given was tailored to the medications patients were taking. During the session, an interactive tablet application was used to ensure the nurse covered CVD medication information in a structured and consistent manner. A personalised pill card with images of the participant's medications was also provided. The research nurse also conducted pre- and post-session data collection in relation to medication knowledge and health literacy practices as part of each of the three sessions described above.

Evaluation

Kaupapa Māori evaluations are collections of culturally embedded activities that endeavour to contribute towards Māori agendas (Masters-Awatere, 2015). These activities assess the quality and value of interventions, making judgements against clear aims, objectives, goals, and aspirations. The purpose of this study was to carry out a kaupapa Māori evaluation of the *Cardiovascular Disease Medicines Health Literacy Intervention* outlined above with a few of the participants in the Ngāti Porou Hauora site only. The evaluation aimed to benefit Ngāti Porou Hauora and the community it served by exploring the effectiveness of the intervention (as defined by the Ngāti Porou Hauora patient participants and selected health practitioners working with the organisation). This involved semi-structured interviews with six[26] of the 56 patients participating in the intervention plus three of the health practitioners involved.

The kaupapa Māori evaluation included impact and outcome components to identify experienced strengths of the intervention and suggest improvements. The evaluation specifically aimed to identify patient and whānau (a) experiences of the intervention; (b) reports of changes in medication practices; (c) changes in understandings of CVD medications; (d) satisfaction with the intervention, including interactions with research nurse, use of CVD medication booklet, electronic tablet application and pill card; and (e) suggestions for potential improvements.

The kaupapa Māori evaluation approach focused on aspirations of co-ownership, mutually beneficial outcomes, and shared power by prioritising the patients' voices to shape the evaluation criteria for defining the intervention as "effective." Invitations to participate were part of the collaborative process. Ngāti Porou Hauora were involved in methodological decisions, interpretation of data, and the analysis and discussion stages of the evaluation. The research was approved by the Massey University Ethics Committee (MUHECN 12/095), and patient and health practitioner interview schedules

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[26] Constraints entailed in the parent project meant availability of participants was restricted to the number of participants available for the evaluation due to the inclusion criteria of that study.

were developed with feedback and approval from the Ngāti Porou Hauora research coordinator and other parent project team members.

Patients

Three 60- to 120-minute semi-structured, face-to-face interviews were conducted with each of the six patients and their attending whānau, with whom the research nurse also had delivered the parent project intervention (Crengle, 2016). The three interviews were carried out after the six patients' first and third intervention sessions and six to seven months after the intervention; a total of 18 interviews.

Health Practitioners

Three Ngāti Porou Hauora health practitioners directly involved with the parent project intervention trial were interviewed: the research nurse, kaiāwhina, and GP based at the Ngāti Porou Hauora Matakaoa and Tikitiki health centres in those communities at the northern end of the East Coast. These interviews were 60 minutes in duration, semi-structured, and face-to-face and were carried out immediately after the completion of the intervention and then again six to seven months later.

Analysis

Interviews were audio-recorded and transcribed verbatim. Thematic analysis (Braun & Clarke, 2006) was used to identify, explore, and describe patterns within the data. This method allowed the researcher to draw on content, rhetorical, discursive, and narrative analytic techniques as required (Yanchar et al., 2005).

Feedback was sought from Ngāti Porou Hauora on the draft theme development and findings from analysis of the interviews. The Ngāti Porou Hauora research advisory group included a pakeke (Māori), a Ngāti Porou Hauora board member (Māori), the Ngāti Porou Hauora research coordinator and "local investigator" on the parent project team (Pākehā), a manager (Māori), a chronic care nurse (Māori), a general practitioner (Pākehā), and a kaiāwhina (Māori).

Health Literacy in Action

Analysis of the data identified five core themes. This paper concentrates on three core themes with a particular focus on the six patients' experiences of the health literacy intervention in action, its effectiveness and potential ways to improve and implement it as "service as usual." The three core themes of whakaaro – fluidity of understanding, tūrangatira – presence, and whanaungatanga – building relationships were selected because of their interconnection with the relational prominence of health literacy in action. They focus on patient experience, understanding, belief, and practice in relation to the intervention.

Whakaaro – Fluidity of Understanding

Patients spoke about building knowledge around their CVD medications during the intervention and gaining a sense of understanding of what their medications were for, including generic and brand names, categories and sub-categories, their look, how to administer them, and side effects.

> **Hemi:** She [research nurse] more or less told us what they're really for. The metoprolol slows your heart down and you're supposed to have it every 24 hours. I didn't know that. Like, I used to have it sometimes at lunch time. It makes your

> heart play up if you don’t take them. And that one’s for life, gonna have to keep taking that metoprolol. I didn’t know that. (First interview)

This excerpt reflects other patients’ accounts, in which they spoke about gaining understanding from interactions with the research nurse and learning what their medications were “really for.” It is clear that Hemi has learned about his medications when he articulates what his medications are for. Beyond this excerpt, Hemi indicated that what he was told about his medications before the intervention was not sufficient. There was inadequate information given at the time of prescription, despite the fact that some were lifelong medications.

Patients spoke about becoming more aware of their medications’ side effects and feeling a sense of relief at having their questions answered by the research nurse.

> **George:** . . . now that I’m doing this (laughs) [intervention] I want to learn more about myself. You know. I’m starting to ask questions yeah, before oh well I just accepted [the information] . . . now you ask for second opinions, not just take his [the GP’s] word. (Second interview)

For George, the health literacy sessions ignited curiosity to expand understanding – a shift from acceptance towards practices of reflection and asking questions. He suggests that participation in the intervention gave him confidence to ask for a second opinion.

Health practitioners spoke about patients’ knowledge increasing as they learnt their medication names and categories, making it easier to confirm what medications they were taking. The local GP gave his account:

> **Matt:** It made it a lot easier to figure out what they were taking. I think adherence is probably the biggest thing I struggle with: "What are you taking?" "Oh, I forget my pills," full stop. And then it became: "Oh what are you taking?". . . They have their charts out and "I'm taking these ones and these ones . . . and I remember what they are called." So that helped. (First interview)

Matt spoke about a shift in conversations with his patients, from silence ("full stop") to patients utilising the intervention resources and communicating their understandings.

All patients spoke about changing their behaviour in relation to their medications. Patients started monitoring and recording health information and having conversations about their medications. All spoke of talking about their medications with whānau and whanaunga, where previously they had not. Conversations were not only occurring in the home but also in clinic waiting rooms and more public spaces such as their local marae.

> **Kiriama:** We just say "how're things going? How's the pills?", then we say, "don't forget your pills," whaikōrero on the marae and say to the old people "don't forget to take your pills" [laughing]. I make sure I tell everyone "don't forget everyone, take your pills tonight," throw it at each other, just joke about it. But we mean it seriously though, aye. (First interview)

The actions of Kiriama, in sharing his advice in public settings, underscore the message of collective responsibility among those present to "take your pills tonight"; his actions embody urgency as well as manaaki and aroha for his peers, his people.

In the third round of interviews, patients widely acknowledged that the intervention was valuable, to be shared and available for all, including as a preventive measure for those who have not had "an event" – heart attack or stroke.

> **Kiriama:** I think it's a good thing. I think it makes us more aware of how important it is for us to know what we're swallowing these pills for . . . it made me realise how important it is to know . . . I think it's a good thing, but they should look at not only us, but all our people, especially those in their fifties up. (Third interview)

Overall, patients spoke about the significance of the intervention for them in relation to how they gained an understanding of the importance of taking their medications. However, as with most forms of human understanding, the newly attained CVD medication knowledge wavered over time; it was experienced as a fluid rather than fixed or static state.

> **Kiriama:** We did understand what the medications are for, but now that I've got new ones.
> **Interviewer:** So, are you uncertain about taking your medications now?
> **Kiriama:** Nah, yeah just back to swallowing them.
> **Interviewer:** What would support you in your understanding more?
> **Kiriama:** It's hard we don't have a doctor anymore. (Third interview)

Kiriama made it clear that he does not have the resource, knowledge, or skill to understand his new medications and has reverted "back to swallowing them."

Medication knowledge is complex, and the skills involved in applying that knowledge add additional barriers. Patients and whānau are being asked to remember the information, understand it, apply it, and analyse and evaluate what is happening (side effects) in order to identify its importance and then, if necessary, to have a conversation with a health practitioner (Adams, 2015). In this intervention, knowledge was attained and expressed for moments in time but had to be nurtured to be maintained in relation to changing and evolving health circumstances. This underlines the importance of the relational nature of the intervention, specifically the relationship building with the research nurse. In turn, this needed to be understood and sustained by health services; ideally, all health practitioners should be trained and supported to use health literacy approaches and services.

Tūrangatira – Presence

Tūrangatira is about participation practices between patients and health practitioners and was an important focus of the intervention. Patients were encouraged to become more assertive and ask questions during their engagement with health practitioners. Through the intervention, patients began to enquire about their medication side effects in consultations with the GP. The kaiāwhina shared her experience.

> **Interviewer:** Any feedback? Are they still on their medications? Still going okay?
> **Mereana:** Yes. I went to visit one of them and they said that the doctor changed their medications . . . they realised they could come back to the doctor and say that they were unhappy with it, and they did . . . one of them had like a cough, and he didn't know it was related to the pill, the medication he was taking. Then he changed it and the cough went away. (Second interview)

In Mereana's experience, patients learnt through participation in the intervention that they were entitled to ask questions and revisit medication scripts with their GPs. After many years of taking long-term medications, this was a powerful revelation for all patients but depended on the knowledge bearers to pass on the information. A shared realisation that responsibility for health literacy lies with everybody is required to make substantial systemic change.

During the intervention, patients learned more about their medications and became familiar with their prescribed regimen. In one instance, this led to patient's discovery of a prescription mistake that she subsequently corrected, as described to the research nurse.

> **Joan:** I went and grabbed my [CVD medication booklet] and thought right I'm going to suss it out and see which one I have to take and when, I turned them over, it actually got breakfast wrong . . . I checked them and in the book it says that some have to be taken at night and not in the morning. (Second interview)

The information the patients attained in the sessions with the research nurse, coupled with the medications booklet, supported patients in exercising their health literacy skills to review and improve medication use. Patients made positive steps towards self-care in monitoring and reviewing medications.

Another aspect of knowledge acquisition was patients' lack of medication knowledge in relation to engagement practices with their GP. The research nurse reflected on her experience.

> **Jen:** I don't think that's necessarily the people not knowing about their meds, I think that's because they found that the doctors have been unapproachable, or they felt that they've taken up their time and they just felt that they've been a burden . . . I think patients have to be a bit more assertive, to come forward, talk about your pills, anything that you're unsure of, you have a voice and you have a right to speak. (First interview)

The nurse implies that the solution lies with the patient. However, engagement in the consultation room is about more than two individuals talking, where the doctor has power and the patient has power; it is about power acknowledgement and shift. The voice of the patient may not only be about patients' right to speak and tone, content, and context. Rather, it may be about who is willing to listen with compassion and contextual and cultural understanding. The intervention may also have provided patients with a platform of baseline knowledge about their medications and enabled them to execute their understandings in a way that was visible to health practitioners. This approach, however, may have limited patients' whanaungatanga experience in health encounters, as they carried the weight of changing engagement practices.

> **Interviewer:** Since the intervention, do you feel more confident about asking questions?
> **Hemi:** I've always asked questions. So that hasn't changed much. It is hard though when all the doctors keep changing, you have to start fresh each time, and it's just a matter of getting the basics done never mind "how are you?" (Third interview)

All patients made it clear that they did not have an issue with asking questions and it was about whether the health practitioners engaged with patients' rights and abilities to bring their own knowledge, skills, and power to the health encounter.

Another issue for patients was access – working to maintain relationships and rapport with their health practitioners when they "keep changing." This made building health literacy practices a secondary focus. Health practitioners stated that embedding the intervention in the community was invaluable.

> **Mereana:** If we didn't have this intervention, I think it would have a significant impact on the patients and for those that are out there that missed out, that didn't have the opportunity, that's where I can make a difference to Ngāti Porou Hauora, but who's going to make a difference to [our other centres], that's why it's highly imperative that the whole organisation does the health literacy. (First interview)

Mereana is stressing the need to expand access to the intervention so that others on the East Coast may benefit. She highlights that the responsibility for building the health literacy skills of patients and whānau sits with clinical staff and, more broadly, Ngāti Porou Hauora. A shift needs to occur, not only in terms of access to the intervention but also in providing health literacy training (a key component of this intervention) throughout the organisation and to implement the health literacy organisational review process.

Whanaungatanga – Building Relationships

In their accounts, the patients and health practitioners stressed that the design of the intervention to support relationship building was its most effective feature. The intervention focused on valuing patients as autonomous beings holding their own important and expert knowledge about their lives. The research nurse provided tūhononga, aroha, manaaki, and ahua within the intervention. From this foundation, relationships formed based on trust, reciprocity, and admiration.

> **Joan:** I will say one thing I have found by meeting with the nurse – I feel really safe. . . I feel safe because she supports us, we all benefit. So, if anything comes out of this whole [intervention] is that I found [research nurse] is really good, . . . she's awesome . . . it was how she put it across and sometimes I felt "oh I'm so thick!" but she took her time. Sometimes she went longer, didn't push. (Second interview)

For Joan, feeling safe was an important part of building a relationship with the research nurse, reinforcing practices of support and trust. Joan also spoke from a whānau and community perspective in acknowledging that the research nurse's presence in her home had positive effects for the community. The community is a small rural town where people live communally; therefore, the actions of one impact on many: "We all benefit." The health practitioners expressed a very similar view.

> **Matt:** The importance of relationships was one of the most important things in the intervention, especially with the [research nurse], they trusted her, she had been there for a long time, she was one of them, they could go to her if they had health issues, or even family issues, they could go to her.

As a long-term member of the community and passionately involved in community activities, the research nurse was trusted by her patients. She appreciated and connected with whānau, facilitated information sharing, and effectively communicated knowledge.

> **Jen:** I think it's [intervention] made me a better person, better nurse, better person like I pride myself on communication, I think that without that you don't have much at all and our whole team is like that, but it's just doing this and doing the health literacy training . . . I think a big challenge was trying to get those patients that were just absolutely no, the ones that weren't taking their pills had to work a little bit harder but to see at the end of it . . . It's taught me patience, you can't just try and teach somebody in 10 minutes, if you're going to take on something like this then you have to give time, time is a huge factor. (Second interview)

Jen's account sends a powerful message that she was not deterred by the challenge. She reflects that her role combined skills in patience, listening, and teaching coupled with customised and structured resources and dedicated quality time.

An important finding was the importance of the research nurse's ability and time for developing strong positive relationships with patients. She made contact with patients in their own homes and to suit their time schedules; healthcare was not limited to the clinic environment and time frames. The hard work and effort put into the intervention and gaining buy-in from the participants to complete the intervention was richly rewarded – 56 patients completed the three educational sessions. The space and time allowed for building relationships between health practitioners and patients was a very significant feature of the intervention. It may not have been as successful had the research nurse not brought her already practiced repertoire of engagement and connection. In turn, the intervention heightened her skill and took her health literacy practices to a new level of engagement and professionalism. Furthermore, the “extra time” for delivery of the intervention built into the research nurse’s contract was also a significant factor compared with time frames available in clinical contracts.

Discussion

The effectiveness of the intervention approach for patients and health practitioners, based on building patient knowledge of CVD medications, centred on four key factors: extended time frames, being home- rather than clinic-based, tailored educational resources and materials for both staff and patients, and, most importantly, the connection and relationship with the research nurse who had been trained in health literacy skills.

Changes resulting from the *Cardiovascular Disease Medicines Health Literacy Intervention* can be grouped under three themes. Whakaaro – fluidity of understanding – signifies that knowledge was experienced as a fluid state, understood and practised for moments in time, but needed to be maintained and nurtured through health professional support. Tūrangatira – presence – signifies the dynamic and systemic nature of effective health literacy practice, where solutions lie in concerted efforts at an intra- and inter-organisational and sectorial level of the health system. Whanaungatanga – building relationships – is interwoven through all the themes and is a prerequisite for effective and sustained health literacy practices and environments, founded on connection, and respectful and responsive relationships that are ongoing and accessible.

The intervention delivered to patients a foundation for understanding medications and provided tailored medication information and tools to facilitate communication with their health practitioners. The intervention provided a platform for patients to gain a sense of understanding of their CVD medications; they gained knowledge and some health literacy skills. They learnt about CVD; CVD medication labels, names, and categories; how they work; how to take them; side effects; targets; what questions to ask health practitioners; and how to ask them. Many positive outcomes were highlighted, including gaining a sense of purpose when taking their medications, asking health practitioners questions, wanting to learn more about their health, using more medical vocabulary, recording health information, encouraging other whānau and whanaunga to take their medications, reviewing medications, and identifying prescription mistakes. Patients also said that they benefited from having their own copy of the CVD medication booklet and pill cards, as these contained clear actionable and educational material to refer to whenever needed. After the intervention was completed, however, when they were no longer in contact with the research nurse, patients became less sure of their medication knowledge, and this was when their health literacy skills became vitally important.

The intervention delivered health literacy training to health practitioners involved, incorporating the three-step ABC model (Health Quality & Safety Commission New Zealand, 2013) into their practice. The three steps are to first ask in order to find out what the whānau know, then build on that knowledge, and finally check you have been clear and prompt to build any knowledge that the health practitioner is not clear about. These health literacy practices were vital to the effectiveness of the intervention sessions with patients. Health practitioners made a conscious shift in their practice and took responsibility for not being clear if whānau did not understand, instead of focusing on patients as not understanding.

The evaluation underlined that health literacy – obtaining, processing, and understanding health information and services – entails a complex, varied, fluid, and often conflicting state for patients. Patient accounts detailed that the knowledge and emerging understanding attained during the intervention was not enough to effect long-term sustainable change in relation to medication use and practice. However, when coupled with ongoing whanaungatanga practices, the intervention was far more powerful and influential (Carlson et al., 2016).

Conclusion

The healthcare system is complex and challenging to virtually everyone but more so to those who are marginalised, impoverished, and isolated; all factors that exacerbate health literacy barriers. The intervention highlighted that the responsibility for improving health literacy lies with everybody in making substantial systemic change. In this intervention, the focus of responsibility for building health literacy skills with patients and whānau sat with front-line health practitioners, specifically some nurses and kaiāwhina.

The evaluation highlighted that basic functional literacy and numeracy skills and communicative–interactive (applying information to changing circumstance) skills related to medication use are some, but not the only, important components for improving health literacy with health practitioners and Māori patients and their whānau. Much of the focus in health literacy research has been on analysing the associations between individual-level patient skill and various health outcomes.

In keeping with many interventions, this initiative was developed as part of a finite project. Given limited resourcing and multiple demands, many initiatives that show promise do not continue past their initial trial phase. Further support and resourcing is needed to promote and sustain the practices and resources developed and tested in the *Cardiovascular Disease Medicines Health Literacy Intervention*. Careful and considerate planning is needed to support the ongoing development of the intervention in order to embed and expand the promise of the initiative.

Here, we argue that health literacy approaches need to be implemented at a service level, where organisations are supported by the system to implement effective health literacy policies. The provision of health literacy training and systems design for health service policy and contract developers, governors, managers, and all front-line staff can in turn impact on the type of service patients are receiving.

LINK FOUR

In *Chapter Seven*, I explored the dynamics and manifestations of health literacy in Aotearoa, with particular emphasis on what it does and could mean for Māori with chronic conditions, calling for whanaungatanga practices of connection, continuity, and collaboration to be implemented at a service level. The following chapter, *The Power to Define: Decolonising Health Literacy,* builds on this by drawing attention to the importance and impact of whanaungatanga, whakapapa, and mana motuhake, honouring a pathway of transformation through decolonising methods.

This chapter is about the emerging *Ngāti Porou Hauora Health Literacy Evaluation Framework,* which was developed alongside the kaupapa Māori evaluation. I enjoyed writing the chapter, as it afforded me the opportunity to explore and promote my iwi history, bringing the lived histories and ways of being to the fore.

Material in this chapter was first presented at the Ngāti Porou Hauora ICIHRP Health Literacy and Cardiovascular Disease Medicines Project – intervention trial findings and evaluation hui in 2014, at Te Puia Springs, East Coast.[27] The presentation, *Kaupapa Māori Evaluation of a Health Literacy Cardiovascular Disease Intervention*, consisted of two phases. The first phase was based on the findings of the kaupapa Māori evaluation (which became the basis for chapter five), and the second phase focused on the development of the evaluation framework. At this point, I met twice with Ngāti Porou

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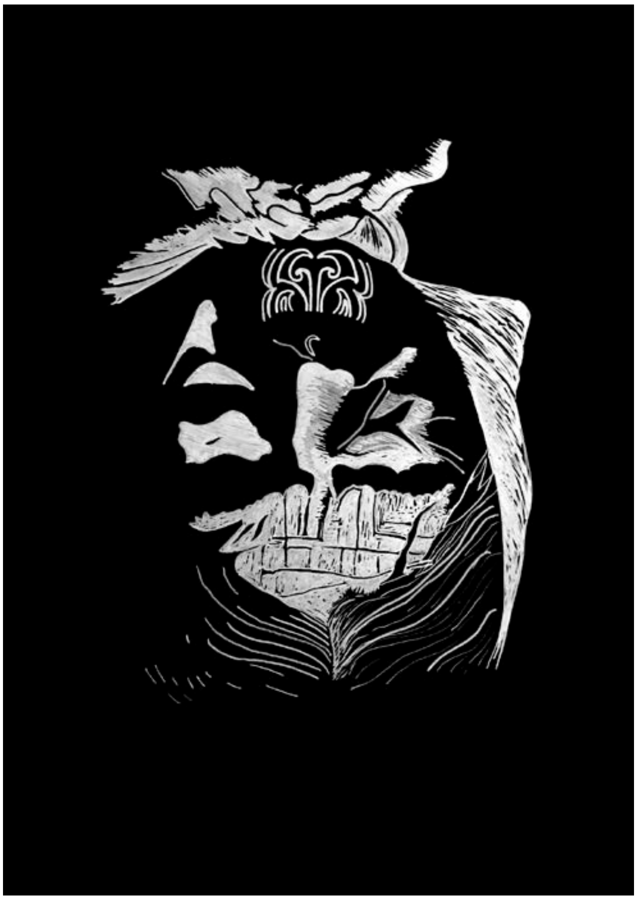
[27] Carlson, T. (2014, April). *Kaupapa Māori evaluation of a health literacy cardiovascular disease intervention*. Paper presented at Ngāti Porou Hauora ICIHRP Health Literacy and Cardiovascular Disease Medications Project – intervention trial findings and evaluation hui, Ngāti Porou Hauora, Te Puia Springs, New Zealand.

Hauora and had previously communicated by email on an initial draft of the framework. The presentation was the fourth hui on the preliminary findings from my participants and my interpretation of incorporating the core themes, literature on Māori health, and evaluative models into the framework. A fifth and final hui was conducted after the submission of the paper.

Structurally, the framework design was shaped by the relationship between the parent project and Ngāti Porou Hauora. I followed the Ngāti Porou Hauora board policy by using te reo me ōna tikanga o Ngāti Porou. I also attended several hui and communicated face-to-face and via email, inviting participation and seeking input and feedback.

The paper was written for Ngāti Porou iwi, hapū, and Ngāti Porou Hauora as well as health practitioners, social scientists, and policy makers. I chose to submit the paper to *Public Health Journal*, specifically because of their special issue on the health of Indigenous peoples. The special issue aimed to bring together a collection of papers from across the world that celebrated the resilience, resistance, and resourcefulness of diverse Indigenous peoples in the pursuit of holistic health and wellbeing.

CHAPTER EIGHT: THE POWER TO RECLAIM

[28]

I fill in the lines above, highlighting form, reclaiming the space. The years have passed now in my research journey. I have met many inspiring people and their words remain with me.

> When we name and reclaim our truth – the historical and contemporary injustice, we can reclaim the truth in our own power . . . our power as Māori is innately relational, depends on the gathering of networks, recognising the entitlements of individuals [mana] that are exercised within the wellbeing of the collective [mana motuhake] (M. Jackson, personal communication, March 23, 2017).

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[28] Teah Carlson, Painting my gaze – who I am, what I have learnt, and what I see, 2017
Liquid chalk on black card, 637 × 415 mm, Private collection, Auckland

Abstract

This paper explores decolonising health literacy by reclaiming historical practices shared by Māori (the Indigenous peoples of Aotearoa) to develop a kaupapa Māori health literacy evaluation framework. The work is based on a research innovation within a Primary Health Organisation – Ngāti Porou Hauora – that defines health literacy within the context of the community. This research promotes reclamation of health literacy as a space for Māori to be ourselves; a space that is negotiated, adaptive, and shaped by people, whānau, and communities.

The framework attempts to reflect participants' voices, perceptions, understandings, and experiences. Its design was informed by kaupapa Māori praxis and aspires to co-ownership, mutually beneficial outcomes, and shared power through prioritising participants' voices to shape and develop the criteria for determining the goals and action areas in relation to health literacy. The framework includes overall goals and action areas for practicing effective health literacy at individual, whānau, health practitioner, intervention/programme, and organisational levels. This paper is an example of how Māori can promote and practice health literacy in the context of our histories, honouring a pathway of transformation through decolonising methods.

Introduction

In Aotearoa, the effects of colonisation on Māori health have resounded through the Māori world in deep and devastating ways, so the need for decolonisation toward Māori tino rangatiratanga is a powerful counter narrative. Through decolonisation, we attempt to unravel what is distinctly ours and what is theirs, while what remains unclaimed is a matter for debate (Smith, 2014). How do we create pathways to health that are free from colonialism and grounded in tino rangatiratanga and mana motuhake (autonomy)? To what extent might this be possible? We must begin with what makes us Māori: our place – whānau, hapū and iwi; our space – relationships, connections to each other, our environment, and our spiritual cosmos; and our time – our lived history, including resisting colonisation and a constant striving for action and change.

Through intensive research, mostly 'on' Māori, Western researchers have Māori have (re)discovered, fragmented, appropriated, and objectified Māori knowledge – "They came, they saw, they named, they claimed" (Smith, 1999a, p. 80). But improved outcomes have not been forthcoming (Bishop, 1999; Irwin, 1994; Smith, 1999b). Consequently, it is not surprising that many Māori question the value of health research and its agenda and contemporary research with Indigenous peoples requires approaches and methods that catalyse constructive change and are relevant to the lives of the people who participate. Decolonising research must address the issues of power, especially the power to identify issues, determine the research and evaluation agenda, identify issues, and prescribe a methodologies/methods (Bishop, 2005; Durie, 2004; Smith, 1999a).

In Aotearoa, kaupapa Māori research advances the decolonisation agenda by privileging Indigenous voices and epistemologies in collaborative or collective research processes. Kaupapa Māori research utilises a wide range of methods, including evaluation (Pihama et al., 2002b). Kaupapa Māori evaluation can be described as a process of exploration, innovation, and explanation using Māori forms of enquiry and accountability measures and criteria (Cram & Lenihan, 2000; Kawakami et al., 2007). This paper explores the potential of kaupapa Māori evaluation from the standpoint of a local, iwi-based health organisation in my home territory of Ngāti Porou. I have focused on creating an evaluation framework for a health literacy initiative, underpinned by a powerful commitment to mana motuhake. I begin by contextualising the work to the region and people among whom it arose and was implemented. Next I explore impacts of colonisation on health/health services and health literacy in particular, before introducing kaupapa Māori health literacy. Along with an interrogation of conventional evaluation approaches. I discuss the use of kaupapa Māori evaluation practices in the development of a location-specific health literacy evaluation framework. The framework is described as an exemplar of a kaupapa Māori evaluation of a collaborative approach based on mana motuhake.

Colonisation and Health

For over a thousand years, Māori have adapted and innovated in response to our environment. The natural environment provided spiritual, theoretical, and ethical foundations that "gave rise to codes for living that would ensure the well-being for future generations" (Durie, 2013, p. 183). In the years after settling Aotearoa, Māori were healthy, robust, agile, and mentally active. They lived in tune with nature and, when mature, were at the peak of fitness, as the weak would not survive the hardships of primal life (Pomare, 1909).

Some of the earliest European observations of life in Aotearoa described an Indigenous people with a strong health philosophy and a health system based on social and cultural concepts practiced successfully within the community (Beaglehole, 1955; Salmond, 1991). Shortly after European contact, Māori were described as well-built, fit, and remarkably healthy (Hanham, 2003; Nicholas & Watkins, 1838). Māori were observed to have healthy skin and a rapid healing ability, indicating a healthy immune system (Hanham, 2003). Health and wellbeing were understood as conditions of moral and spiritual wholeness. “Spiritual” practice aligned every action to the workings of the natural world on which Māori depended (Hanham, 2003). Good health, “ora,” was important and appreciated. “Hauora” (health and wellbeing) described a holistic state of wellbeing and abundance (Hanham, 2003).

However, contact with Pākehā and subsequent colonisation brought new diseases, technologies, and novel foods, as well as introducing racism, oppressive religion and education, discriminatory governance, and exploitative economic practices. From the 1820s, Māori communities suffered intertribal conflict, military invasion, land alienation, resource destruction, dehumanisation, and deculturation (Durie, 2013). Customary traditions were tested by new social and material practices that were inherently unsustainable and caused extensive ecological destruction (Cram, 2009). Māori populations declined, damaging the effectiveness of tribal organisation and often threatening the very existence of smaller tribal groups.

A Ngāti Porou Perspective on Holistic Health

The impacts of colonisation were felt by Ngāti Porou, and the effects of colonial force still reverberate in contemporary Aotearoa. The people of Ngāti Porou are descendants of Māui-Tikitiki-a-Taranga. When Māui fished up Te Ika-a-Māui, two rocks appeared. He named these two rocks Hikurangi and Aorangi after two maunga that stood in his homeland of Hawaikii. It was Hikurangi that raised his waka, Nukutaimemeha, out of the water, and it rests there to this day. Ngāti Porou boundaries span from Toka-a-Taiau to Pōtikirua in the Te Tai Rawhiti region of Te Ika a Māui.

The communities engaged with my research are located in the area north of the Waiapu awa, known as Rangitukia. Whakapapa links them to Ngāti Porou ki Potikirua ki Whangaikena, Whangaikena ki Waiapu, Pohautea ki Te Onepoto, and Te Onepoto ki Rahuimanuka. The name "Rangitukia" means to break through to heaven, acknowledging terrestrial space. If you journey up the awa to Tikitiki, you arrive in the area known as Tikitiki-o-rangi, another form of heaven – the telestial space. You then make your way to Hikurangi, the most prominent maunga on the East coast. "Hikurangi" is the celestial heaven. The names of these places acknowledge the creator for giving us these lands. This is mana whenua (power from the land).

Descriptions of life in the 1800s and early 1900s in the Rangitukia and neighbouring Matakaoa regions describe lands that were thick in vegetation and divided by natural formations, awa, and maunga (Mahuika, 2010). "The land back then was anybody's and everybody's. There weren't any exclusive boundaries between the families . . . there was a tremendous community spirit" (Karaka, 2000, p. 3). Communities were small, and everyone had a role and work to do. The ngahere, moana, awa, pūkaki, and wairepo were places of resource, sustenance, and rongoā. Whānau knew what could be consumed, what was poisonous, and what healed. Whānau knew the lands well, walking them every day to hunt for kai (food) and gather supplies.

For Ngāti Porou at this time, the health and wellbeing of the people were based on common sense and an intimate connection with the environment. Knowledge and everyday living were guided by tikanga (customary system). The Waiapu awa was (and is) their source of life, providing kai and spiritual sustenance. The health and wellbeing of the awa is intimately connected to the people. When the awa flooded, it was a sign that tapu had been breached and atua were offended (Karaka, 2000). When the waters were clear and flowing, life was in balance. The wellbeing of the people was based on a value system that was shared and understood by all, as captured by this Ngāti Porou whakataukī.

Tautoko tetehi ki tetehi	*To support one another*
Awhina tetehi ki tetehi	*To help one another*
Aroha tetehi ki tetehi	*To show love for one another*

The Introduction of Colonial Health Services

In 1885, the government established the Cook and Waiapu Hospital Boards to manage the provision of hospital services in the East Coast region. In 1903, a small one-bedroom hospital was opened to serve almost the entire region. By 1900, the people of Ngāti Porou were suffering heavily from infectious diseases and other forms of illness. Typhoid and tuberculosis (TB) had hit the people at epidemic levels, and isolation huts became a common sight in communities. “It is an utter disgrace what has happened to our people. Tauiwi brought in diseases that killed off whole families, like typhoid, T.B., and influenza" (Tangaere, 1999, p. 30). The very limited level of government help meant that many people relied on tohunga. However, in 1907 the Tohunga Suppression Act was passed, outlawing Māori customary medical practices (Tangaere, 1999). In 1918, an influenza pandemic struck Aotearoa, killing over 8,000 people in two months. Two thousand Māori died, a fatality rate over seven times that for Pākehā (Lange, 1999).

The significant disparities in health between Māori (including Ngāti Porou) and Tauiwi have persisted since the 1920s (Robson & Harris, 2007). In 1988, the Director General of Health characterised the development and implementation of government health policy and national health services as mono-cultural (Mahuika, 2010). For example, until the 1970s, there was very limited Ngāti Porou representation on the Cook and Waiapu Hospital Boards. In response, Māori communities have been establishing their own health providers.

Ngāti Porou Hauora was initially established in 1995 as an incorporated society to provide integrated health services for all people residing within the iwi boundaries. At that time, the rohe faced many issues, including poor health outcomes, limited access to services, and low rates of employment. There was a yearning for an innovative, locally relevant service that reflected Mana Motuhake o Ngāti Porou. Ngāti Porou Hauora is currently the main provider of health services in the rohe, operating seven community health centres and a small rural hospital, offering various public and clinical health services at low to no cost for enrolled patients.

Health Literacy

Given the emergence of kaupapa Māori health providers, consideration of kaupapa Māori health literacy seems the next logical step. The word *literate* is from the Latin *litteratus* – one who knows the letters, which later came to mean educated (Harper, 2012). In Western epistemology, being educated equates to being schooled, well read, and knowledgeable. The term health literacy first appeared in a 1974 paper calling for minimal health education standards to be implemented in U.S. schools (Mancuso, 2009). Since then, the concept has evolved, with numerous studies examining ways to measure "health literacy" and describing problems related to low levels of health literacy (Schulz & Nakamoto, 2013). The WHO describes health literacy as "the degree to which people are able to access, understand, appraise and communicate information to engage with the demands of different health contexts in order to promote and maintain good health across the life-course" (Kanj & Mitic, 2009, p. 4). Because of their supposed impact on individual health and healthcare costs, most examinations of health literacy have focused on functional aspects, which include basic literacy and numeracy. More recently, the concept of health literacy has expanded to encompass communicative/interactive literacy and critical literacy (Nutbeam, 2009). However, social and cultural considerations are rarely discussed in the literature (Carlson et al., 2016).

The growing acknowledgement of its multi-layered nature has advanced the notion of health literacy as a social practice, positioning it as a health system issue rather than as an issue of individual skill deficits. Health literacy, when understood as embedded in social and cultural practices (Papen, 2009; Rudd, 2012). Rudd, McCray, & Nutbeam (2012) requires an examination of context and consideration of patient agency and participation. Papen (2009) stressed critical analysis of information, social determinants of health, and engagement in collective action. Ross, Culbert, Gasper, & Kimmey (2009) suggested that strategies to improve health literacy must include multi-level approaches that practice collaborative, communitarian partnerships among people. A systematic review by Sørensen et al. (2012) provided an overview of existing health literacy definitions and conceptual models and after thorough empirical review of the dimensions of the domain, proposed a model integrating medical and public health views. Their integrated model of health literacy indicates that, as a concept, health literacy is oriented to understanding how it functions within a system, so that as an intervention practice, its interests and concerns are also intra-systemic, rather than a critical analysis of the underpinning values and principles it promotes. Given that, in this country and similar settings, the system so surfaced is un-reconstructed colonialism, this evolution represents a profound ideological, theoretical and practical problematic for indigenous people since it submerges and marginalises longstanding concerns with social injustice and objectives around self-determination. In the absence of an overtly decolonising imperative, Māori communities will question the assumptions, agendas and values that health literacy approaches and interventions serve and how they address the aspirations of the people (Damschroder, Aron, Keith, Kirsh, Alexander, & Lowery, 2009).

Evaluating Health Literacy

Health literacy is multidimensional, encompassing systematic and environmental demands and complexities as well as individual skills and attributes, which are influenced by contextual, social, and cultural factors (Pleasant et al., 2016). Elsewhere, I have argued that health literacy researchers must analyse literacy as a set of practices entrenched in broader social accounts and cultural activity that reflect issues of equity, equality, and self-determination (Carlson et al., 2016). Accordingly, I propose that the effectiveness of health literacy practices and processes needs to be evaluated and defined by the people that are affected by it – in this case, Māori whānau, hapū, and iwi.

Advancing kaupapa Māori health literacy involves acknowledging other forms of *knowing*. Early Polynesian voyagers navigated across the vast expanse of the Pacific Ocean guided by their own literacy, measures, and practices, none of which involved using the written word to communicate or record (Balmer, 2015). Being literate about the motions of the earth, sun, cosmos, and the migratory behaviour of birds and sea life was highly valued. The discovery of new lands occurred because specialised knowledge was passed down from one generation to the next (Balmer, 2015). This *knowing* is another practice of literacy – communicated through whakapapa, waiata, and whakairo (carvings), which have been refined and tested through millennia (Spiller, Barclay-Kerr, & Panoho, 2015).

Because the use of the word "literacy" typically privileges Western ways of knowing, *literacy* has been described as a tool of privilege and power in the communication and practice of the West (Papen, 2006). Health literacy has similarly been described as legitimising colonial power, its world view, principles, and values. However, history presents an important twist. Until the 1860s, there were more Māori literate in te reo Māori than British colonists literate in English. These relative levels of literacy were only changed by civil war and the emergence of discriminatory policies, such as the Native Schools Act of 1867. Drawing on traditions of Māori health philosophies, and a re-imagined understanding of "literacy," I propose "*re*writing and *re*righting" the historical account and practices of health literacy as a practice shared by Māori. In this paper, I explore decolonising health literacy through kaupapa Māori evaluation (Smith, 1999a, p. 28).

Reviewing Colonial Evaluation Practices

Research into Māori health has focused on the realms of Western (bio-medical) science, rather than Māori notions of wellbeing, which are far broader than physical health or the absence of disease (Gracey & King, 2009). The colonial gaze also manifests in evaluation practices, which promote dominant discourses based in reductionist, deficit-based views (Kawakami et al., 2007). Conventional evaluative processes may minimise community involvement at developmental stages, limit collaborative participatory approaches, ignore cultural practices of the researched, and/or disseminate results in inappropriate forms (Bishop, 1999). Western evaluative measures emphasise the importance of outputs over process, consultation over meaningful relationships, and short time frames over long-term sustainability measures. Frequently, the processes used to determine "value" within programmes respond only to the surveillance needs of external administrative bodies, such as funders. The resulting reports may ignore explanatory frameworks or incorporate manipulated or watered-down versions (Kawakami et al., 2007).

Articulating Value from Māori Perspectives

As a result, Māori communities have often endured evaluations that are not "culturally and historically meaningful" (Kawakami et al., 2007, p. 330). However, I wish to reclaim evaluation as a helpful tool and process for monitoring and assessing the effects of colonial force on Māori society and health and wellbeing in the rohe and for building a pathway of restoration, healing, and autonomy. The critical question for evaluation is: "Who determines what is of value to our people?"

Within Te Ao Māori, something that is "valued" is understood to be worthy or highly regarded, based on its connectedness to te tai ao (environment), pūmotu (elements), whānau, tūpuna, and te reo Māori (Kawakami et al., 2007). In accordance with our deep connection to the spiritual power inherent in land, whakapapa, and whānau, "value" is based on principles and standards that determine the collective good (Durie, 2013). Whānau, hapū, and iwi may determine "value" within their context, including a specific time and place. Within the Māori world view, the meaning of an evaluation is measured in terms of its practical and respectful impact on the lives of the participants and communities concerned (Mead, 2003). Evaluations must be ethical, action-oriented, restorative, transformative, decolonising, and participatory. Processes must honour collective engagement approaches and create pathways towards self-determination and cultural autonomy (Denzin & Lincoln, 2008). Determining what we value is vitally important to the evaluation process because values determine the criteria for assessing the effectiveness or success of approaches and practices. This research provides an insight into the "value" we place on health literacy.

Practice in the Context of History

The term "evaluation" in te reo Māori has been translated as "aromātai." "Aro" means to take interest, to face towards, and "matai" means to gaze intently and longingly. Contained within Māori histories are descriptions of processes and metaphors that relate to evaluative processes and theories, including collective advancement, problem solving, and decision making (Walker et al., 2006). Empirical observation, analysis, problem solving, and progression have been part of our histories – from Tāne Mahuta, who sought to bring the first human form into the world as Hineahuone, to Māui, who restrained the sun, fished up land, brought fire into the world, and searched for immortality. These processes of gaining knowledge embody the many environmental, economic, and social practices adopted and adapted by tangata whenua (people of the land). These pūrākau (ancient legends) and histories are gifts from tūpuna that construct a platform of knowledge, innovation, and connection from which Māori can launch into the world of evaluation practice.

Kaupapa Māori Evaluation

Kaupapa Māori evaluation is built on consensus and inter-subjective understandings and embedded in Māori worldviews. From an Indigenous perspective, an effective model of evaluation has at its centre people, relationships, connections, and a sense of place and belonging. Kerr (2012) provides an excellent overview of kaupapa Māori theory, practice and scope. Data, analysis, interpretation, recommendations, and uptake all depend on collaboration and connection. Mainstream methods are utilised to collect data, but subtle signs and inferences provide insight into cultural value and practice. Evaluation is about listening, reflection, and assessing whether or not a programme adds value to our collective cause and our quest for mana motuhake (Cram, 2001).

Kaupapa Māori evaluation embodies decolonisation (Cram, 2016). Through kaupapa Māori evaluation, we can reclaim mātauranga Māori and empower Māori individuals and communities, including both those who are researched and those who are researchers (Edwards et al., 2005). Decolonisation is about refusing to legitimise the dominance of Western knowledge and instead seeking power in our own philosophies, truths, and stories (Jackson, 2017). Decolonising evaluation practice takes place within a space of history, presence, and future aspirations. Kaupapa Māori evaluation is part of a collective movement towards Māori autonomy that extends respectful, reciprocal, and meaningful relationships with people, place, and space (Cram & Mertens, 2016). Kaupapa Māori evaluation is political, and evaluators must understand that self-determination powers the aspirations of the community (LaFrance & Nichols, 2010). Kaupapa Māori evaluation strives to make a positive, transformative difference in communities (Cram, 2016), serves to strengthen Māori, draws from core values, and promotes being active.

Collaboration is critical to kaupapa Māori evaluation and, by definition, these collaborations are context specific. Collaboration is based on interconnection and commonality as Māori, whānau, hapū, iwi, health consumers, and health workers. Collaborative approaches can include engaging and resourcing patients to become co-designers and researchers from the inception of the research through to the end. Tikanga provides a benchmark against which all relationships, recognised or potential, can be measured and includes ways of communicating that are respectful and responsive (Mead, 2003).

Māori philosophies emphasise being open to evaluation and reflection in order to assess what is tika, the right way (Henry & Pene, 2001). Just as programme stakeholders and participants are located within whānau, hapū, and iwi, so too are the evaluators who evaluate the “success” or “failure” of these programmes. Kaupapa Māori evaluation marries the ethical and moral practice of research with the political imperative to reclaim Māori cultural practices (Masters-Awatere, 2015). For Māori evaluators, our role is not simply a job. The success of the evaluation depends on our ability to connect, express, and reflect our perceptions, way of life, and understandings of who we are as Māori (Denzin & Lincoln, 2008). At each level, Māori evaluators may feel a commitment to simultaneously “write back” against colonial authority and to write to ourselves in support of mana motuhake (Smith, 1999a). Kaupapa Māori evaluation intends to honour individual contributions that reflect diverse Māori experiences and realities, while striving towards collective advancement and Indigenous sovereignty (Cram, 2016).

Methods

The kaupapa Māori evaluation approach used in this study aspired to co-ownership, mutually beneficial outcomes, and sharing power by prioritising patients’ voices to develop the criteria for determining the effectiveness of the intervention. Ngāti Porou Hauora was involved in decision making about methodology, interpreting and analysing data, and in the concluding stages of the evaluation. My collaborative journey through the kaupapa Māori evaluation relationships went deeper than evaluation partnership or collaboration, as I was both an insider – iwi member – and an outsider – evaluator. While my methodology is located within kaupapa Māori, it draws on and, at times aligns with elements of community-based action participatory research (Cram, 2012; Stringer, 2007), co-operative inquiry (Heron & Reason, 1997), and co-design (Boyd, McKernon, Mullin, & Old, 2012).

Other phases of my doctoral research were attached to the aims of a wider study called the *Cardiovascular Disease (CVD) Medicines Health Literacy Intervention* (Lambert, Luke, Downey, Crengle, Kelaher, Reid, et al., 2014). They involved me in semi-structured interviews with patients and whānau, health professionals, to gain insight into their perceptions, practices, and experiences of the intervention (Crengle, 2009). To complement these understandings I interviewed expert Māori and indigenous health literacy key informants to add broad, professional knowledge to my developing understandings of the area.

The final component of my study was built on those learnings to develop wider understandings of the health literacy interventions with Māori and Indigenous communities. The intention was to collaboratively design this as a kaupapa Māori evaluation framework, specifically to assess the effectiveness of health literacy interventions. I worked with a Ngāti Porou Hauora research advisory group included a pākeke (cultural advisor), a board member from the community in which the parent project was sited, a research coordinator and Ngāti Porou Hauora investigator, a manager, a chronic care nurse, a general practitioner, and a kaiāwhina (community support worker).

Collaborative Hui to Develop the Framework

A seriers of hui were held with the advisory group to plan, outline, develop, and refine the kaupapa Māori evaluation framework. Equitable collaboration and partnership were imperative to ensure that the information generated from the evaluation was context focused and that the process honoured te reo me ōna tikanga o Ngāti Porou.

A key first step was being formally introduced to the intended collaboration partners, particularly members of the research advisory group. I gave a short presentation about the proposed evaluation and research processes and answered questions in a discussion session. I invited them to participate collaboratively in my doctoral project, secured permission to attend their hui, and obtained agreement that they would provide advice and feedback on aspects of my work.

The second hui focused on gaining insight into the principles and aspirations that guide this specific research advisory group. I supplied a background paper, which presented an overview of the research and proposed a kaupapa Māori methodological approach (Carlson et al., 2016). I aimed to explore both the “principles” and “values,” and to begin developing the “practical enactment” of these values in the form of evaluative criteria. I asked each participant to write down their goals and aspirations for the health and wellbeing of the communities they serve. I also asked them to write down the important principles that guide their practice in their respective roles. These goals, aspirations, and principles were written on Post-it notes, placed on a whiteboard, and collaboratively grouped under themes.

Working with the goals and aspirations expressed, I sent an initial draft[29] of the Ngāti Porou Hauora Health Literacy Evaluation Framework to all research advisory group members for feedback. The draft also outlined data-collection plans backed by literature on current evaluation models and frameworks used in kaupapa Māori health contexts.

At the fourth hui, I presented preliminary findings from the earlier interview phase to the research advisory group and my interpretation of these core themes of relevance to

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[29] The third hui was held via email (telehui was offered, but email was the preferred contact method) because of resource and time constraints (related to the parent project and out of my control).

the draft framework. The advisory group was asked to provide feedback on the interpretations and framework development.

The final hui included sharing developments in the framework resulting from the incorporation of key informant data and feedback and other Indigenous framework developments (Hawai'i)[30] and gathered final feedback from the advisory group.

The Framework

The early stages of developing the framework focused on aspirations and values. The framework was also influenced by Durie's health-promotion model, *Te Pae Mahutonga* (1999), and the Ngāti Porou Hauora strategic plan (2014). The research advisory group worked with me to determined Mana Motuhake o Ngāti Porou as an underpinning principle of the framework – the first level. The non-negotiable right of mana motuhake was recognised as a commitment towards decolonising our pathway forward. We then identified the second level of goals of hauora for the community: toiora – healthy lifestyles, te oranga – participation in society, and waiora – ecological wellbeing. These goals form the second level, outlining specific goals that connect and shape hauora. These goals were linked to key elements of Ngāti Porou tikanga: mauri ora – lived practices of te ao Māori; whakapapa – ancestral inheritance and interconnectedness; pakari – collaboration and partnership; manaakitanga – equality and equity; and mātauranga – quality practices and services. These elements encompassed the many

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[30] The *Ngāti Porou Hauora Health Literacy Evaluation Framework* was expanded to incorporate Indigenous health practitioners and community representative perspectives on goals and aspirations of health and wellbeing for the communities they serve at the 2014 World Indigenous Peoples' Conference on Education. Kapiʻolani Community College: Oʻahu in the Hawaiʻi Archipelago.

forms of an effective and successful health literacy practice, directed, and shaped the five action areas in the Ngāti Porou Hauora health literacy evaluation framework.

The consensus was that these principles, goals and elements covered core tikanga and hauora practices and the range of concepts that need to be attended to in health interventions and evaluations. These principles are interwoven expressions of what is important and necessary to health and wellbeing for Ngāti Porou. The process grounded grounded our subsequent co-design processes to identify specific criteria that would determine the effectiveness of health literacy within the Māori health organisation and more broadly within the community.

The Framework

The current framework is presented as my conceptual synthesis of domains and action areas that relate to the principles, goals, and elements of effective health literacy practice for Ngāti Porou Hauora. It is grounded in the collaborative work of the research advisory group, informed by my analysis and interpretation of interviews with patients, health professionals, key informants. The framework is complemented with relevant literature including health literacy, patient-centred care, cultural competency, kaupapa Māori evaluation and action research literature and grounded in theory, see for example (Cram, 2016; Ministry of Health, 2015b; Reason & Bradbury, 2006; World Health Organisation, 2007).

Table 12
Ngāti Porou Hauora health literacy evaluation framework

Domains		**Individual/whānau voice level**	**Health practitioner level**	**Intervention/ programme level**	**Organisational level**	**Health system level**
Action areas	**Whanaungatanga** Relational practice	Active collaboration	Shared power approaches	Partnership and collaboration	Deliberative engagement	Policy guidelines to support health literacy leadership pathways and encourage shared power approaches
	Te ū o te kaha Strengths based	Te reo me ōna tikanga o Ngāti Porou	Provide supportive and culturally safe environments	Build on individual/whānau knowledge base and understanding	Prevention and wellness focus	Provide health system pathways that have reduced health literacy demands
	Te raupapa whare ora Capacity and capability building	Positive change and sustainability	Promoting, coordinating awareness of, and building health literacy skills and cultural safety and competency practice and training	Long-term investment/funding pathways and resource implementation	Leadership and accountability	Develop partnerships with research, education, and practice communities to build capacity and capability
	Te ia o te kaupapa Context specific and fit for purpose	Honour our diversity	Skilled in facilitation and knowledge sharing Implement health literacy practices	Resources and approaches that are simple, clear, understandable, and tailored to specific peoples	Organisational health literacy planning	Provide strategic guidance on implementing health literacy planning for organisations, services, and interventions.
	Te hua me te rautaki Effectiveness and efficiency	Accountability and transparency	Critical reflective practice and learning	Implement Ngāti Porou evaluative processes from inception to dissemination	Reflective and evaluative organisational culture	Provide strategic guidance on implementing reflective and evaluative organisational culture

The framework reflects how each action area within domains of health systems/services can contribute towards building health literacy and now I discuss each of these in more detail, highlighting the role of the diverse data sources on my conceptual work.

Whanaungatanga – relational practice – relates to establishing and maintaining meaningful, reciprocal, and respectful relationships. This goal focuses on shared power approaches to decision making, accountability, and resource distribution at every level of health engagement. Whānau emphasised that all approaches, services, and systems must seek to actively collaborate. For health practitioners, relational practice means valuing patients as autonomous beings holding their own important and expert knowledge. This practice is developed through shared interests and consistency of care; that is, building a relationship by repeatedly seeing the same health practitioner. At the programme level, whanaungatanga is about streamlining approaches, preferably through kanohi kitea, so that interventions align to ways of living and being. For health service providers, relational practice is about encouraging and creating collaborative approaches between organisations practicing health literacy and the health workforce, including sharing resources when possible. Within the health system, this involves providing policy guidelines for organisations to develop health literacy leadership pathways and encourage shared power approaches (Ministry of Health, 2015a).

Te ū o te kaha – Strengths-based approaches promote prevention and wellness pathways. Creating these pathways requires holistic approaches to healthcare through understanding the interconnectedness of hinengaro, tinana, wairua, relationships, environment, and cosmos. Whānau voices were concerned with the importance of offering space to lead, implement, and practice te reo me ōna tikanga o Ngāti Porou at every stage of engagement. Strengths-based health literacy practice involves health practitioners, health workforce, and health service providers creating supportive environments to practice cultural protocols, native language, and intergenerational connections. Specific actions could include providing adequate consultation times, building relationships, and enabling family and extended family to be involved at the individual's request. Strengths-based programmes utilise approaches and practices that build on whānau knowledge and understanding. For health service providers, te ū o te kaha means prioritising and investing in prevention and wellbeing pathways. To achieve this, tensions between the clinical agenda (bio-medical orientated) and patient-centred (public health/primary) healthcare need to be identified and reduced. The health system role is to provide strategic guidance to the health sector to support literacy activities, prevention, and wellbeing approaches – embedding literacy in policy and utilising health literacy as an asset in all health targets and approaches.

Te raupapa whare ora – Capacity and capability building necessitates sustainable resources and practices. Whānau voiced the need for interventions to make a positive difference in our communities, strive towards practices of sustainability, and consideration of long-term impacts and outcomes on future moko-mokopuna (next generations) and their environment. Health practitioners need to be skilled in facilitation and knowledge sharing. Interventions that build capacity and capability will offer patients options to develop their health literacy knowledge and skills, including invitations to review approaches and change treatment options. Te raupapa requires health practitioners to participate in cultural safety and cultural competency training and practices, which should be offered, supported, and implemented by organisations. At an intervention/programme level, te raupapa highlights the need to create sustainable practices through long-term investment, from initial funding through to resource implementation and dissemination. Health service providers play a role in developing partnerships with research, education, and practice communities to build capacity and capability in all approaches and action and to maximise Māori participation in leadership roles from inception through to dissemination. The health service and system role means developing partnerships with research, education, and practice communities to build capacity and capability in all approaches and action.

Te ia o te kaupapa – The aspiration to create context-specific and fit-for-purpose interventions recognises and promotes the significance of rohenga tīpuna (shared ancestors, history, and location), local contexts, and diversity for all health literacy approaches. Whānau voices focused on the need to consider context in terms of rural and urban locations, access to resources and services, and favoured home visit options and extended periods when working with whānau. Context-specific interventions require long-term involvement, engagement, and investment in the community. Health practitioners need to immediately action health literacy practices and tools.[31] At the intervention/programme level, health engagements should be supported with resources that are simple, clear, and understandable. These resources should be tailored to specific audiences and easy for patients to take home and personalise. For health service providers, te ia o te kaupapa means reviewing service and systemic practices of health literacy by examining the use of resources, signs, forms, educational material,

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[31] Examples include the teach back method – checking understanding by asking patients to state in their own words what they know or do about their health; three-step model – ask what people know, build health literacy skills and knowledge, and check for understanding; and patient medication review – encouraging patients to bring all of their medicines and supplements to their visit and reviewing them.

and systems to reduce health literacy barriers. Additionally, when service providers conduct health literacy planning and decision making or develop health resources, it is important to use high-quality ethnicity data that are routinely analysed and reported. Health service providers need to act on these data, for example, by spending more time and resource with populations identified as high need or high risk. In regard to the health system, collective priorities means providing strategic guidance on implementing health literacy planning for organisations, services, and interventions to make it easier for people to utilise the system.

Te hua me te rautaki encompasses a commitment to effectiveness, efficiency, and action in all health literacy approaches. Whānau require accountable and transparent practices that ensure all resources, outcomes, and outputs are disseminated in ways accessible to the community. For health practitioners, te hua me te rautaki means continually reflecting and evaluating their practice. Striving to deliver effective and efficient health literacy means health practitioners and organisations promote and coordinate action to raise awareness of and build skills in health literacy practice. When developing interventions or programmes, it is vital to implement evaluative components from inception to dissemination, improving practice along the research, intervention/programme pathway. Action-based, participatory methodologies promote relationship-building practices. Organisations are responsible for supporting a culture of reflection and evaluation and for ensuring that programmes focus on processes and outcomes, not just outputs. Again, organisations must provide training and time to undertake evaluation and reflective activities. The health system role means providing strategic guidance on implementing a reflective and evaluative organisational culture.

Reflection

This research promotes the re-claiming of health literacy as a space for Māori to be ourselves, a space that is negotiated, adaptive, and shaped by people, whānau, and communities (Carlson et al., 2016) and that asserts the value of kaupapa Māori evaluation in addressing issues of self-determination (Cavino, 2013; Cram, 2016; Kerr et al., 2010). Identifying, naming, and defining are powerful acts that can change perceptions and determine who and what has value and then drive subsequent actions, such as policy development and research (Köhler, 1992). When Western terms, definitions, and approaches are utilised in Indigenous communities, they can reinforce colonial power processes by legitimising Western systems of ideas. Māori and the Crown have a political, legal, and spiritual covenant of equitable partnership through Te Tiriti o Waitangi (Henare, 1987). This research suggests that, rather than rejecting Western terms and approaches, we can cautiously reclaim health literacy concepts and practices as our own, drawing on both mātauranga a-iwi and Western discourse. This approach is captured eloquently by Tā Apirana Ngata.

> *E tipu e rea i ngā rā o tōu ao. Ko tōu ringa ki te rākau ā te Pākehā hei oranga mo te tinana, tōu ngākau ki ngā taonga ā o mātou tīpuna hei tikitiki mo to māhunga, a ko tōu wairua ki te Atua nāna nei ngā mea katoa.*

The *Ngāti Porou Hauora Health Literacy Evaluation Framework* represents the multidimensional interrelationship of goals and actions involved in establishing effective community health literacy initiatives. The framework presented in this paper reflects participants' voices, understandings, experiences, and perceptions through adapting a Tauiwi concept/approach to support Māori health development. The co-design process for the framework reflects the practice of mana motuhake within the area of health literacy, opening up engagement between two paradigms to inform transformative and inclusive changes in our communities, our organisations, and our health system. The framework is specific to the iwi context – developed with an iwi health provider for iwi members – therefore, its strength is founded on mana motuhake o Ngāti Porou.

The framework reflects how steps can be taken towards building health literacy through whanaungatanga – establishing and maintaining meaningful, reciprocal, and respectful relationships; te ū o te kaha – promoting and participating in prevention and wellness pathways; te raupapa whare ora – focusing on sustainable resources and practices; te ia o te kaupapa – recognising the value of local context and diverse experiences, as well as prioritising high-needs/-risk populations; and te hua me te rautaki – commitment to action, effectiveness, and efficiency.

Exploring the importance of health literacy to Māori means recognising the social and cultural environments people live within, addressing issues of power, and developing relationships that are reciprocal and responsive. Potentially, this understanding enables health practitioners and evaluators to expand beyond limited functional and interactive forms of health literacy, which position Indigenous peoples, both as patients and clinicians, as less “literate” in this domain. Interventions developed under these framings often focus on issues of individual upskilling and educational approaches rather than setting out a negotiated and shared journey. In comparison, within the *Ngāti Porou Hauora Health Literacy Evaluation Framework*, mana motuhake is manifested in engagement and collaborative and relational practices within a framework of self-determination and Indigenous control. The strength and power of this framework is in the process.

Beyond Ngāti Porou, I envisage that this framework could be adapted by other Māori health organisations for application in other research and evaluative capacities. However, I do not intend the action areas in the framework to be seen as having a linear relationship, where specific goals intersect to produce one set of actions applicable to all health literacy interventions, programmes, and approaches. Rather, the framework is intended as a basis for discussion and as a decision-making and negotiation tool for evaluation stakeholders. Evaluators using this framework must pay attention to the specific objectives of any initiative and use the framework as a reference point rather than as a checklist to plan an intervention.

Conclusion

I began the paper with what makes us exceptional and remarkable, our Ngāti Poroutanga: our place – maunga, awa, and whenua; our space – whanaungatanga, pakari, mauri ora, manaakitanga, mātauranga; and our time – lived history. I have recognised the impact and continued effects of colonialism and our motivation in striving for action and change. I have focused on what matters to Ngāti Porou, our vision, aspirations, and goals for self-determination, abundance, health, and wellbeing. Finally, I have explored how reclaiming our power and decolonising health literacy enables such outcomes from a Nati[32] perspective/context – for their own purposes.

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[32] Nati means people who descend from Ngāti Porou iwi.

Health literacy is an approach/concept embedded in our ways of knowing and being. Kaupapa Māori evaluation is founded on mana motuhake and committed to transformative and decolonising pathways: visions of health and wellbeing for all, support for healthy lifestyles, participation in society, and ecological wellbeing. Health literacy is inherently relational, collaborative, focused on deliberative engagement and shared power approaches and guided by te reo me ōna tikanga o Ngāti Porou, where kaupapa Māori is the theory, practice, and the framework.

Whānau see health literacy as a relational practice, a collective responsibility for all, and grounded in pathways of transparency, sustainability, accountability, and positive change. Health practitioners are asked to take ownership and responsibility for their practice and individual/whānau understanding by utilising shared power approaches, promoting and coordinating health literacy practice and tools, and providing culturally safe environments. Approaches and structures are required to collaborate, build partnerships, and systematically support/provide environments for health practitioners to grow, train, and lead. I have focused on the exo domain of health systems/services, but I also acknowledge the importance of systemic changes that can be made at health system and societal levels to challenge cultural and social norms.

As Māori, and as peoples of Ngāti Porou, we are defining and deciding for ourselves what health and wellbeing mean. As part of this, we want to reclaim the ways in which health literacy, supported by kaupapa Māori evaluation, can create pathways forward to support one another, help one another, and show love for one another.

CHAPTER NINE: INDIGENOUS HEALTH LITERACY


[33]

In this moment I am complete. I am perfect. I am enough. There are no more strokes to be made, no more gaps to be filled no more lines to include. As I pause I look out into the distance and consider Indigenous.

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[33] Teah Carlson, Painting my gaze – who I am, what I have learnt, and what I see, 2017
Liquid chalk on black card, 637 × 415 mm, Private collection, Auckland

Introduction

The following chapter builds on the previous chapters by extending the development of the health literacy evaluative framework to a broader Indigenous context. This chapter covers the development of the framework, detailing the discussion and design processes and how the framework emerged from the workshop – honouring our truths and Indigenous understandings.

During my doctoral study, I made a concerted effort to attend conferences and workshops to challenge, enhance, and connect my thinking and understandings with others. I remember listening to Leonie Pihama at the Tikanga Rangahau Wānanga Series at Auckland University, and her words resonated with me: "One of the things we tend to not do here in Aotearoa is look globally enough for relationships and tools that other Indigenous nations have to offer us." (L. Pihama, personal communication, August 30, 2017). This chapter is my attempt to begin to invite Indigenous voices/perspectives on health and wellbeing, as it may aid in shaping, challenging, and broadening our understandings.

Attributed to the developmental stages of the Indigenous framework, I chose to present this chapter as an initial insight into exploring health literacy in a global context; this chapter presents the beginning of an explorative journey to decolonising health literacy and reclaiming it as our own Indigenous practice.

International Workshop

In 2014, I attended WIPC: E at the Kapiʻolani Community College, Oʻahu in the Hawaiʻi Archipelago. As well as presenting a paper, I facilitated a two-hour conference workshop[34]. My personal aim for the workshop was to present my doctoral work to a global Indigenous audience, not only telling them about my methodology but also taking them through the process for themselves and in turn developing my learnings in relation to health literacy perceptions, practices, and approaches within Indigenous communities. This was an important journey, as it enabled me to broaden my analysis of Indigenous knowledge and understanding in the context of health literacy and directly informed the development of an Indigenous health literacy framework. I conclude the chapter by synthesising findings from the qualitative data, specifically the *Ngāti Porou Health Literacy Evaluation Framework,* and integrate the Indigenous findings into an Indigenous health literacy evaluation – exploring contributions towards Indigenous health literacy.

I saw the workshop as an opportunity to engage with Indigenous peoples interested in the field of health literacy. The process involved relating to each other as Indigenous peoples, sharing where we are from, who we are, our histories, and how we draw on stories and experiences for inspiration and innovation and as steps towards problem solving.

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[34] A week prior to presenting at WIPCE I was given confirmation of my time slot and realised I was allocated more time than anticipated. I took this opportunity to extend beyond a PowerPoint presentation on my research shifting towards more interaction and attendee participation. As this was an unexpected opportunity the workshop process was not included in the Massey University Human Ethics application.

The conference abstract invited attendees to participate in a workshop in the field of Indigenous health and to collaboratively develop an evaluative framework to assess how health literacy might contribute towards and align or not align with our Indigenous aspirations and ideas of health:

> This workshop provides a distal understanding of interpersonal dynamics of health literacy that is vital to understanding how it might be more useful in the context of Māori communities and asks audience members to participate in a framework design process to begin to question if health literacy has a place within their Indigenous health and wellbeing approaches and communities.

The aim of the workshop was to develop wider learnings in relation to health literacy approaches with Māori and Indigenous communities.

After my PowerPoint presentation, I asked the attendees if they would like to participate in an interactive exercise, and asked if they had any questions. All attendee's gave verbal agreement and remained present. I also asked whether they were agreeable to the materials produced being included in my thesis; if they consented to their drawings being included, they were asked to leave them with me at the end of the workshop.

Attendees

Nine attendees participated in the workshop:[35]

Community Engagement Coordinator – Kanaka ‘Oiwi, Hawai’i
Evaluation and Research Coordinator – Kanaka Hawai’i
Family Literacy Specialist – First Nations/Cherokee Nations

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[35] Participants’ nation and ancestral links are presented with permission and include specific clan, totem, and hapū information.

Family Literacy Specialist – First Nations – Turtle Island

Health Facilitator – First Nation/Plains Cree – Saskatchewan

Director of Health – Athabasca Chipewyan/First Nation

Community Education Advisor – Eora Nation, Australia

Post-Doctorate Research Fellow – Torres Strait Islander

Whānau Ora Rangatahi Coordinator – Māori, Waikato/Tainui, Ngāti Porou, Te Whānau a Apanui – Aotearoa

Workshop Process

The first part of the workshop involved presenting an overview of my doctoral research and kaupapa Māori evaluation methodological approach, outlining the values of partnership (active collaboration), participation (deliberative engagement), and reciprocity (values-based relationships). Health literacy was introduced as an evolving concept that focuses on health engagement practices in each health encounter within the health field, which includes patient, health practitioner, organisational, and systematic levels (dimensions of health literacy were discussed in step two).

Step One – Goals and Aspirations of Health and Wellbeing

I began by asking each attendee to draw a flag that represented their goals and aspirations for health and wellbeing for the communities they serve. I chose a flag because it commonly encompasses simple and symbolic designs and uses a basic colour template. I did not want the attendees to focus on the aesthetic look/value, but rather their ability to convey meaning. I then asked each attendee to stand and tell us about your design and what it means to you, your peoples, community and/or whānau.

This design process allowed attendees to share emotions, feelings, perceptions, understandings, and practices of health and their desires for change. The flags became visual depictions of principles and values that were important to attendees and their context. Following their explanation, each attendee placed the flag on the far-right side of a vision board (large white board).

Figure 9. Photograph of vision board, step one

Step Two – Our Collective Values and Principles

I then asked (with the flags on the vision board in sight) attendees to “write down (on Post-it notes) the values, principles, guidelines that underpin those goals and aspirations.” As each person came to the board and placed their Post-it notes, they began to group similar principles and values. From here, we took a collective step back and began discussing groupings and patterns in the ideas offered. We then placed the Post-it notes under headings/themes by moving them together, circling them with a marker and adding a title. The theme headings were self-determination, equity, redress, and sustainability.

Figure 10. Scanned copy of some of the Post-it notes

Step Three – Colonial Health Literacy

Next, I placed existing and recognised dimensions of health literacy from the academic literature on the far-left side of the vision board. I drew from the Sørensen et al. (2012) systematic review and integration of health literacy definitions and models. This paper provides an overview of existing definitions and conceptual models of the most comprehensive empirical dimensions of health literacy and proposes a model integrating medical and public health views.

Dimensions of health literacy include the following:

- **Skills and abilities:** Cognitive qualities of knowledge, competence, motivation.
- **Actions:** Competencies to gain access to/obtain, understand, process/appraise and apply/use.
- **Information:** Clinical health information (quality of information/ communication provided).

- **Objectives:** Promote and maintain good health, function in healthcare environments, make appropriate health decisions, a critical empowerment strategy to increase people's control over their health, reduce health risk, increase quality of life, and form sound judgements.
- **Place:** Patients in healthcare encounters and settings (healthcare setting); individuals at risk of disease (disease-prevention system), citizens in relation to health promotion efforts (outside of health system – community, workplace, education system, political).
- **Time:** Skills and competencies of health literacy develop during life course –cognitive, psychosocial development, previous and current experiences.
- **Lens:** Understanding health literacy on a continuum from an individual/ medicalised approach to a population public health approach.
- **Determinants:** Matrix from personal (age, gender, race, socio-economic status, education, occupation, employment, income, and literacy) and situational (social support, family, peer influences, media use, and physical environment) to social and environmental (demographic situation, culture, language, political context, and social systems).
- **Impact:** Health service use and health cost, health behaviour and health outcomes, participation and empowerment, and equity and sustainability.

With each key term, I drew a corresponding symbol or picture to illustrate its meaning. These illustrations were placed next to the definitions on the right-hand side. The illustrations were utilised to follow the imagery practice in the workshop.

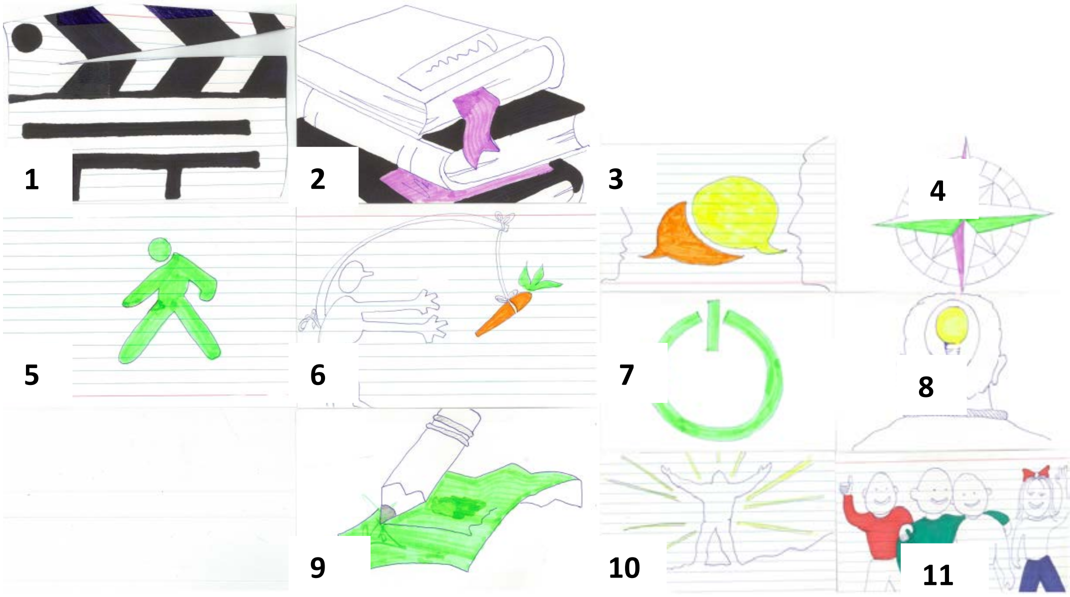


Figure 11. Scanned copy of definition images, step three.

Beginning top left-hand corner, moving right: (1) actions, (2 & 8) information, (3) impact, (4) time/life course, (5) abilities, (6) objective, (7) determinants, (9) skills, (10) lens, and (11) place.

Figure 12. Photograph of vision board, step three

Step Four – Health Literacy Actions and Criteria

From here, I asked attendees to write down specific "actions or criteria that would support your visions and goals of health and wellbeing through the lens of the identified values, principles, guidelines." I also asked them to write down "criteria or actions that would be necessary to bridge the gap between your goals and aspirations for health and wellbeing and health literacy."

The Post-it notes were then placed on the vision board.

Figure 13. Scanned copy of grouped Post-it notes, step four

Step Five – Health Literacy Action Areas

We again took a collective step back and began grouping the actions and criteria and placing them under titles/themes (moved Post-it notes together, circled them with a marker, and titled them with a theme heading).

Figure 14. Photograph of Post-it notes, step five

This process was not straightforward by any means. It took time, careful processes, explanations, negotiation, and compromise, arriving at collaboration. I found that these negotiations gave the framework more value as it allowed greater diversity and multiple perspectives.

From here, we reflected on the way in which we, as a group, spoke about health and wellbeing and the pathways (specific actions and criteria) that enabled our goals to become a reality. We then analysed how the dimensions of health literacy were presented.

The co-design process allowed attendees to focus on a positive goal that was value and principle centred. The aim of the exercise was to encourage free association by providing minimal, focused instruction that incorporated visual mediums.

Figure 15. Photograph of completed vision board

The workshop was only the beginning of developing the framework. In many ways, it was more about learning whether there was a space to create understanding and consider various perspectives on the versatility, use, and effectiveness of the concept of health literacy. It provided an opportunity for me as a participant, as well as a facilitator, to grapple with the dynamics of what purpose the concept serves: Does it have an Indigenous purpose? Who owns it? Can it be rejected, redefined, transformed, decolonised, reclaimed?

Each attendee was invited to leave their contact details if they wanted to be updated on the development of the framework. All attendees left their contact details and five wanted to be updated with the development of the framework.

Analysis

The analytical process began during the workshop when we collectively decided to move and theme the evaluative criteria under collective titles/themes. As the workshop had a short time frame, the sorting of the input only went so far. I grouped information from the workshop by reading critically, sorting the workshop materials (Post-it notes, photographs of the vision board, and my notes), identifying connections, formulating judgements, and making sense of the complexities of the responses. I immersed myself in the information to find the core themes and reflect on the experiential (felt) and *knowing* experiences in the workshop.

Eventually, the lists of themes (topics) were narrowed down to two areas: The first focused on underpinning principles (self-determination, equity, redress, and sustainability), and the second related to action areas and criteria (cultural conditions, health visions, health approach, health goals, and criteria).

Learnings

Visual Expressions of Exploring Truths

When attendees shared their health and wellbeing goals (flag drawings) and respective values and principles (Post-it notes), they gave insight into how they lived and engaged with the world.

From the lands of Hawai’i came the values and principles of mālama ‘āina (sustainable measures): ahupua’a (an ancient concept of resource use and management based on families living in a division of land that connects the mountains to the reefs and the sea); aloha kekahi i kekahi (caring for one another, showing respect); pule (prayer and appreciation); ‘ai pono (good ancestral food; meaning if we care for the land, it will grow healthy food for us); a‘o aku, a‘o mai – (reciprocal learning; based on the notion that the learner will one day be in the position to teach, so learn well); ho’oponopono (conflict resolution; practice of reconciliation and forgiveness); and ma’e ma’e (pure spirit; maintaining spiritual cleanliness, clean house, clean body and mind).

Figure 16. Flag from Kanaka Hawai’i

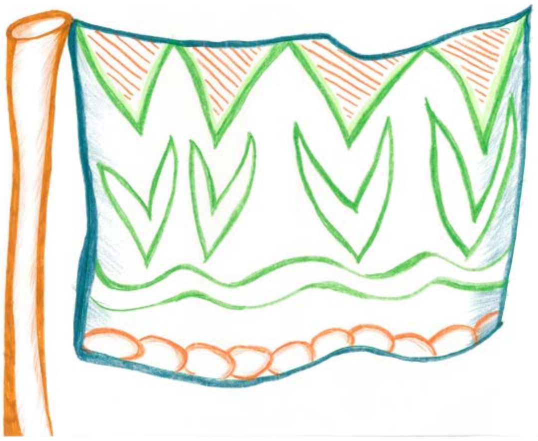


Figure 17. Flag from Kanaka ‘Oiwi, Hawai’i

Attendees from Turtle Island spoke of the seven grandfather teachings. Each teaching honours one of the basic virtues intrinsic to a full and healthy life and is embodied by an animal to reinforce how our decisions manifest in the physical world. These seven teachings provide a foundational understanding that our health and wellbeing are intimately connected to and in harmony with nature, our family, and our community: love – eagle – love must be unconditional; respect – buffalo – live with a sense of balance; courage – bear – practice fortitude and willingness to stand up for what you believe in; honesty – sable – accepting who we are; wisdom – beaver – knowing what your limits are with respect to your body and life around you; humility – wolf – devotion to protecting family; and truth – turtle – being grounded, careful, attentive to details.

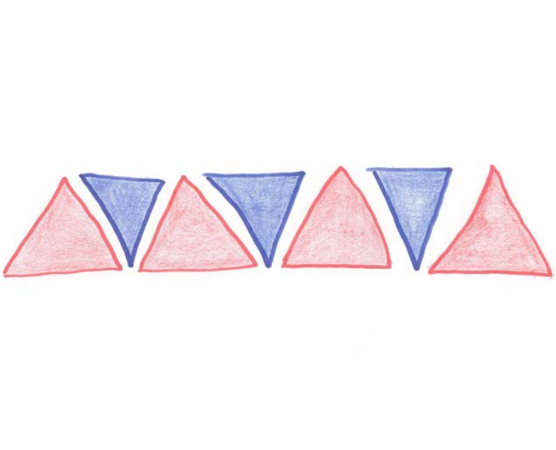


Figure 18. Flag from First Nations

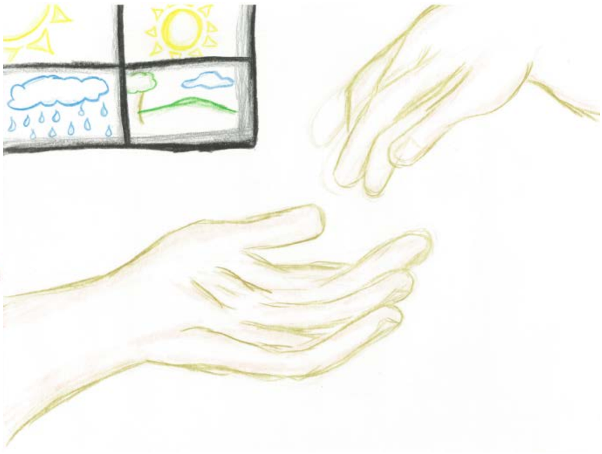


Figure 19. Flag from First Nations/Cherokee Nation

Figure 20. Flag from First Nations/Plains Cree

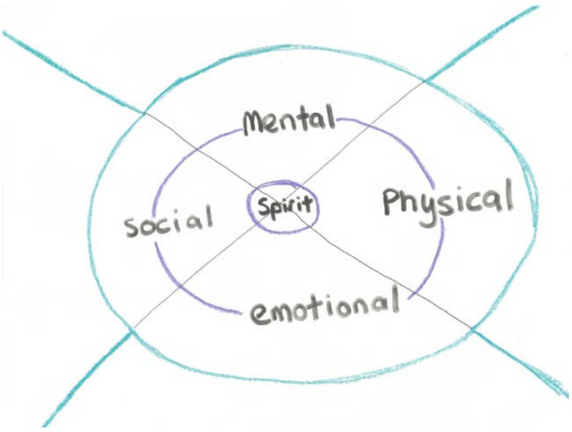


Figure 21. Flag from Athabasca Chipewyan, First Nations

The two Australian Aboriginal peoples described values and principles of kinship (extended family; determines how people relate to each other and their role, responsibilities, and obligations in relation to one another, to ceremonial business, and to land); land and spirituality (connection to environment; human relationships with the land); the dreamtime (stories; history of Aboriginal peoples and their relationships with the environment and of their connection with their spirituality); skin group/moieties/clan (identity; governs social behaviour, interactions, and relationships, determining who individuals can and cannot speak with or marry and trade with, and also determines natural enemies); totem (allegory; defines people's relationships to each other and gives them particular rights and roles within the language group and their territories); sun (mother; giver of life); and moon (father; protector).

Figure 22. Flag from Torres Strait Islander

Figure 23. Flag from Eora Nation

From Aotearoa, Māori health values and principles were explored in terms of whanaungatanga (encouraging supportive, sustaining, reciprocal relationships and kotahitanga [unity] within whānau, hapū, and iwi); kaitiakitanga (guardianship of creation and all the resources available to humans; a kaitiaki normally protects or cares for people, property and the environment); manaakitanga (to enhance another person's wellbeing by showing respect, courteousness, goodwill, and thoughtfulness and acknowledging and caring for people); and wairuatanga (understanding and believing we are intimately connected spiritually to all things, animate and inanimate, all of which have their own wairua).

Figure 24. Flag from Waikato, Tainui

Following on from the process of exploring Indigenous values, I considered how they might look collectively. I came to understand that the foundation of understanding begins with the core values and principles shared amongst the attendees; these related to the mind, body, spirit, relationships (family), environment, and cosmos.

An Indigenous Health Literacy Model

Drawing directly on *Step Four – Health Literacy Actions and Criteria* and *Step Five – Health Literacy Action Areas*, I developed an Indigenous health literacy model (Figure 25). The model is represented as underpinning principles, action areas, and criteria that are positioned to reflect the relationship between them.

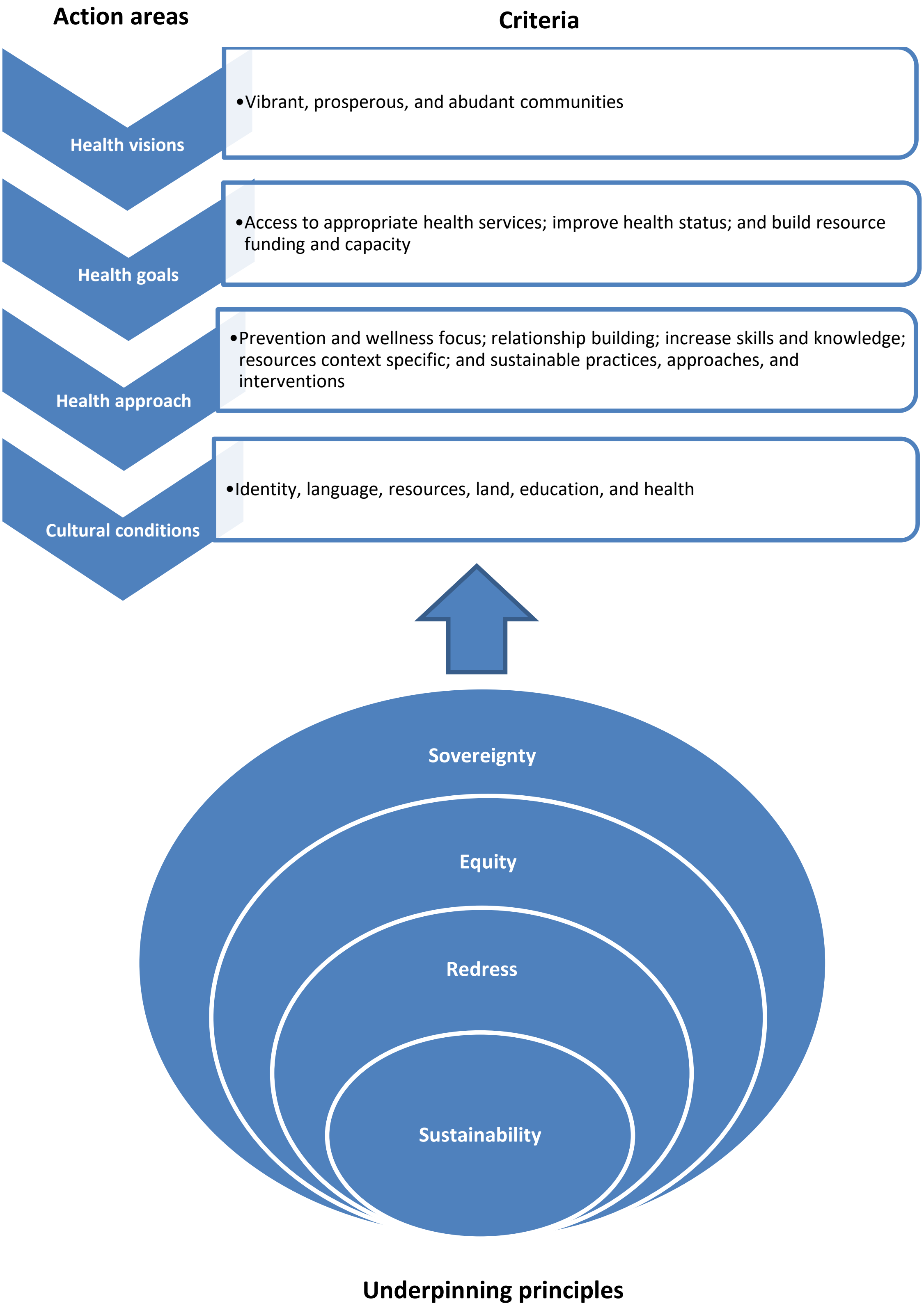


Figure 25. Indigenous health literacy model

The lower circular layers represent the foundational principles from which all the following domains derive. This largest circle is self-determination (tino rangatiratanga), and the next layer represents equity with regard to gender, ethnicity, and culture. Redress is presented next and encompasses apology, financial and commercial redress, and cultural redress. Cultural redress means spiritual, cultural, historical, or traditional associations with the natural environment, sites, and areas within an area of interest of the Indigenous group. The final principle interwoven in all the domains of the model is sustainability – ongoing commitment to long-term investment and change. The underpinning principles form a foundation in which cultural conditions can be formed, such as revitalisation of identity, language, resources, land, education, and health. This expands to the broad visions of health (health visions) – vibrant, prosperous, and abundant communities. These visions encompass health approach*,* which means holism, including spiritually – the seven teachings of love, respect, courage, honesty, wisdom, humility, and truth; physically – healthy kai, traditional foods, cleanliness, absence of violence; environmentally – healthy land, clean water; and mentally – education.

The next level, health goals encompasses access to appropriate health services (culturally and context specific; geographically, economically, and socially) and improved health status. Building resource funding and capacity and capability are identified as the goals for Indigenous peoples' health development.

The next level represents a set of criteria that relate to the principles to provide a practical context in which the principles play out in relation to a health intervention: prevention and wellness focus – early intervention; relational practice – mutual accountability and respect, sharing ownership, connection (feeling), and reciprocal learning; increasing skills and knowledge (critical analysis, cultural analysis, context analysis); and context-specific resources – personalised and accessible.

These domains summarise attendees' perceptions of key developments that could potentially guide the groundwork for new interventions and complement the previous developments in health literacy and other important areas of health practice with Indigenous health service providers.

Indigenous Health Literacy Framework

The workshop learnings were set alongside the findings from the broader study. Four closely related and overlapping goals emerged from this synthesis:

- Self-determination – health structures and practices focusing on shared power approaches
- Holistic conceptualisations – promotion of and participation in prevention and wellness pathways
- Capacity and capability building – sustainable resources and practices
- Collective priorities – honouring collective priorities of Indigenous communities that we serve to support and advance Indigenous aspirations

All these goals encompass relational practices and approaches, which include collaborative, participatory, and action-focused descriptions.

Table 13 outlines the framework criteria and guidelines that also emerged from the synthesis. The presented action areas are emergent – resulting from non-linear interactions between systems and the components that make up the systems.

Table 13
Indigenous health literacy evaluation framework

	Goals	**Health workforce/ practitioner practice**	**Health approaches/ interventions**	**Health organisation/services**	**Health system**
Action areas	Equitable relationships	Relational practice and shared power approaches	Streamline to align with participant context and participation in community spaces	Deliberative engagement and Indigenous leadership and management	Policy guidelines to support health literacy leadership pathways and encourage shared power approaches
	Holistic health	Holistic understandings of health and wellbeing	Build on whānau knowledge base and understanding	Investment in prevention and wellness approaches	Provide health system pathways that have reduced health literacy demands
	Capacity and capability building	Culturally safe and competent practice and environments	Long-term involvement, engagement, and investment in the community	- Coordinating between providers, health workforce and share resources - Strengthening of operational policies and protocols, with appropriate workforce development strategies	Develop partnerships with research, education, and practice communities to build capacity and capability
	Collective priorities	Contextual understanding of the patient's health and wellbeing and promoting and coordinating action to raise awareness of and build skills in health literacy	Invest in resources and approaches that are simple, clear, and understandable and tailored to specific audiences	Implement and promote a reflective and evaluative organisational culture	Provide strategic guidance on implementing health literacy planning for organisations, services, and interventions

Self-determination

Indigenous peoples being able to define what health literacy practice, approaches, interventions, and evaluation looks like in our communities. Committing to transformative and decolonising pathways, visions of health and wellbeing for all, support for healthy lifestyles, participation in society, and ecological wellbeing

**Note*. These are not exhaustive action areas and goals, but they indicate some of the key features of Indigenous health literacy

Transforming health literacy praxis at all levels requires re-orientation and re-configuration of power relations, congruent with current debates and discussions about decolonisation. Decision-making and recruitment processes need to be grounded in Indigenous worldviews, self-determination, and autonomy and guided by Indigenous values and goals. Specific actions include investing in cultural safety and competency training, applying new standards of practice and ensuring internal and external Māori involvement at all levels of engagement.

The framework represents both a centring of Indigenous health literacy practice and implied changes to power relations, grounded on the underpinning principle of self-determination. Self-determination involves committing to transformative and decolonising pathways, developing visions of health and wellbeing for all, supporting healthy lifestyles, and participating in society and ecological wellbeing. Achieving these aspirations involves the reclaiming of health literacy as a space for Indigenous peoples to be ourselves, a space that is valued, adaptive, and shaped by people, whānau, and communities (Carlson, 2016). This transformation asserts the value of kaupapa Māori evaluation in addressing issues of self-determination and building capacity and capability for institutional change at all levels (health workforce, organisations, systems). The framework identifies four core actionable goals of effective health literacy practice, beginning with equitable relationships.

Equitable Relationships

This goal is grounded on relational practice – promotion and practice of meaningful, reciprocal, and respectful connections, relationships, and environments. Equitable relationships relate to health approaches, structures, and practices focused on shared power approaches to decision making, respect, accountability, and resource distribution at every level of health engagement.

Equitable relationships means valuing patients as autonomous beings holding their own important and expert knowledge; therefore, individuals and families become partners in managing their own health and wellbeing (Ministry of Health, 2015b). Health practitioners will need to be trained in facilitation and knowledge-sharing practices (co-construction). It also means health practitioners appreciating family structures, which could include shared responsibility practices and extended family involvement (Connolly, 2015).

When practising equitable relationships, patients and families ask that approaches be streamlined, preferably through kanohi kitea, so interventions align to ways of living and being. Relational practice at a community level means asking researchers, evaluators, and intervention/programme developers to participate in community spaces such as attending hui, sport activities, marae, and other cultural events.

Organisational change is most effective when there are high-level “agents of change” willing to lead, promote, and challenge cultural shifts towards behaving differently (Reason & Bradbury, 2006). Organisational change means growing Indigenous leadership and management capacity and capability in the health workforce, organisations, and systems and – moreover – training the health workforce in facilitation and knowledge-sharing practices. Shared power approaches at an organisational level could involve service users in the development of health literacy processes, interventions, and resources (co-design). Within the health system, this involves providing policy guidelines for organisations to develop health literacy leadership pathways and encourage shared power approaches (Ministry of Health, 2015a).

Holistic Health

Holistic health relates to holistic understandings and approaches to healthcare. Creating these pathways requires holistic understandings and approaches to healthcare through the understanding of the interconnectedness of hinengaro, tinana, wairua, relationships, environment, and cosmos. Holistic health requires promotion and participation in prevention and wellness pathways. At the health practitioner level, having a holistic focus in healthcare practice means adopting a more humanistic approach, viewing and respecting the needs of individuals as a whole and as interconnected and interwoven into relationships with multidimensional needs (World Health Organisation, 2007). Holistic health approaches could include expanding treatment and care options to include complementary and alternative medicine. Therapy options could include nutrition, exercise, homeopathy, prayer, acupuncture, and meditation.

Health literacy practice involves health practitioners, the health workforce, and health services providing supportive environments to practice cultural protocols, native language and intergenerational connections. This means providing adequate consultation times, timely referrals, thorough case management, relationship-building practices (consistency of care), and allowing family and extended family to be involved at the patient’s request (Connolly, 2015).

At the health intervention level, holistic health means utilising approaches and practices that build on the whānau knowledge base and understandings to make informed decisions and access effective services to cater to their holistic needs. Within health services, it requires prioritising and investing in prevention and wellbeing pathways/approaches; to achieve this, tensions between the clinical agenda and the patient-centred agenda need to be identified and reduced (World Health Organisation, 2007).

The health system role provides strategic guidance to the health sector to support literacy activities, prevention, and wellbeing approaches – embedding literacy in policy and utilising health literacy as an asset in all health targets and approaches. Holistic health includes equitable relationships within services and systems that are responsive and accountable, with the aim of providing affordable, accessible, safe, ethical, evidence-based, and holistic healthcare.

Capacity and Capability Building

The goal for this theme focuses on sustainable resources and practices. Capacity and capability building necessitates making a positive difference in our communities, striving towards practices of sustainability, and considering long-term impacts and outcomes on future moko-mokopuna and their environment. For individuals and families, capacity and capability building means accessing and navigating practical, reasonable, attainable, and timely services. Health practitioners need to be skilled in facilitation and knowledge sharing and to continually reflect on and evaluate their practice. They need to always offer patients options to build their health literacy knowledge and skill, offering invitations to review approaches and change treatment options.

At the health workforce level, personal attitude and behaviour change is an important part of building health literacy practice through participation in cultural safety and competency training, supported and implemented by organisations. At an intervention level, te raupapa highlights the need to create sustainable practices through long-term investment pathways, from initial funding through to resource implementation and dissemination, as well as prioritising employment and training opportunities for the health workforce and community members.

Health service providers play a role in strengthening operational policies and protocols, with appropriate workforce development strategies that incorporate health literacy practices. Capacity and capability building also involves coordinating between providers and the health workforce and sharing resources when appropriate. As well as making links to social movements and aligning with local capacity, organisations that are already empowered and aware are an important part of capacity and capability building. The health service and system role means developing partnerships with research, education, and practice communities to build capacity and capability in all approaches and action.

Collective Priorities

Collective priorities relates to action and usefulness, honouring the collective priorities of Indigenous communities that we serve to support and advance Indigenous aspirations. Collective priorities are driven by contextual understanding, and health priorities and needs may vary between families, communities, and groups. Accordingly, there is a need to recognise and promote the significance of local contexts and diversity for all health literacy approaches, as well as prioritising high-need/high-risk populations.

Advancing the collective priorities of high-need/high-risk populations has the effect of lifting the health literacy status of the entire population (Came, 2012). Health literacy practice requires the immediate implementation of health literacy practices and tools. For individuals and family, this goal is achieved when they are invited to design and evaluate the health services they utilise and contribute towards improvement approaches, including health literacy processes, interventions, and resources.

Health literacy practice means health practitioners promote and coordinate action, raising awareness of and building skills in health literacy practice. This could include training incentives and developing best practice, particularly sustaining best practice guidelines when working with patients and families. At the health intervention level, collective priorities is concerned with investment in resources and approaches that are simple, clear, understandable, and tailored to specific audiences and that can be taken home and personalised.

For health service providers, collective priorities means reviewing service and systematic practices of health literacy by examining the use of resources, signs, forms, educational material, and systems to reduce barriers to health literacy. Additionally, when services conduct health literacy planning and decision making and developing health resources, it is important to commit to utilising high-quality ethnicity data that are routinely analysed and reported and acting on these; for example, by spending more time and resources with high-need/high-risk populations.

The health service role focuses on the implementation of a reflective and evaluative culture, utilising action-based, participatory methodologies, and tools and approaches that promote relationship-building practices. In regard to the health system, collective priorities means providing strategic guidance on implementing health literacy planning for organisations, services, and interventions to make it easier for people to utilise the system.

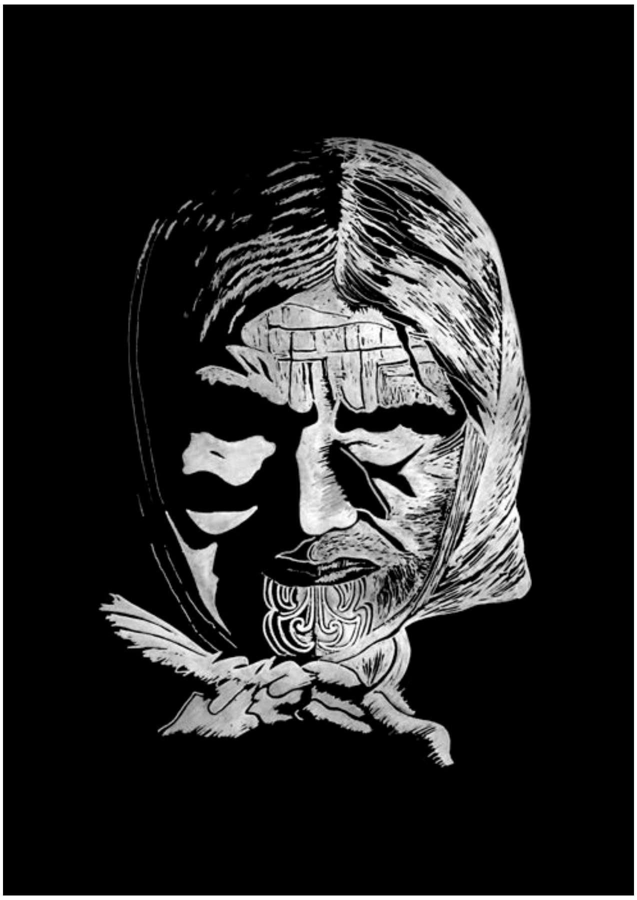
Summary

This chapter presents the interrelationship of principles, action areas, and criteria involved in understanding Indigenous health literacy. The workshop process contributed towards broadening my analysis of Indigenous knowledge and understanding in the context of health literacy and directly informed the development of an Indigenous health literacy framework. Synthesising the findings from the qualitative data from the thesis, I explored Indigenous global perspectives for conceptualising the decolonisation of health literacy.

Our Indigenous understandings are expressed through our narratives – our lived history – contextualising our understandings of the world, how we came to be, and our relationship with it. Our narratives hold meaning, lessons, and entertainment – condensing facts and beliefs into recognisable forms (Fulford, 1991). They inform and are tested through our lived experiences and are thereby contextualised to current social and political contexts. Our lived experiences then inform our knowledge – knowledge, attitude, skills, and abilities. These practices are enacted in diverse situations, including patient–health practitioner encounters over health literacy.

The model and framework presented in this chapter reflect participant voices, understandings, experiences, and perceptions. Reflections on the qualitative data from the patients, health practitioners, and key informants and the workshop learnings made it clear that the decolonisation of health literacy underpinned all these contributions. There are also important similarities between the emerging *Ngāti Porou Hauroa Health Literacy Evaluation Framework* (chapter eight) and the broader Indigenous health literacy exploration. Both advocate Indigenous control – self-determination, autonomy, and self-management – and encompass conditions, values, and goals of action, reclamation, transformation, and decolonisation. This is an important insight, as it informs how we might go about understanding Indigenous health literacy – as our ways of attaining, assessing, examining, and applying health information are embedded in the ways we come to know and be in the world. By understanding that our histories/narratives and our context/experiences inform our practices, we can build a foundation to explore how Indigenous peoples can reclaim and define health literacy concepts and practices.

CHAPTER TEN: DECOLONISING HEALTH LITERACY


[36]

I turn the painting 180 degrees.
Ko Ramari Heremia toku tūpuna

Ko au te mata o toku tūpuna. Together we are kaupapa Māori.

As I come to the end of my thesis, I reflect on my journey through the chapters. I reflect on the questions I have asked and outline pathways I took to follow my thoughts. My purpose was to seek knowledge and go wherever my thoughts took me. At times, I had to be brave and creative, to revisit what is acceptable, and to ask is this what our tūpuna imagined for us, is this what they meant?

Titiro ki muri kia whakatika ā mua
Look to the past to proceed to the future.

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[36] Teah Carlson, Painting my gaze – who I am, what I have learnt, and what I see, 2017
Liquid chalk on black card, 637 × 415 mm, Private collection, Auckland

Introduction

This thesis set out to evaluate the effectiveness of a CVD medicines health literacy intervention. I used kaupapa Māori evaluation to gain insights from patients/whānau and Ngāti Porou Hauora health practitioners as well as other members of the Ngāti Porou community. I developed broader insights into Indigenous health literacy approaches by synthesising Māori and international Indigenous key informant interviews with analyses of the evaluation data. In addition, the study sought to ground understandings of health literacy interventions and approaches with Indigenous communities in other colonial contexts by collaboratively designing and testing an evaluation framework at an international workshop. By conducting this study, I was also able to comment on the praxis of kaupapa Māori evaluation in the context of an iwi-centred approach.

In this concluding chapter, I review the major findings, draw out contributions to Indigenous scholarship, reflect on the potential use and usability of the Ngāti Porou health literacy framework, and consider possible future research directions. I offer this research as a contribution to a critical Indigenous approach to health literacy and potentially to the decolonisation and reclamation of this domain through transformative kaupapa Māori praxis.

Features of Kaupapa Māori Health Literacy

The kaupapa Māori evaluation that I conducted was conceptualised as a collaborative journey. The evaluation gave prominence to “voice” – perceptions, practices, and experiences of Māori and Indigenous participants receiving and delivering health literacy services in communities, along with the knowledge and conceptual work of Indigenous scholars of health literacy.

Findings from the kaupapa Māori evaluation of the *Cardiovascular Disease Medicines Health Literacy Intervention* provided understandings of what effective health literacy means for a specific Māori community. Overall, health literacy was seen as complex, somewhat fluid, and often conflicted. Social and cultural environments, power, and reciprocal and responsive relationships were overarching features of the dynamic contexts within which health literacy initiatives and the Ngāti Porou initiative develop and operate.

The effectiveness of the specific intervention evaluated in this study, which was based on building patient knowledge about the use of CVD medications, centred on four key factors:

- Home- rather than clinic-based practice
- Extended time for visits
- Tailored educational resources for both staff and patients
- The nature of the relationship with the research nurse, who had been trained in health literacy skills.

As well as key findings across the three sets of participants, there were themes more specific to each grouping.

Patients viewed health literacy knowledge as dynamic – understood and practised for moments in time but maintained and nurtured through health practitioner support. Health literacy practice was seen as more effective for patients if it was grounded in whanaungatanga – reciprocal, responsive relationships – that entailed active collaboration, shared power, partnership, and deliberative engagement. Whanaungatanga processes were nurtured by practices and systems that valued connection by linking patients and health practitioners through wider contexts of whenua, awa, maunga, and wharenui.

Health practitioner insights on effective health literacy practice centred around their responsibility for ensuring whānau understanding, taking ownership of their communication practices, and avoiding blaming patients for misunderstandings. Whanaungatanga was also critically important to health practitioner roles in maintaining good health literacy practices and health literacy-promoting environments. Effective facilitation and knowledge sharing were seen as key skills needed by health practitioner to provide a safe space for conversations and to build patient and practitioner understandings.

Key informants felt that a values-based approach was needed to develop high-quality health literacy practices. Acknowledgement of cultural specificities and the context-dependent nature of health literacy practices and systems were a key part of this approach. They highlighted the systemic, institutional nature of problems with many current health literacy concepts and practices and advocated holistic approaches. Concerted efforts were seen as required at all levels of the health system to improve the effectiveness of health literacy practice.

These major findings highlight the complexity and contextuality of health literacy and the challenges inherent in using this approach as a contribution to healthier lives for Ngāti Porou and other Indigenous peoples.

Ngāti Porou Health Literacy

Exploring colonial impacts on the history of Ngāti Porou drew me away from my initial focus on redefining health literacy towards ways of reclaiming and restating what *was.* A key impetus for this was the recognition that our own practices around what is referred to as health literacy have always been part of our ways of knowing and engaging. Reclamation requires us to forge a space (practice, actions, approaches, systems, and environments) where Māori can be Māori – a space that is negotiated, adaptive, and shaped by people, whānau, and communities. This exercise extends health literacy beyond the delineation of specific principles and practices. To transform health literacy, I drew on traditions of Māori health philosophies and re-imagined understandings of health literacy as a practice shared by Māori.

In this study, transformation required moving beyond a focus on improving efficacy for specific interventions toward concerted efforts to understand participants' lived experiences and ways of knowing and being in the world. I also needed a deeper understanding of the nature of the relationship between patients and practitioners because they are the centre of the health system. Based on these understandings, I argue that, for health literacy to assist in transformation, it needs to broaden its scope to examine practices embedded in broader social narratives and cultural agency. Without a commitment to issues of equity, equality, and empowerment, interventions might fail to deliver meaningful patient care outcomes and sustainable best practice.

These insights contributed to the development of the *Ngāti Porou Hauora Health Literacy Evaluation Framework*. In the framework*,* mana motuhake manifested in engagement and collaborative and relational practices encompassed within broader aspirations for self-determination and Indigenous control. The current framework includes five core actionable goals of effective health literacy practice for Ngāti Porou.

Whanaungatanga – Relational practices and understandings related to establishing and maintaining meaningful, reciprocal, and respectful relationships. Equitable relationships need to be embedded in health approaches, structures, and practices, through shared decision making, respect, accountability, and resource distribution and at every level of health engagement.

Te ū o te kaha – Strengths-based approaches that promote prevention and wellness pathways. Creating these pathways requires an understanding of the interconnectedness of hinengaro, tinana, wairua, relationships, environment, and cosmos.

Te raupapa whare ora – Capacity and capability building necessitates making a positive difference in our communities, striving for sustainability and consideration of long-term effects/outcomes for future moko-mokopuna and their environment.

Te ia o te kaupapa – Create context-specific and fit-for-purpose interventions that value and promote rohenga tipuna (shared ancestors, history, and location), local contexts, and diversity.

Te hua me te rautaki – A commitment to effectiveness, efficiency, and action in all health literacy approaches.

It is hoped that this framework can be applied to achieve transformative collective action to strengthen Indigenous health and wellbeing. Although developed for health literacy approaches, it may have wider applicability to other Indigenous interventions.

Contributions Towards an Indigenous Health Literacy

The experience of running a research workshop with Indigenous health literacy scholars from other colonised countries helped me to crystallise and ground the study in wider Indigenous experiences and aspirations. The collaborative co-design of an Indigenous health literacy evaluation framework demonstrated commonalities across diverse jurisdictions and Indigenous groups, suggesting that suggesting that at least some global perspectives are shared. Both frameworks are underpinned by Indigenous control – self-determination, autonomy, and self-management – and encompass conditions, values, and goals of action, reclamation, transformation, and decolonisation.

From the Indigenous framework, four transformative themes are apparent – relational praxis, holistic conceptualisations, capacity and capability building, and collective priorities – that clearly resonate strongly with the parameters of the Ngāti Porou framework. These themes directly relate to and overlap with the Ngāti Porou framework; however, the focus was less specific in the Indigenous framework. Where the iwi framework positioned whānau voice at the centre of all engagement levels, the Indigenous framework provided a broader approach to environment and context.

Similarities were evident. For example, the workshop reiterated the need to transform health literacy praxis through a re-orientation and re-configuration of power relations, congruent with current debates and discussions about decolonisation. Transformation also required Indigenous leadership, adherence to Indigenous aspirations, cultural competency training, new standards of practice, and Indigenous involvement at all levels of engagement. Ideas around decolonising health literacy involved acknowledging integrated Indigenous thinking around the association between health literacy and hauora, revamping decision making, and recruitment processes grounded in Indigenous world views.

Exploring these formulations of Indigenous knowledge, I was more able to understand Indigenous health literacy and compare it with Western constructions of health literacy. Contributions towards an Indigenous health literacy are based in Indigenous “ways of knowing” grounded in our narratives and embodied through our connections to place, time, histories, lineage, and the universe. In turn, these are reinforced by long experiences of defining and refining what it means to be Indigenous and how we reflect and enact this in all spheres, including health literacy interventions.

In contrast, Western constructions of knowledge have a considerable, albeit increasingly challenged, history in realist, decontextualising, empirical research that, under the mantle of scientific method, has become crystallised as objective information and sedimented into colonial cultural knowledge structures. There is merit in both paradigms, but it is vital to retain vigilance about what happens at the intersections and guard against the unwarranted and unjust imposition of the dominant over the Indigenous.

I propose utilising both systems to understand health literacy. This can be done by positioning Indigenous knowledge as the basis for understanding and enacting health literacy, reclaiming Indigenous health literacy praxis, privileging participant/community voice, and acknowledging the importance of cultural knowledge and context.

Kaupapa Māori Praxis

As a methodological practice, kaupapa Māori evaluation facilitated critical reflection on my research method, methodology, and ethics, revealing multiple issues and nuances. For example, I began with the ideal of collaboration when working with our communities in search for understanding and knowledge with community; this evolved to a focus on practices of shared power rather than equal input. This highlights a key challenge with kaupapa Māori evaluation over what collaboration can mean in the entrenched colonial, political, structural, and systematic climate of Aotearoa New Zealand. "Collaboration" needs to include what this means for communities, not just the researcher, and to be driven by what they want and what they are prepared and able to contribute – power and respect rather than knowledge and the level of input become the driving considerations.

Another thread that weaves through the thesis is development, particularly around my role and approach as an evaluator and researcher but hopefully also in terms of wider change percolating in the conceptual space of health literacy. Kaupapa Māori evaluation provides a methodology and process for decolonising health literacy (and other topics) and constitutes a transformational praxis for Māori advancement (Durie, 2013, Moewaka Barnes, 2009). As a reflective and analytical process, kaupapa Māori evaluation in this study was about determining the merit, worth, and value of health literacy against the goals of mana motuhake o Ngāti Porou and the contributions of Indigenous global perspectives. Kaupapa Māori praxis meant operationalising the Indigenous capacity and capability of communities to reclaim their practices of health literacy and more broadly develop their own theories of these practices.

I undertook this research to challenge the colonial power structures and disparaging discourses in which Indigenous peoples have been identified (Moreton-Robinson, 2016; Smith, 1999a) and entangled. This is part of exercising the right to decolonise our lived realities and explore what Indigenous alternatives might mean, even if we cannot yet imagine them (Warrior, 1995). I have sought to make my kaupapa Māori journey as transparent as possible so that it might add to the literature in an honest, accountable, and honourable way by detailing the assumptions, biases, and limitations from which I work. The task was all the more complex because I conducted and wrote up this research in an academic environment that is dominated by studies of Indigenous peoples through non-Indigenous scholarship (Moreton-Robinson, 2016).

Reclaiming and Decolonising Health Literacy

Whānau, hapū, and iwi are at the heart of the social, political, and economic foundations of Aotearoa and have the right to determine and construct their own meanings and practices of literacy for their own purposes. I argue that literature, research, and practice around health literacy are preoccupied with understanding how it functions and interacts within its own paradigm rather than critical analysis that might reveal the values and principles it promotes in colonial settings. There is a need for studies that question the goals, visions, and outcomes envisioned for health literacy, particularly when it operates from monocultural organisations working with Indigenous peoples. In the absence of an overtly decolonising imperative, Māori communities must question the agendas and values that health literacy interventions serve and how they address the aspirations of the people.

Indigenous peoples have a long history of dealing with change in which environmental adaption and innovation are at the heart of survival and advancement. The natural environments provided spiritual, theoretical, empirical, and ethical foundations guiding tikanga to ensure hauora for future generations (Durie, 2013). Indigenous peoples' power (mana motuhake in Aotearoa) is fundamentally relational and depends on the interaction of networks to ensure the delivery of entitlements of individuals within the wellbeing of the collective (Jackson, 2017). Mana motuhake derives from the foundations of our whakapapa birthright, in which everything has whakapapa; atua ki te tangata, kararehe, rakau, kai, wai, toka ki ngā maunga (Gods to people, animals, trees, food, water, rocks to moutains). This Indigenous knowing encapsulates an understanding of the interconnection of our ways of being to the cyclic motions of the environment, the planet, and the cosmos. I have recognised the impact and continued effects of colonialism as our motivation in striving for action and change. I have focused on what matters to Ngāti Porou and Indigenous peoples, our visions, aspirations, and goals for self-determination, abundance, thriving, health, and wellbeing. What matters is reclaiming our power and decolonising imposed structures and practices, among which health literacy is a salient example.

Limitations

The purpose of this research was to explore, contextualise (Breakwell, Hammond, & Fife-Schaw, 2000), and theorise models of Indigenous health literacy. A detailed, rich, collaborative approach was adopted to evaluate a specific health literacy initiative, with some forays to extend these learnings to broader Māori and Indigenous contexts. This, I argue, was necessary to honour my approach to kaupapa Māori evaluation research and means that, while there may be ideas of value to diverse groups, there is no claim of generalisability. The intention was to contribute to positive change for patients and whānau as well as provide learnings for the health sector and systems.

Conditions arranged with the parent project meant I was restricted to the participants made available to me via the inclusion criteria of that study. The communities involved were small, and I would have liked to broaden the age range of those involved in the research, but this was not possible within the research frame. Patients and whānau recognised this limitation and requested the intervention be extended to others, particularly to those who had not had a cardiac event.

Future Research

I am confident in the value of the ways I used kaupapa Maori as a methodological approach and in the methods (including collaborative and art-based methods) used in this study. I would like to explore decolonising processes further by:

(a) more fully embracing kupu Māori and Māori concepts as a decolonising approach rather than, for example, using the terms “Indigenous health literacy” or “Ngāti Porou health literacy,”

(b) examining possibilities for supplementing or replacing the term “health literacy” with other concepts/approaches (such as “patient activation”) as a form of resistance and a way of shifting our thinking around the purpose and focus of health literacy, and

(c) working with Ngāti Porou Hauora to implement the framework – within their organisation and at all levels of the healthcare environment.

Closing Comments

In the final dissemination hui, conducted with Ngāti Porou Hauora in November 2017, the feedback and comments were overwhelmingly positive. Attendees, from community representatives to staff and senior management, discussed the research and particularly the framework in terms of how it could inform their professional practice and guide the implementation of effective health literacy within Ngāti Porou Hauora. The Chief Executive asked for permission to consider the framework as an evidence-based contribution in developing a “Ngāti Porou model of care.” A small working group was convened to start work on distilling the model, and I have been invited to contribute to these developments. I see this as an opportunity to support the interpretation and uptake of the framework and further honour the voices of Ngāti Porou patients, whānau, and communities.

In the nine years I have been involved in this area of medication use with Māori patients and whānau who have chronic disease, I have presented at various hui, conferences, and workshops and always hear people’s stories of heartache, struggle, and sorrow in relation to the healthcare system and services. Of the participants/whānau involved in my research over the years, more have passed away than are still living. I always wanted this research to highlight the realities faced by my people, our people, and to contribute towards actionable and transformative change. I leave the last words in this thesis to a kaumātua who shared his story.

George

> I had time with myself just the other day, last Sunday, my wife would of been 80. My wife was on medications and she was given an overdose, that's what started everything off, oh crikey, there were black rings all over her body, even the doctors wouldn't accept it. She got really sick, and nothing they could do to reverse it. There was an investigation and it was a medical mistake . . . In the community, the word is going out [intervention], people are starting to understand why we take our medications and get more on to it, just like me, well I didn't know half of what the doctor's word was all about until recently, till you came in. With my wife, she didn't have that. We were just ignorant of the fact, we just accepted. Not until afterwards when mother passed away, mea ['whatsit'], she's the nurse in the city now, she told me afterwards that she was sorry and she honestly said, "you could've got us all in trouble." I looked up and said, "well I'm sorry for my whānau, too late now, she's gone" . . . So, you get out there, girl, and get the word out, get them to know how it works and what's it's all about, get these doctors and boss man [managers] on board too, it's not good enough not knowing anymore.

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APPENDICES

APPENDIX A: Research nurse script

Patients and whanau introduction to the evaluation

Research nurse script

To be said to patient when patient has signed the ICIHRP consent form on Julia's first visit to them to provide ICIHRP Information Sheet, answer questions and seek consent (and if time and appropriate complete ICIHRP baseline data collection at end of that same visit)

As well as participating in the cardiovascular disease & medicines intervention research project, you are also being invited to be a part of the evaluation of the intervention. The intervention is being evaluated to understand peoples' experience of the intervention and its impacts. The external evaluator, Teah Carlson (Ngati Porou, Whanau a Apanui and doing a PhD with Massey University) is very interested in your & your whanau experiences of the intervention in the context of your personal CVD health journey. You will be asked to participate in three interviews with Teah and a journal. She will tell you more about that involves.

If you would like more information about participating Teah will contact you to arrange a time to meet and talk about the evaluation in more detail and answer any questions you may have. In the meantime here's an Information Sheet from Teah that she'll talk more with you about.

APPENDIX B: Patient and whānau information sheet

MASSEY UNIVERSITY

Evaluation of the cardiovascular disease and medicines intervention

Information Sheet

Kia ora koutou katoa,
I would like to invite you and your whānau to participate in the evaluation of the cardiovascular disease and medicines research project you are a part of with Ngati Porou Hauora. The impact and the effectiveness of this intervention is the focus of the evaluation which is also part of my Doctoral study.

The evaluator:

Ko Hikurangi te maunga, Ko Waiapu te awa, Ko Horouta te waka, Te Whānau a Ruataupare ki Tokomaru, Ko Pākirikiri te Marae, Ko Ngati Porou te Iwi. My name is Teah Carlson. I am currently enrolled as a PhD Candidate at Massey University, SHORE and Whariki Research Centre.

Your contribution

If you agree to participate I will ask you to complete 3 interviews with me and a few notes. You will be contacted by telephone or email to arrange a suitable time and place to meet.

Interviews
I will ask you to take part in 45-minute interviews about your experiences with the intervention: 1) after the first intervention session; 2) at the end of the intervention programme; 3) six months after the end of the intervention programme has finished.

Note keeping
After the first interview is complete, you will be asked to set aside 15 minutes each week during the intervention to note down your experiences of the intervention. Recordings can be done through phone contact, email, written notes and/or voice recording.

What will happen to the information?

With your consent, I will audio record our conversation. The recording will be used to supplement the notes taken during the discussion. I will transcribe each interview using pseudonym and removing identifiable information. I will send the transcript for you to review and to make any amendments.

I will also code and analyse your notes and along with your interview data the pooled information from all participants will be used to evaluate the intervention.

All digital data will be stored on password protected computers. Data will be securely stored by the evaluator and/or supervisor for the minimum 10 year period and will be appropriately disposed of thereafter. The results of this evaluation may be published in academic journals and presented at conferences. You will not be named in any publications (see Privacy below) and no identifying information will be used.

Participant privacy and rights

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

- decline to answer any question;
- withdraw your interview from the evaluation provided you notify the evaluator within 1 week from the interview;
- be provided with a transcript of your interview to make any amendments you see fit, within the timeframe provided by the evaluator;
- you can choose not to participate in any further interviews at any time;
- ask any questions about the evaluation at any time during participation;
- be anonymous in the interview by informing the evaluator before the interview and selecting a pseudonym;
- be supported and feel safe during the evaluation process and in some situations you can be assisted by others to ensure safety but I will not seek support for you without first discussing this with you;
- and ask that the audio recorder be turned off at any time during the interview.

Please note that if you choose not to participate in the evaluation or withdraw this will have no bearing on your involvement in the cardiovascular disease and medicines intervention or your healthcare.

Contact information

If you have any further questions/concerns please contact myself, my supervisor below or the Ngati Porou Hauora internal contact person:

Teah Carlson **Evaluator** **Phone: 021 076 9720** **teah.carlson@gmail.com**	**Associate Professor Helen Moewaka Barnes** **Supervisor** **Phone: 027 2957418** **h.moewakabarnes@massey.ac.nz**
Dr. Jennie Harré Hindmarsh **NPH Research Coordinator** **Phone: 021 963 081** **jennie.harrehindmarsh@nph.org.nz**	**Independent health & disability advocate** **Free phone: 0800 555 050** **Free fax: 0800 2 SUPPORT (0800 27877678)** **advocacy@hdc.org.nz**

This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application 12/095R. If you have any concerns about the conduct of this research, please contact Dr. Ralph Bathurst, Chair, Massey University Human Ethics Committee: Northern, telephone 09 414 0800 x 9570, email humanethicsnorth@massey.ac.nz.

APPENDIX C: Participant consent form

MASSEY UNIVERSITY

Evaluation of the Meds intervention

PARTICIPANT CONSENT FORM

I have read the Information Sheet and have had the details of the study explained to me. I understand the study and my participation in it. My questions have been answered to my satisfaction. I understand that my information will be kept confidential to the researchers and that:

- I can decline to answer any question;
- I can withdraw from the study, provided I notify the researcher within 1 week from the interview, at any time without any disadvantage to me;
- I will be provided with a transcript of my interview to make any amendments I see fit, within the timeframe provided by the researcher;
- I can choose not to participate in a further interview at any time;
- I can ask any questions about the study at any time during participation;
- be anonymous in the interview by informing the evaluator before the interview and selecting a pseudonym;
- I can ask that the audio recorder be turned off at any time during the interview;
- I agree to participate in this study under the conditions set out in the Information Sheet.

Signature: .... **Date:** ....

Full Name - printed ....

☐ Please tick if you would like to be sent a summary of the evaluation

Please send to: ____

____

APPENDIX D: Participant interview guidelines

Interview guidelines for participants

The following information is a brief synopsis of the topic areas to be discussed during the interviews.

First interview guide with patients and whānau (after first intervention session)

The purpose of this interview is to gain an understanding of patients' CVD health journey, including their medication use, patients' and whānau understandings of their medications and health situation, relationships with their health professionals, discuss their expectations of the *cardiovascular disease and medicines intervention* sessions, and their experiences and perceptions of the first session.

Kia Ora my name is Teah and my whānau are from Tokomaru Bay, my Papa is Stan Carlson from Tokomaru and my Nanny Rawinia Waiariki is from Te Kaha. We had the farm up the Mata Road for 40 years Bremnah Station.

- I was wondering if we could quickly go over the information sheet and feel free to ask any questions.
- Would you like to participate in the evaluation, if yes could you please sign the consent form?
- Can you tell me about your whare, do you have whānau living with you?
- Do you care for yourself? Who supports you? Do you receive support outside the whānau?
- Can you tell me about your health? How do you feel?
- Can you tell me about CVD and what it is? How did you learn this?
- Do you take medication? What kinds? Do you know what you take your medication for? Who have you talked to about your medications?
- How do you access your medications? How do you take you medications?
- Who provides you with health care? Do you have a GP, nurse? Do they meet your health needs? Can they improve?

- Can you tell me about when you first heard about the evaluation?
- Can you tell me about why you chose to participate in the sessions?
- How was the recruitment process for you?
- Can you tell me about what happened during the sessions? Was it what you expected? 1) How did you fell about them taking your blood pressure, weight and height measurements (baseline data levels)?
  2) How did you find the application? Was it easy to follow?
  3) How did you find the booklet? Was it easy to use? Have you used it since?
  4) Did you receive pill card, was this helpful for you? Have you used it since?
  5) Do you find the timing and frequency of the sessions okay for you?
- Have you made any changes in your practices with medications?
- Have you shared any of the information you have learnt with others?
- Would you change anything about the sessions?
- Do you have other comments to make about the sessions?

- I would like to invite you to take notes about your experiences in the second and third session. These could be written down, text, phone call etc. the recording of the notes should only take 15mins per week so that's a total of one hour over a month.
- Are you going back for a second/third session? Reasons for your decision?
- What date and time is a good time for us to meet at the next interview? I am aiming to see you after you have completed your third session.
- Thank you for your time today and your invitation into your home, I really appreciate your time with me.

Second interview guide with patients and whānau (at the end of intervention programme)

The purpose of this second interview is to gain an understanding of the strengths, weaknesses and improvement areas of the sessions, to discuss patients' and whānau perceptions, experiences including knowledge of CVD and knowledge/use and access of CVD medications and relationships with health practitioners, with a view to understanding any change that has occurred in these areas. Patients and whānau notes will be referred to where appropriate during the interview and discussed at the end.

Kia Ora, lovely to see you again, how have you been?

- Do you have any questions about the evaluation that you would like to ask?
- Did you find the last interview ok? We will pretty much follow the same process today.
- Have you had any changes with your whare and whānau living with you since we last met?
- Have you had any changes with your health, care providers, whānau and personal perceptions?
- What have you learnt about your CVD? How did you learn this?
- What have you learnt about your CVD medications? The use of them and how you access them? Has anything changed in your practices with you CVD medications?

- How was your second session? Was it what you expected?
- How did you find the application? Was it easy to follow?
- How did you find the booklet? Was it easy to use? Have you used it since?
- Did you receive pill card, was this helpful for you? Have you used it since?
- Can you tell me about your third most recent session? How was it for you? Was it what you expected?
- How did you find the application? Was it easy to follow?
- How did you find the booklet? Was it easy to use? Have you used it since?
- Did you receive pill card, was this helpful for you? Have you used it since?
- Do you find the timing and frequency of the sessions okay for you (go through the patient and whānau notes for additional information)?
- Have you shared any of the information you have learnt with others?
- Do you have other comments to make about the sessions?
- Have you got any suggestions or challenges you would like to share about the session?

  - How did you find taking the notes? Was the process okay for you? Were there any issues?
- What date and time is a good time for us to meet at the next interview? I am aiming to see you in six months' time.
- Thank you for your time today and your invitation into your home, I really appreciate your time with me.

Third interview guide with patients and whānau (six months after end of intervention)

The purpose of the third and final interview is to gain an understanding of any outcomes of the intervention to discuss patients' and whānau perceptions, experiences including knowledge of CVD and knowledge/use and access of CVD medications and relationships with health practitioners, with a view to understanding any change that has occurred in these areas.

- Kia Ora, lovely to see you again, how have you been?
- Do you have any questions about the evaluation that you would like to ask?
- Did you find the last interview ok? We will pretty much follow the same process today.
  - Have you had any changes with your whare and whānau living with you since we last met?
  - Have you had any changes with your health, care providers, relationships, whānau and personal perceptions?
  - Can you tell me about what you have learnt about your CVD?
  - Can you tell me about what you have learnt about your CVD medications? The use of them and how you access them? Has anything changed in your practices with you CVD medications?
  - Do you use your booklet?Is it easy to use? Have you shown anyone else your booklet?
  - Do you use your pill card? Is it easy to use? Have you shown anyone else your booklet?
  - Have you shared any of the information you have learnt with others?
  - How did you find the session? Did you find the sessions helpful? What were the best things about the sessions? What things would you like to see changed or improved?
  - Do you have other comments to make about the sessions?
  - What future support would you like to receive? Would you like to receive any future support with your health needs around CVD and CVD medications?
  - How did you find the experience with participating in the evaluation? What were the strengths of the evaluation? What things would you like to see changed or improved?
- Thank you for your time today and your involvement in the evaluation over the past 7 months I really appreciate your time with me (check contact details for sending information and for providing feedback and summaries).

APPENDIX E: Health practitioner information sheet

MASSEY UNIVERSITY

Evaluation of the cardiovascular disease and medicines intervention

Information Sheet

Kia ora koutou katoa,
I would like to invite you to participate in the evaluation of the ICIHRP cardiovascular disease and medicines research project at Ngati Porou Hauora. One of the aims of the evaluation is to gain insight into the health practitioners' impressions, practices and experiences with the intervention. Key discussion areas will include your practices with patients, whānau members and other health practitioners and your professional reflections on impact and effectiveness of the intervention.

The evaluator:

Ko Hikurangi te maunga, Ko Waiapu te awa, Ko Horouta te waka, Te Whānau a Ruataupare ki Tokomaru, Ko Pākirikiri te Marae, Ko Ngati Porou te Iwi. My name is Teah Carlson. I am currently enrolled as a PhD Candidate at Massey University, SHORE and Whariki Research Centre.

Your contribution

If you agree to participate I will ask you to complete 2 interviews with me. Your contributions to the evaluation are vital to the ongoing development of the intervention and its ability to be effective for patients and positive health outcomes. You will be contacted by telephone or email to arrange a suitable time and place to meet.

Interviews

You will be asked to take part in two 45-minute discussions about your experiences with the intervention: 1) after the intervention has been completed. 2) six months after the intervention is complete.

What will happen to the information?

With your consent, I will audio record our conversation. The recording will be used to supplement the notes taken during the discussion. I will transcribe each interview using a pseudonym and removing identifiable information. I will send the transcript for you to review and to make any amendments. I will also code and analyse your notes and along with your interview data the pooled information from all participants will be used to evaluate the intervention.

All digital data will be stored on password protected computers. Data will be securely stored by the evaluator and/or supervisor for the minimum 10-year period and will be appropriately disposed of thereafter. The results of this evaluation may be published in academic journals and presented at conferences. You will not be named in any publications (see Privacy below) and no identifying information will be used.

Participant privacy and rights

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

- decline to answer any question;
- withdraw your interview from the evaluation provided you notify the evaluator within 1 week from the interview;
- be provided with a transcript of your interview to make any amendments you see fit, within the timeframe provided by the evaluator;
- you can choose not to participate in a further interview at any time;
- ask any questions about the study at any time during participation;
- be anonymous in the interview by informing the evaluator before the interview and selecting a pseudonym;
- and ask that the audio recorder be turned off at any time during the interview.

Please note that if you choose not to participate in the evalaution or withdraw this will have no bearing on your involvement in the cardiovascular disease and medicines intervention or on your employment in the organisation participating in the intervention trial.

Contact information

If you have any further questions/concerns please contact myself, my supervisor below or the Ngati Porou Hauora internal contact person:

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Dr. Jennie Harré Hindmarsh
NPH Research Coordinator
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This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application 12/095R. If you have any concerns about the conduct of this research, please contact Dr. Ralph Bathurst, Chair, Massey University Human Ethics Committee: Northern, telephone 09 414 0800 x 9570, email humanethicsnorth@massey.ac.nz.

APPENDIX F: Health practitioner interview guidelines

Interview guidelines for Staff

The following information is a brief synopsis of the topic areas to be discussed during the interviews.

First interview guide with staff (after end of intervention trial has been completed with all patients)

The purpose of this interview is to gather information from staff involved directly or indirectly with the *cardiovascular disease health literacy and medicines intervention* (through contact with patients who have been participating in the intervention trial). Key topic areas include gaining an understanding of the health practitioners' role including their involvement with intervention and involvement with the participants, perceived outcomes, discuss their expectations of the intervention and discuss the strengths, weaknesses and improvement areas of the intervention and/or its sessions.

- Kia Ora, thank you for accepting the invitation to meet with me to discuss the intervention. I was wondering if I could just quickly go over the information sheet and feel free to ask any questions.
- Would you like to participate in the evaluation, if yes could you please sign the consent form?

o Can you tell me about your current role within the organisation? Do you have any other community roles and responsibilities? Did you have a role in relation to the implementation of the ICIHRP intervention trial?

Patients and whānau

o How did the recruitment process go? Can you tell me about any challenges, difficulties in recruiting patients?

o How did the patients feel about their baseline data levels being collected?

o In what ways were whānau members involved in the intervention trial?

o What expectations do you think patients and whanau had of the intervention trial? What were they wanting to get out of it?

o In what ways do you think their expectations were met? Anyways they were not meet?

o How do you think patients and whanau felt in general about the intervention? PROBE: timing and frequency of the sessions; delivery –home visits?

o Resources: how useful do you think the resources were? Which resources do you think were the most usefu? Why do you think they were useful, not so useful? PROBE:

a) What were the responses and reactions to the application? Did they find it easy to follow? Did they find it useful and applicable for them?

b) What were the responses and reactions to the booklet? Did they find it easy to use? Did they use the booklet?

c) What were the responses and reactions to the pill card? Did they find it easy to use? Did the use the pill card?

- In what ways do you think patients and whanau shared the information they learnt?
- What changes did you see as a result of the intervention? PROBE: knowledge, use of medications, increased confidence, ability to self-management and empowerment in interactions with yourself and other health workers?

Intervention

- What was your perception of health literacy before the intervention trial began at your organisation? Have your thoughts/ideas changed during the intervention trial?
- Can you tell me about any personal learning's from the intervention trial have informed your practice as a health worker? PROBE: Have you experienced any changes in your own ways of working/interacting/communicating with patients &/or whānau and/or other health practitioners?
- Are there aspects of the intervention, particular strengths that could be useful in other interventions" PORBE: Useful to NPH initiatives/ways of working? (Including any further research & evaluation project priorities).
- What do you think would have happened if this intervention had not taken place for yourself and for the patients/whanau?
- Can you tell me about any other observations, comments, suggestions and challenges that you may have in regards to the intervention trial?
- What date and time is a good time for us to meet at the next interview? I am aiming to see you in six months' time.
- Thank you for your time today, I really appreciate your involvement and look forward to meeting you seeing you in six months.

Second interview guide with staff (six months after end of intervention trial)

The purpose of this second and final interview is to gain an understanding of any outcomes of the intervention including if the patients' and whānau medication practices have changed, relationship practices have changed between patients &/or whānau and health practitioners (including themselves), if patients and/or whānau knowledge of CVD and knowledge/use and access of CVD medications has changed, your learning's from the intervention <and/or wider research project activities>, possible future implications and suggestions.

- Kia Ora, lovely to see you again, how have you been? Do you have any questions about the evaluation that you would like to ask? Did you find the last interview ok? We will pretty much follow the same process today.
- Have you had any changes with your role? Involvement in the community? Involvement with the overall ICIHRP research project?

Patients and whānau

- Since we last spoke can you tell me about any further feedback you have received from patients and whānau around their involvement in the intervention trial?
- In terms of the patients and whānau have any perceptions, attitudes towards the intervention trail changed? In terms of acceptability of sessions and attendance.
- Did patients and whānau use their booklet? Did they find it easy to use? Did they show anyone else their booklet?

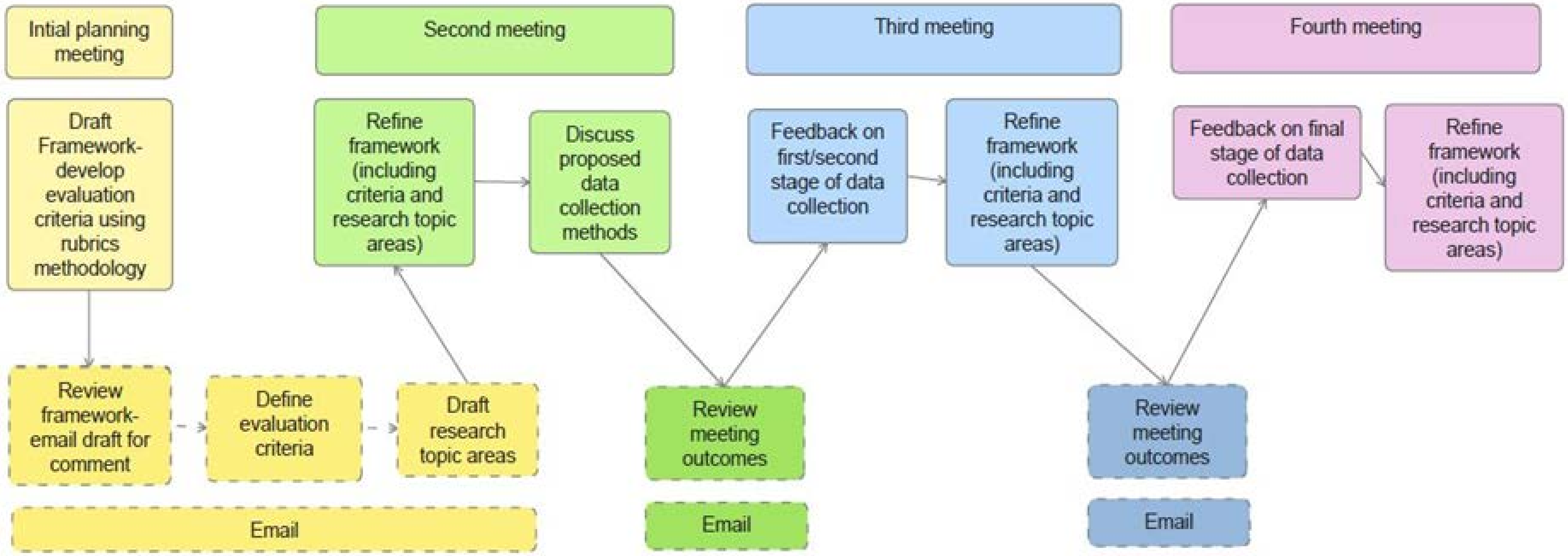
- Did patients and whānau use their pill card? Is it easy to use? Did they find it easy to use? Did they show anyone else their pill card?
- Can you tell me if you observed any changes in terms of the patients and whānau knowledge of medications? Use of medications?
- Did you observe any increased confidence, ability to self-manage and empowerment in interactions with yourself and other health workers?
- Have you experienced any changes in your own ways of working/interacting/communicating with patients &/or whānau and/or other health practitioners?

Intervention

- Can you describe your knowledge and view of health literacy? Have you experienced any changes during the intervention trial?
- Have you observed any learning's that might have on going application within the organisation? What things, resources do you think can be transferrable to the organisation or other initiatives? (Including any further research & evaluation project priorities).
- Do you have any personal learning's from the intervention trial that can inform your practice as a health worker?
- Can you tell me about any other observations, comments, suggestions and challenges that you may have in regards to the intervention trial?
- Have you experienced any changes in your own ways of working/interacting/communicating with patients &/or whānau and/or other health practitioners?
- How did you find the experience with participating in the evaluation? What were the strengths of the evaluation? What things would you like to see changed or improved?

- Thank you for your time today, and your involvement in the evaluation with me over the past 7 months, I really appreciate your involvement (check contact details for sending information, for providing feedback and summaries).

APPENDIX G: Research advisory group engagement plan



APPENDIX H: Key informant information sheet

MASSEY UNIVERSITY

Developing and testing an Indigenous Health Literacy Framework Information Sheet

Kia ora,

I would like to invite you to participate in my doctoral research on developing and testing an indigenous health literacy framework. One of the aims of my research is to develop wider learning's in relation to health literacy interventions with Māori and indigenous communities by gaining insights into health literacy approaches through key informant interviews with Māori and indigenous health literacy informants. Key discussion areas will include your perceptions, practices and experiences working in the health literacy field with and encompass Maori indigenous communities.

The interviewer:

Ko Hikurangi te maunga, Ko Waiapu te awa, Ko Horouta te waka, Te Whānau a Ruataupare ki Tokomaru, Ko Pākirikiri te Marae, Ko Ngati Porou te Iwi. My name is Teah Carlson. I am currently enrolled as a PhD Candidate at Massey University, SHORE and Whariki Research Centre.

Your contribution

If you agree to participate I will ask you to complete 1 interview with me. Your contributions to the research are vital to the ongoing development and refinement of the framework and its ability to be effective for Maori and indigenous organisations. You will be contacted by telephone or email to arrange a suitable time and place to meet.

Interview

You will be asked to take part in one 60-90 minute interview about your professional experiences with in the field of indigenous health literacy.

What will happen to the information?

With your consent, I will audio record our conversation. The recording will be used to supplement the notes taken during the discussion. I will transcribe each interview using a pseudonym and removing identifiable information. I will send the transcript for you to review and to make any amendments.

All digital data will be stored on password protected computers. Data will be securely stored by the interviewer and/or supervisor for the minimum 10 year period and will be appropriately disposed of thereafter. The results of this research may be published in academic journals and presented at conferences. You will not be named in any publications (see Privacy below) and no identifying information will be used.

Participant privacy and rights

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

- decline to answer any question;
- withdraw your interview from the research provided you notify the interviewer within 1 week from the interview;
- be provided with a transcript of your interview to make any amendments you see fit, within the timeframe provided by the interviewer;
- you can choose not to participate in a further interview at any time;
- ask any questions about the study at any time during participation;
- be anonymous in the interview by informing the interviewer before the interview and selecting a pseudonym;
- and ask that the audio recorder be turned off at any time during the interview.

Contact information

If you have any further questions/concerns please contact myself, my supervisor below or the Ngati Porou Hauora internal contact person:

Teah Carlson	**Associate Professor Helen Moewaka Barnes**
Interviewer	**Supervisor**
Phone: 021 076 9720	**Phone: 027 2957418**
teah.carlson@gmail.com	**h.moewakabarnes@massey.ac.nz**

This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application 12/095R. If you have any concerns about the conduct of this research, please contact Dr. Ralph Bathurst, Chair, Massey University Human Ethics Committee: Northern, telephone 09 414 0800 x 9570, email humanethicsnorth@massey.ac.nz.

APPENDIX I: Key informant interview guidelines

Interview guidelines for key informants

The aim of the interview would be to gain an understanding of the key informant's role and professional experience in the health literacy field. Key topic areas include gaining an understanding of the key informant's perceptions, practices and experiences working in the health literacy field with and encompass Māori and indigenous communities.

- Mihimihi
- Kia Ora, thank you for accepting the invitation to meet with me. I was wondering if I could just quickly go over the information sheet and feel free to ask any questions.
- Do you agree to participate in the research, if yes could you please sign the consent form.
    - Can you tell me about yourself, your whanau and where you are from?
    - Can you tell me about your current role?
    - Does your role involve or impact on indigenous communities?
    - Do you have any other community roles and responsibilities?
    - Can you tell me about your experience working in the health literacy field?
    - What was your perception of health literacy?
    - Does your professional role encompass health literacy practices? What practices of health literacy do you use in your professional role?
    - Have you been involved in any health literacy interventions and projects, other than the ICIHRP?
    - Can you tell me about the specific Māori and indigenous approaches, ethics, methods that were used?
    - Can you tell me about the strengths of the intervention(s)/project(s)?
    - Can you tell me about the improvement areas of the intervention(s)/project(s)?
    - Do you think health literacy is an important approach to improving health for Māori and indigenous communities?
    - In your opinion who do you believe is responsible for health literacy?
    - What are your goals and aspirations for Health literacy in Aotearoa?
    - If you could have an endless pool of funding and support what would the most effective HL intervention for Māori and Indigenous people look like?
    - From your New Zealand Herald article (2012) you wrote about "There is no quick fix for New Zealand's health challenges and the health sector is taking commendable steps to improve New Zealanders' health outcomes. The best results will be achieved if health practitioners and policymakers do more to reduce the health literacy demands being placed on people, and spend time building people's knowledge and skills."
    - Do you think we need to do more than building knowledge and skills?
    - What HL targets should we be working towards on an individual, whanau level?
    - What HL targets should we be working towards on a community level?
    - What HL targets should we be working towards on a population level?

- In terms of the development of the intervention what were the key health literacy features of the intervention?
- Can you tell me about the selection criteria and why the specific target group was chosen?
- Can you tell me about the resources that were used in the intervention? Was the use of the application, booklet, pill card effective?
- For my own clarification were the participants asked to keep the intervention information to themselves, not to share with the wider whanau? Can you explain why this was?
- What were the strengths of the intervention?
- What were the improvement areas for the intervention?
- What have you learnt from being involved in this intervention?
- How were HL levels measured in the intervention? Did they improve?
- In terms of the development and conduct of the intervention what were the key engagement areas relating to Māori
- Did the project incorporate kaupapa Māori approaches? What did they involve?
- I understand Canada and Australia were involved in the project. What important indigenous understandings of health literacy were present in the development and conduction of the intervention?
- What organisational interactions did you have with NPH throughout the project? I understand HL was offered was this completed?
- Is the intervention going to be rolled out? What are the future developments of the intervention, improvement areas?
    - Would you recommend any readings, books that would enhance my research?
    - Would you recommend any other contacts that would be appropriate for this research?
- Thank you for your time today, I really appreciate your involvement (check contact details for sending information, for providing feedback and summaries).

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APPENDIX J: Massey University Ethics Committee approval letter

MASSEY UNIVERSITY
ALBANY

8 March 2013

Teah Carlson
c/- Associate-Professor H MoewakaBarnes
College of Humanities & Social Sciences
Massey University
Albany

Dear Teah

HUMAN ETHICS APPROVAL APPLICATION – MUHECN 12/095
Kaupapa Māori Evaluation of a Health Literacy-Appropriate CVD Programme

Thank you for your application. It has been fully considered, and approved by the Massey University Human Ethics Committee: Northern.

Approval is for three years. If this project has not been completed within three years from the date of this letter, a 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

Dr Ralph Bathurst
Chair
Human Ethics Committee: Northern

cc: Associate-Professor H MoewakaBarnes
College of Humanities & Social Sciences

Te Kunenga
ki Pūrehuroa

Research Ethics Office
Private Bag 102 904, Auckland, 0745, New Zealand Telephone +64 9 414 0800 ex 43279 humanethicsnorth@massey.ac.nz

APPENDIX K: Ngāti Porou Hauora research approval letter

NGATI POROU HAUORA
'Nati' Healthy, Wealthy and Wise

14 January 2013

Teah Carlson
PhD Scholar
Massey University - Auckland
Email: teah.carlson@gmail.com

Kia ora Teah

Kaupapa Maori Evaluation of ICIHRP Health Literacy & CVD Medications Intervention
- PhD Research Proposal

Thank you for the sub-proposal to 'nest' your Health Research Council funded PhD project in the current *ICIHRP Health Literacy and CVD Medications* project, led by Dr Sue Crengle and already approved by the Ngati Porou Hauora Board, to be based with NPH in Matakaoa for 2011/13.

This is to confirm that the CE and Management Team approve your proposal provided that:
- ethics approval is also obtained
- project details as proposed are negotiated to the CE and MT's satisfaction.

We have noted that:
- your PhD is registered with Massey University (SHORE and Whariki Evaluation Research Centre) with Associate Professor Helen Moewaka Brown & Dr Tim McCreanor as your supervisors, and Dr Sue Crengle as research advisor.
- you propose to work with the NPH ICIHRP Project Advisory Group to co-construct the evaluation criteria and other details for the framework.

Please continue to liaise with our Research Coordinator, Dr Jennie Harré Hindmarsh regarding your project, including to obtain her feedback on your draft ethics application and to convene the planning workshop and final details for approval. Her phone number is 021 738 272 & email jennie.harrehindmarsh@nph.org.nz

We look forward to contributing to and learning from your project, and in the process supporting completion of your PhD thesis. And finally, our congratulations on being awarded an HRC scholarship for this PhD project.

Naku noa na

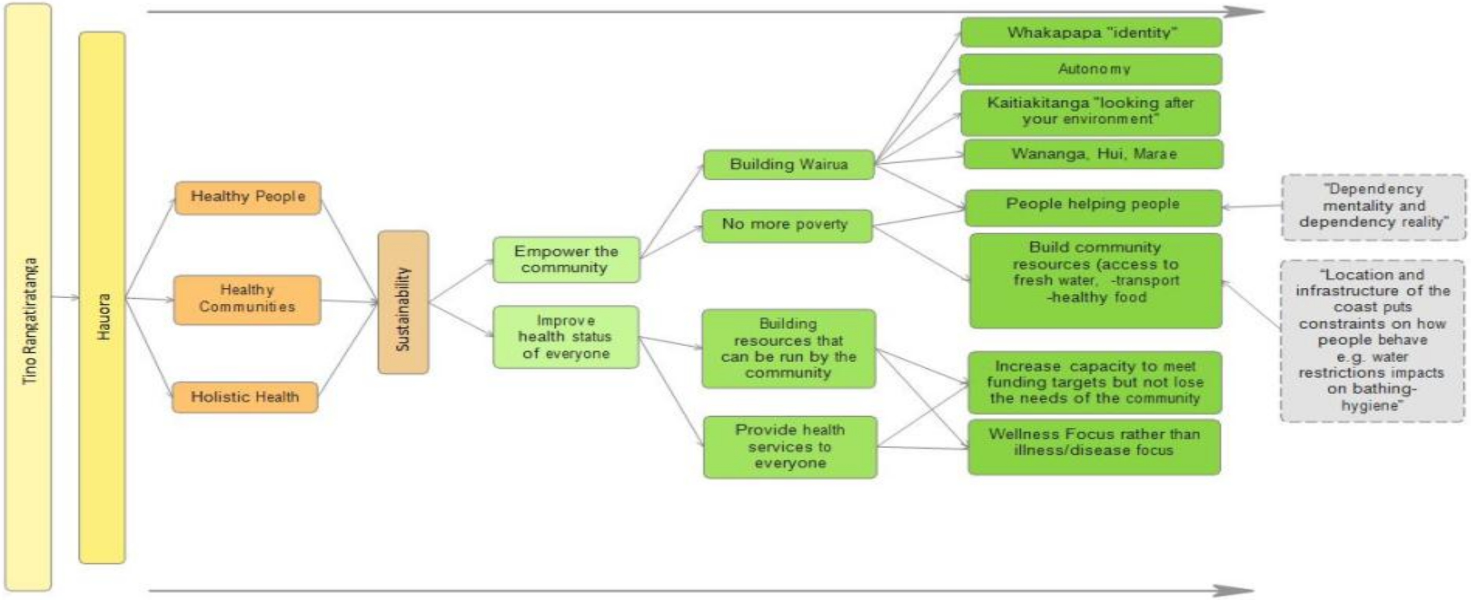
Helen Milner
Acting Chief Executive

Ngati Porou Hauora Charitable Trust
PO Box 2,
Te Puia Springs 4048

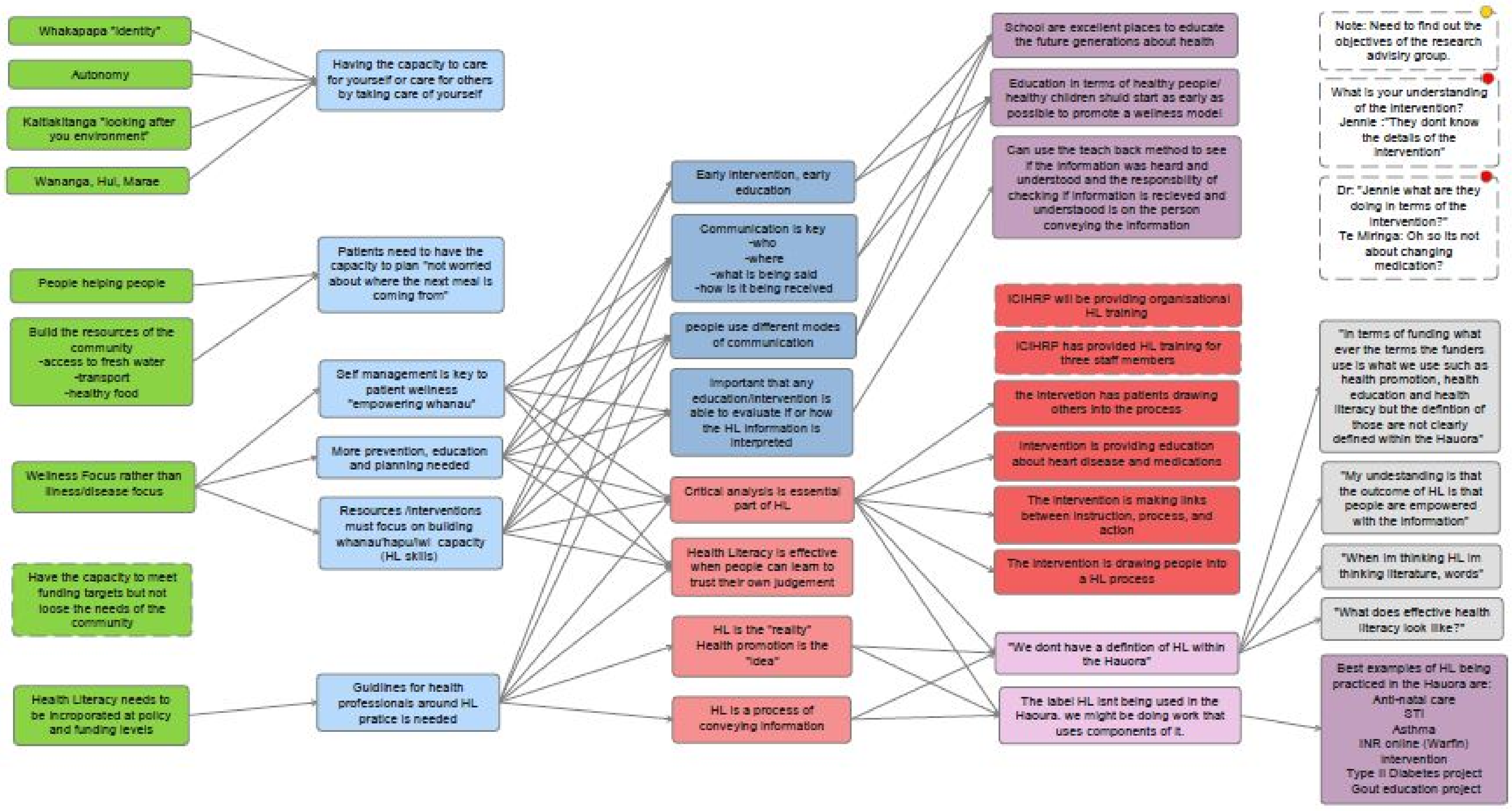
tel: 06 864 6803 | helen.milner@nph.org.nz

APPENDIX L: Previous snapshots of the framework development

Ngāti Porou Hauora evaluation framework page 1 Research advisory group second hui



Ngāti Porou Hauora evaluation framework development page 2: Research advisory group second hui



Whakapapa "identity"

Autonomy

Kaitiakitanga "looking after you environment"

Wananga, Hui, Marae

People helping people

Build the resources of the community
-access to fresh water
-transport
-healthy food

Wellness Focus rather than illness/disease focus

Have the capacity to meet funding targets but not loose the needs of the community

Health Literacy needs to be incroporated at policy and funding levels

Having the capacity to care for yourself or care for others by taking care of yourself

Patients need to have the capacity to plan "not worried about where the next meal is coming from"

Self management is key to patient wellness "empowering whanau"

More prevention, education and planning needed

Resources /interventions must focus on building whanau/hapu/iwi capacity (HL skills)

Guidlines for health professionals around HL pratice is needed

Early intervention, early education

Communication is key
-who
-where
-what is being said
-how is it being received

people use different modes of communication

Important that any education/intervention is able to evaluate if or how the HL information is interpreted

Critical analysis is essential part of HL

Health Literacy is effective when people can learn to trust their own judgement

HL is the "reality"
Health promotion is the "idea"

HL is a process of conveying information

School are excellent places to educate the future generations about health

Education in terms of healthy people/ healthy children shuld start as early as possible to promote a wellness model

Can use the teach back method to see if the information was heard and understood and the responsbility of checking if information is recieved and understaood is on the person conveying the information

ICIHRP will be providing organisational HL training

ICIHRP has provided HL training for three staff members

the intervetion has patients drawing others into the process

Intervention is providing education about heart disease and medications

The intervention is making links between instruction, process, and action

The intervention is drawing people into a HL process

"We dont have a defintion of HL within the Hauora"

The label HL isnt being used in the Haoura. we might be doing work that uses components of it.

Note: Need to find out the objectives of the research advisiry group.

What is your understanding of the intervention?
Jennie :"They dont know the details of the intervention"

Dr: "Jennie what are they doing in terms of the intervention?"
Te Miringa: Oh so its not about changing medication?

"In terms of funding what ever the terms the funders use is what we use such as health promotion, health education and health literacy but the defintion of those are not clearly defined within the Hauora"

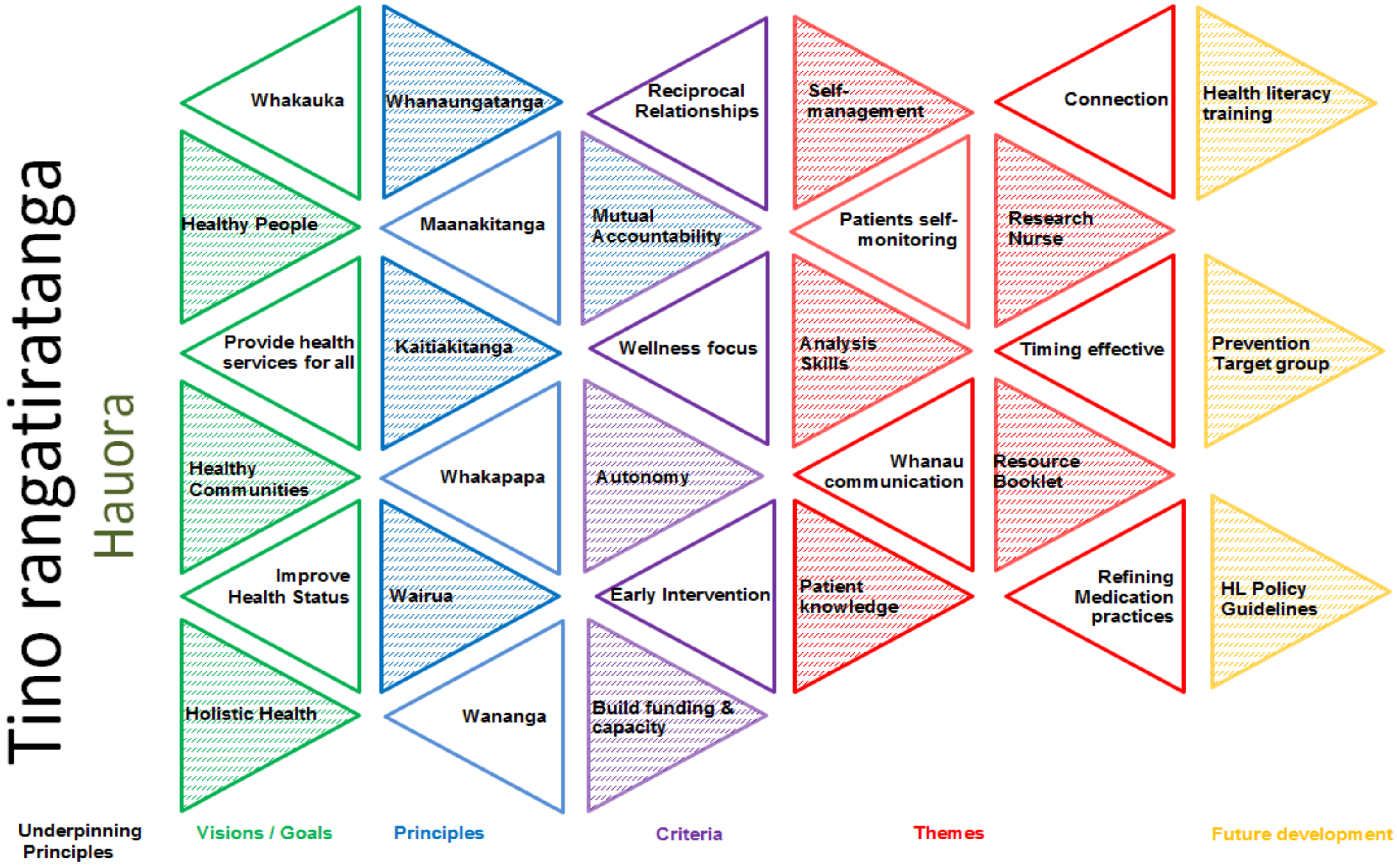
"My undestanding is that the outcome of HL is that people are empowered with the information"

"When im thinking HL im thinking literature, words"

"What does effective health literacy look like?"

Best examples of HL being practiced in the Hauora are:
Anti-natal care
STI
Asthma
INR online (Warfin) intervention
Type II Diabetes project
Gout education project

Ngāti Porou Hauora evaluation framework development: Research advisory group third hui



Ngāti Porou Hauora Framework Development: Research advisory group fourth hui

			Organisational Level	**Health Professional Level**
Goals of Indigenous Health Literacy Approaches	Transformative	-Pathway towards self-determination -Decolonising -Identify power relations -Prioritise Indigenous knowledge and experience	Leadership *Commitment to invest money, resources & policy development*	Leadership *Build likeminded groups* *Build awareness'* *Normalise health literacy practices*
	Indigenous Participation	-Leadership -Maximise Indigenous participation -Partnership & Collaboration -Reciprocal Relationships -Mutual accountability	Consumer development *of health literacy resources, programmes, initiatives* *Guided by latest research*	Commitment *To assess, improve and to support*
	Strengths Based	-Whanau knowledge base -Prevention & Wellness focus	Training workforce *Professional development* *Competencies*	Training *Health literacy training* *Incorporate adult learning principles*
	Capacity Building	--Coordination between providers, including Māori organisations -Coordinate with community initiatives to support practice - sustainable practices -sustainable resources	Improve access and navigation *-Introduce Māori navigator roles* *-Access patient pathways and reduce barriers*	Practice *Teach back, paper bag method, patient education, universal approach, anticipate next steps, information sequence list, ask open ended questions, use HL resources.* *Include anatomy and physiology core components*
	Context Specific	-Hapu hou -Tailor resources, initiatives & programmes _quality ethnicity data that s routinely analysed and reported to inform HL planning and decision making	Improve communication oral and written *Review of resources, signs, forms, educational material, systems need to adapt to support HL practices*	Reflection *Reflexivity*
	Targeted Focus	-Address high needs/risk population		
	Effectiveness & efficiency	-Identify schedule/timeframe that aligns with the community -need to be prioritised over economic drive -Disseminate research information in an appropriate form to the relevant stakeholders		

Appendix M: Kaupapa Māori evaluation: A collaborative journey

Appendix N: Whanaungatanga: A space to be ourselves

Appendix O: Statement of Contribution